

- Samuel, P., Rillotta, F., & Brown, I. (2012). The development of family quality of life concepts and measures. *Journal of Intellectual Disability Research, 56*, 1–16.
- Schalock, L., Keith, D., Verdugo, A., & Gomez, E. (2010). Quality of life model development and use in the field of intellectual disability. In R. Kober (Ed.), *Quality of life: Theory and implementation*. pp. 17–32. New York: Sage
- Schippers, A., & van Boheemen, M. (2009). Family quality of life empowered by family oriented support. *Journal of Policy and Practice in Intellectual Disabilities, 6*, 19–24.
- Summers, A., Poston, J., Turnbull, P., Marquis, G., Hoffman, L., Mannan, H. (2005). Conceptualizing and measuring family quality of life. *Journal of Intellectual Disability Research, 49*, 777–783.
- Turnbull, A., Turnbull, R., Wehmeyer, M., & Shogren, K. (2013). *Exceptional lives: Special education in today's schools* (7th ed). Pearson Inc.
- Wang, M., Summers, A., Little, T., Turnbull, A., Poston, D., & Mannan, H. (2006). Perspectives of fathers and mothers of children in early intervention programmers in assessing family quality of life. *Journal of Intellectual Disability Research, 50*, 977–988.
- Werner, S., Edwards, M., Baum, N., Brown, I., Brown, I., & Isaacs, J. (2009). Family quality of life among families with a member who has an intellectual disability: An exploratory examination of key domains and dimensions of the revised FQOL survey. *Journal of Intellectual Disability Research, 53*, 501–511.
- WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment *Psychological Medicine, 28*, 551–558.
- World Health Organization. (1996). Quality of life (WHOQOL) – Brief questionnaire, field trial version. Geneva: WHO.
- http://www.e.gov.kw/sites/kgoEnglish/Portal/Pages/CitizensAndResidences/SpecialNeeds_Information.aspx
- Zuna, I., Turnbull, A., & Summers, A. (2009). Family quality of life: Moving from measurement to application. *Journal of Policy and Practice in Intellectual Disabilities, 6*, 25–31.
- Zuna, N., Summers, A., Turnbull, P., Hu, X., & Xu, S. (2010). *Theorizing about family quality of life*. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities: From theory to practice* (pp. 241–278). Dordrecht, the Netherlands: Springer.

- Brown, I., Anand, S., Isaacs, B., Baum, N., & Fung, W. L. (2003). Family quality of life: Canadian results from an international study. *Journal of Developmental and Physical Disabilities, 15*, 207–230.
- Brown, I., Isaacs, B., McCormack, B., Baum, N., & Renwick, R. (2004). *Family quality of life in Canada*. In A. P. Turnbull, I. Brown, & H. R., Turnbull, III, (Eds.). Families and people with mental retardation and quality of life: International perspectives (pp. 185–222). Washington, DC: American Association on Mental Retardation.
- Dardas, L., & Ahmad, M. (2014a). Quality of life among parents of children with autistic disorder: A sample from the Arab world. *Research in Developmental Disabilities, 35*(2), 278–287.
- Dardas, L., & Ahmad, M. (2013a). Coping strategies as mediators and moderators between stress and quality of life among parents of children with Autistic Disorder. *Stress and Health*. doi:10.1002/smi.2513.
- Dardas, L. A. (2014). Stress, coping strategies, and quality of life among Jordanian parents of children with Autistic Disorder. *Autism, 4*, 127. doi:10.4172/2165-7890.1000127
- Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual & Developmental Disability Research, 34*(2), 153–162.
- Dunst, J., Trivette, M., Hamby, W., & Bruder, B. (2006). Influences of contrasting natural learning environment experiences on child, parent and family well-being. *Journal of Developmental and Physical Disabilities, 18*, 235–250.
- Gardiner, E., & Iarocci, G. (2012). Unhappy (and happy) in their own way: A developmental psychopathology perspective on quality of life for families living with developmental disability with and without autism. *Research in Developmental Disabilities, 33*, 2177–2192.
- Gine', C., Gra'cia, M., Vilaseca, R., & Balcells, A. (2010). *Quality of life for families of people with intellectual disability in Spain*. In R. Kober (Ed.), Enhancing the quality of life of people with intellectual disabilities: From theory to practice (pp. 349–361). Dordrecht, the Netherlands: Springer.
- Gomez, I., & Gomez, M., (2013). Quality of life of parents of Filipino children with special needs. *Education Quarterly, 17* (2), 42–57.
- Haimour, A., & Abu-Hawwash, R. (2012). Evaluating quality of life of parents having a child with disability. *International Interdisciplinary Journal of Education, 1*(2), 37–43.
- Hoffman, L., Marquis, G., Poston, J., Summers, A., & Turnbull, P. (2006). Assessing family outcomes: Psychometric evaluation of the Beach Center Family Quality of Life Scale. *Journal of Marriage and Family, 68*, 1069–1083.
- Isaacs, J., Brown, I., Brown, I., Baum, N., Myerscough, T., Neikrug, S. (2007). The international family quality of life project: Goals and description of a survey tool. *Journal of Policy and Practice in Intellectual Disabilities, 4*, 177–185.
- Malhotra, S., Khan, W., & Bhatia, M., (2012). Quality of life of parents having children with developmental disabilities. *Delhi Psychiatry Journal, 15* (1), 171–176.
- Meadan, H., Halle, J. & Ebata, A. (2010). Families with children who have autism spectrum disorders: Stress and support. *Exceptional Children, 77*(1), 7–36.
- Meral, B., Cavkaytar, A., Turnbull, A., & Wang, M., (2013). Family quality of life of Turkish families who have children with intellectual disabilities and autism. *Research & Practice for Persons with Severe Disabilities, 38* (4), 233–246.
- Neikrug, M., Judes, J., Roth, D., & Krauss, B. (2004). *Family quality of life in Israel*. In A. P. Turnbull, I. Brown, & H. R., Turnbull, III, (Eds.). Families and people with mental retardation and quality of life: International perspectives (pp. 151–184). Washington, DC: American Association on Mental Retardation.
- Ohaeri, U., Awadalla, W., El-Abassi, M., & Jacob, A. (2007). Confirmatory factor analytical study of the WHOQOL-Bref: Experience with Sudanese general population and psychiatric samples. *Medical Research Methodology, 7*(37), 7–37.
- Park, J., Hoffman, L., Marquis, J., Turnbull, P., Poston, D., Mannan, H. (2003). Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *Journal of Intellectual Disability Research, 47*, 367–384.
- Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life: A qualitative inquiry. *Mental Retardation, 41*, 313–328.
- Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385–401.

genders. This result is consistent with other studies (e.g., Gomez & Gomez, 2013). In this regard, Gomez and Gomez (2013) mentioned that the gender of the child does not affect the QOL of parents (p. 51).

Finally, the children's type of disability was not affecting parents' QOL as results of this study showed no statistically significant difference were found in parents' QOL based on this variable. This result is consistent with results achieved by Davis and Gavidia-Payne (2009) and contradicts the result achieved by Haimour and Abu-Wawwash (2012). Although no significant differences between the types of children's disability were included in this study, looking at mean scores of parents' QOL (see Table 2) one can notice that parents of children with Autism had the lower mean scores among other groups followed by parents of children's with Intellectual Disabilities. On the other hand, parents of children with Sensory impairments and Physical and Health impairments had the highest mean scores. These differences might document what has been noted in the literature, that the severity of a child's disability affects parents' QOL and that the parents of children with autism had been documented to be the lower in QOL when it was compared with other groups (e.g., Dardas & Ahmad, 2014a; Dardas, 2014; Dardas & Ahmad, 2013a; Gardiner & Iarocci, 2012; Wang et al., 2004).

Conclusions and Limitations

The purpose of this study was to investigate parents of children with disabilities QOL in the State of Kuwait using the Arabic translated version of WHOQOL-BREF. Results of the study showed that parents' perceptions of their QOL were ranked in the medium level. In addition, results revealed no statistically significant difference in parents QOL could be attributed due to their characteristics or their children's characteristics.

It is necessary to mention that results of this study need to be considered in light of the study limitations. One of these limitations is the absence of a comparison group (e.g., children without disabilities). Another limitation is the absence of an outside measure (e.g., professional and social support, coping strategies, level of stress and anxiety, religious belief, employment status, child's severity, and type of educational services) as these measures were concluded in the literature to be associated with parents QOL

A third limitation is that parents participated in this study voluntarily expressed their intention to participate in the study. This could limit the results to those parents only especially when information related to the type of educational services provided were missing in the current study and that might reflect their satisfaction with these services and affect their QOL. Finally, the unequal distribution of numbers among the various variables included in this study might impact the results

especially in testing for any significant differences among these variables.

Overall, results of this study are important and warrant for future investigations. Service providers and counselors working with parents of children with disabilities in the State of Kuwait might benefit from these results by considering parents QOL in measuring their intervention functionality and/or in determining their intervention priorities. Having a child with a disability represents a burden as documented in the literature. This burden might affect the psychological needs of of parents and that by itself needs more investigation and consideration in providing support or services. Measuring the concept of QOL in parents of children with disabilities represents a new direction in research in the Arab world. The number and type of studies investigating this concept in the region are limited. This study can add to this literature. This by itself empowers the importance of this study regardless of its limitations or overall results.

References:

- AL Jabery, M., & Arabiat, D. (2013): *Diversity and Cultural Issues in Early Detection and Intervention*. In Frances Page Glascoe, Kevin Marks, Jennifer K Poon, & Michelle M. Macias (Editors), *Identifying & Addressing Developmental-Behavioral Problems: A Practical Guide for Medical and Non-Medical Professionals, Trainees, Researchers, and Advocates*. PEDSTest.com, LLC.
- Al-Krenawi, A., Graham, R., & Al Gharaibeh, F. (2011). The impact of intellectual disability, caregiver burden, family functioning, marital quality, and sense of coherence. *Disability & Society, 26*, 139–150.
- Arabiat, D., Elliott, B., Draper, P., & AL Jabery, M. (2011). Cross-cultural Validation of the Pediatric Quality of Life Inventory™ 4.0 (PedsQL™) generic core scale into Arabic Language. *Scandinavian Journal of Caring Sciences, 25*, 383-833.
- Arabiat, D., & AL Jabery, M. (2013). Health Related Quality of Life in Pediatric Chronic Health Conditions: A comparative Study among Children and Adolescents in Jordan. *Health, 5* (11B), 19-24.
- Arabiat, D., AL Jabery, M., Abed-alqader, R., & Mahadeen, A. (2013). Jordanian Mothers' Beliefs About the Causes of Cancer in their Children and Its Impact on the Maternal Role. *Journal of Transcultural Nursing, 24*(3), 246-253.
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research, 51*(9), 702–714.

With respect to other variables, mothers and fathers scored similarly in all domains with nearly high scores on the social relations domain in fathers and the psychological health domain in mothers. On the other hand, the physical health domain was the lowest among other domains for both mothers and fathers. Looking at mean scores based on type of disability variable, results also indicated similar mean scores among the four groups included in the study. However, looking at mean scores for each domain across groups, it could be concluded that parents of children in the Autism group appear to have the lowest mean score in comparison with other groups, followed by Intellectual Disabilities group. On the other hand, parents of children with sensory impairments and physical and health impairments appeared to have higher mean scores, respectively.

Furthermore, to test for any statistically significant differences among participants in their QOL mean scores for each domain, results of independent sample *t*. test (see Table 2) revealed no statistically significant differences in the mean QOL score for each of the four domains and parents' gender (mothers vs. fathers), $t(138) = -.984, p = .327$; $t(138) = .387, p = .699$; $t(138) = 1.684, p = .094$; $t(138) = -.183, p = .855$, respectively. In addition, results revealed no statistically significant differences in the mean QOL score for each of the four domains and marital status (married vs. single), $t(138) = 1.076, p = .284$; $t(138) = .766, p = .445$; $t(138) = 1.748, p = .083$; $t(138) = 1.044, p = .298$, respectively. Finally, results also revealed no statistically significant differences in the mean QOL score for each of the four domains and gender of children (males vs. females), $t(138) = -.085, p = .954$; $t(138) = .582, p = .561$; $t(138) = .741, p = .460$; $t(138) = .128, p = .898$, respectively.

Consequently, results of One-Way ANOVA, in addition, revealed no statistically significant differences that could be attributed to parents' age ($p = .945$; $p = .227$; $p = .546$; $p = .410$), for each domain respectively; as well as parents' level of education ($p = .267$; $p = .274$; $p = .276$; $p = .265$); parents' SES ($p = .639$; $p = .165$; $p = .224$; $p = .740$); children's type of disability ($p = .089$; $p = .094$; $p = .160$; $p = .229$); and age of children ($p = .107$; $p = .323$; $p = .933$; $p = .893$), for each domain respectively (see Table 2 for details).

Finally, results of the first question "*How would you rate your quality of life?*") indicated that 85% ($n = 120$) of participants described that their quality of life was as either good or very good. For the second question "*How satisfied are you with your health?*", the results indicated that 70% ($n = 98$) of participants were either satisfied or very satisfied with their health.

Discussion

The purpose of the current study, was to investigate the QOL of parents of children with disabilities in the state of Kuwait. It is worth mentioning that the main

aim of this study was to explore parents' perceptions of their QOL; it was not our intention to either compare these perceptions to other group of parents (e.g., parents of children without disabilities), or associate them with other measures (e.g., social support or professional support). In line with that, results of the study showed almost similar perceptions of QOL between fathers and mothers participated in the study with ratings ranged around the medium-high level of QOL (see table 1). Results of *t*. test revealed no statistically significant difference between mothers and fathers in their perception of QOL. This result is consistent with other studies (e.g., Dardas & Ahmad, 2014a; Dardas, 2014; Dardas & Ahmad, 2013a; Gomez & Gomez, 2013; Meral, Cavkaytar, Turnbull, & Wang, 2013; Malhotra, Khan, & Bhatia, 2012; Werner et al., 2009; Wang et al., 2006) and was not unusual in QOL studies (Brown et al., 2003; Wang et al., 2006).

In terms of parents' socioeconomic status, education level, and marital status; results of this study revealed no statistically significant differences were presented among these variables and parents' QOL. This result is consistent with other studies (e.g., Dardas & Ahmad, 2014a; Dardas, 2014; Dardas & Ahmad, 2013a; Meral, Cavkaytar, Turnbull, & Wang, 2013) and inconsistent with other studies (e.g., Gomez & Gomez, 2013; Davis & Gavidia-Payne, 2009; Wang et al., 2004). Results of the current study warrant further investigations regarding the significant of these results. However, a possible explanation might be a cultural one, in which a holistic sense of happiness in life might not relatively be formulated by better education or higher income; rather, it might be related to the sense of believing in God's will and accepting what God has planned for everyone (AL Jabery & Arabiat, 2014). This result might also be explained by understanding the collective family orientation, in which the extended family is the key feature of family orientation in Kuwait. This family orientation could be considered a great source of help and support for families and their efforts to overcome the impact of their children disability (AL Jabery & Arabiat, 2014).

It is worth mentioning that in the State of Kuwait, parents of children with disabilities (especially the mothers) are provided with monthly allowance from the General Authority for the Disabled Affairs alongside with other supports provided from the government such as caregiver retirement pension of 100%, reduced working hours, and a full salary special leave (www.e.gov.kw). These provided services could, up to some degree, explain the absence of differences in QOL perceptions between parents based on their SES; since all Kuwaiti parents of children with disabilities are subject to these services.

In addition, results of the study showed no significant differences in parents' QOL perceptions due to their ages as well as due to their children's ages and

Table 2 Means, Standard Deviations, results of t. test, and One-Way ANOVA of WHOQOL-BREF Domains Based on Participants' Variables

Variable	Physical Health <i>M (SD)</i>	Psychological-al Health <i>M (SD)</i>	Social Relations <i>M (SD)</i>	Environmental <i>M (SD)</i>
Parents				
Mother	13.94 (2.10)	14.74(2.30)	14.55 (2.86)	13.96 (2.30)
Fathers	13.57 (1.98)	14.90 (2.53)	15.53 (1.94)	13.88 (2.64)
<i>T</i>	-.984	.387	1.684	-.183
<i>P</i>	.327	.699	.094	.855
Age				
Below 30	13.84 (1.79)	14.78 (2.57)	14.53 (2.68)	13.77 (2.35)
31-44	13.77 (2.26)	14.55 (2.34)	14.86 (2.88)	13.85 (2.41)
Above 45	13.94 (2.07)	15.54 (1.90)	15.25 (1.44)	14.54 (2.54)
<i>F</i>	.057	1.499	.607	.899
<i>P</i>	.945	.227	.546	.410
Marital Status				
Married	13.95 (2.16)	14.89 (2.22)	15.06 (2.52)	14.07 (2.37)
Single Parent	13.54 (1.80)	14.56 (2.70)	14.22 (2.78)	13.61 (2.50)
<i>T</i>	1.076	.766	1.748	1.044
<i>P</i>	.284	.445	.083	.298
Educational Level				
High school and below	13.10 (2.05)	13.86 (2.39)	13.79 (2.20)	13.28 (2.64)
Bachelor degree	14.22 (2.01)	15.24 (2.18)	15.31 (2.69)	14.22 (2.19)
Graduate degree	14.86 (.40)	17.07 (1.53)	17.07 (1.73)	16.00 (1.17)
<i>F</i>	5.678	8.629	7.985	4.544
<i>P</i>	.267	.274	.276	.265
Socioeconomic Status*				
Lower class	13.49 (2.00)	14.31 (3.00)	14.49 (3.26)	13.87 (2.80)
Middle class	13.93 (2.11)	14.65 (2.27)	14.64 (2.62)	13.85 (2.38)
Upper class	13.63 (1.99)	15.52 (2.25)	15.57 (2.14)	14.25 (2.33)
<i>F</i>	.450	1.828	1.510	.301
<i>P</i>	.639	.165	.224	.740
Disability Type				
Intellectual Disabilities-IDD	13.49 (1.68)	14.23 (2.25)	14.15 (2.62)	13.53 (2.40)
Autism Spectrum Disorders-ASD	12.35 (2.42)	14.10 (2.53)	14.29 (2.63)	13.50 (2.36)
Sensory (hearing or visual) Impairments	14.84 (2.21)	15.63 (2.56)	15.44 (2.75)	14.70 (2.24)
Physical and Other Health Impairments	13.30 (1.48)	15.39 (1.70)	15.64 (2.22)	13.86 (2.67)
<i>F</i>	2.807	2.171	1.750	1.459
<i>P</i>	.089	.094	.160	.229
Gender of Children				
Male	13.82 (2.08)	14.89 (2.28)	14.95 (2.65)	13.96 (2.24)
Female	13.84 (2.06)	14.66 (2.49)	14.62 (2.58)	13.90 (2.63)
<i>T</i>	-.085	.582	.741	.128
<i>P</i>	.954	.561	.460	.898
Age of Children				
Below 5	14.32 (2.55)	15.18 (1.89)	14.98 (2.13)	14.03 (2.25)
6-12	13.92 (1.91)	14.87 (2.38)	14.81 (2.63)	13.96 (2.49)
Above 13	13.04 (2.19)	14.14 (2.60)	14.67 (2.98)	13.72 (2.23)
<i>F</i>	2.275	1.139	.069	.113
<i>P</i>	.107	.323	.933	.893

*classification made based on parents' judgments. * P < 0.05

As shown in Table 2, mean scores related to the four domains (including participants' responses on the 24 questions) were almost similar. In general, the physical health domain had the lowest mean score among other domains and cross-variables, while the

social relations domain had the highest mean score among other domains and cross-variables. The psychological health and environmental domains were in-between of the other two variables respectively and cross-variables.

Table 1: Participants Demographics (n = 140)

Variable	N (%)
Parents	
Mothers	95 (67.9)
Fathers	45 (32.1)
Age	
Below 30	49 (35)
31-44	68 (48.6)
Above 45	23 (16.4)
Marital Status	
Married	98 (70)
Single Parent	42 (30)
Educational Level	
High school and below	52 (37.1)
Bachelor degree	83 (59.3)
Graduate degree	5 (3.6)
<i>Socioeconomic Status*</i>	
Lower class	15 (10.7)
Middle class	97 (69.3)
Upper class	28 (20)
Disability Type	
Intellectual Disabilities-IDD	44 (31.4)
Autism Spectrum Disorders-ASD	39 (27.9)
Sensory (hearing or visual) Impairments	35 (25)
Physical and Other Health Impairments	22 (15.7)
Gender of Children	
Male	79 (56.4)
Female	61 (43.6)
Age of Children	
Below 5	17 (12.1)
6-12	100 (71.4)
Above 13	23 (16.4)

*classification made based on parents' judgments.

Research Instrument

The Arabic translated version of World Health Organization Quality of Life Brief (WHOQOL-BREF) was used in this study to measure families QOL (see appendix 1). The WHOQOL-BREF is an abbreviated version of the WHOQOL-100 scale and includes 26-self administered questions. It, firstly, begins with two major questions (*How would you rate your quality of life?* and *How satisfied are you with your health?*) and continues measuring the concept of QOL through 24 questions distributed into four domains; physical health, psychological health, social relations, and environment. The range of score for each question ranges between 1 and 5, with higher scores indicating higher QOL levels (WHOQOL Group, 1996, 1998).

Computing scores on the WHOQOL-BREF requests calculating raw scores for each domain and, then, converting them to transformed scores on an either (4-20) or (0-100) scale using the tables presented on the scale instructional manual. The WHOQOL-BREF has strong reliability and validity indicators and it has been validated on several cultural groups (see WHOQOL Group, 1998 for more details). Moreover, the scale has been translated into the Arabic language and it has been validated on Arabic speaking populations (e.g., Dardas & Ahmad, 2014a; Dardas & Ahmad, 2013a; Ohaeri & Awadalla, 2009).

In this study, the Arabic translation of the WHOQOL-BREF was obtained from the WHO permission and licensing center via direct contact. The reliability indicators for the scale using Cronbach's Alpha in the current study were: (0.684) for the Physical Health domain, (0.793) for the Psychological Health domain, (0.612) for the Social Relations domain, (0.785) for the Environment domain; and (0.894) for the entire scale, respectively.

Procedures

To recruit the participants, a direct visit to all special education centers and institutions in the City of Kuwait was conducted. Then, permissions from families to participate in the study were obtained. A 160-copy of the WHOQOL-BREF Arabic version was sent to families and collected after a period of five weeks. A total of 153 copies were retrieved, hence, resulting in a response rate of 95%. A total of 140 responses were used in this study, after the elimination of 13 responses for missing more than 20% of their data (as recommended by the WHOQOL- BREF instruction manual).

Results

Data of the current study were analyzed using the Statistical Package for the Social Sciences (SPSS-16.0). The statistical testing included: (1) computing descriptive statistics (e.g., means and standard deviations), and (2) applying one-way ANOVA and independent samples *t*. test to test for any statistically significant differences between participants' demographic variables and their QOL with a p-value of (0.05). Table 2 presents calculations of means and standard deviations as well as results of *t*. test and One-way ANOVA for each of the four domains distributed based on participants demographical variables.

Regardless of differences among these studies (e.g., type of FQOL measure, origin of population, and purpose of the study), almost all of these studies mentioned lower scores of FQOL in domains related to: (1) receiving social, emotional, and professional support (e.g., support provided from neighbors, extended family members, and service providers); and (2) attaining financial, informational, health, and family counseling services. Results, in addition, indicated that variables related to type of disability, number of disabled children, age and gender of children, severity level of children's disability, household income, poverty, and socioeconomic status were potential, but controversial, predictors of FQOL (see Meral, Cavkaytar, Turnbull, & Wang, 2013 for more details).

Statement of the Problem:

The international attention toward studying the concept of QOL has influenced researchers in the Arab World to contribute in this endeavor. However, the number of these studies is quite limited. The purpose of these studies could be categorized under two main categories: (1) studies that aimed at obtaining a culturally valid and appropriate measure of QOL (e.g., Dardas & Ahmad, 2014a; Arabiat, Elliott, Draper, & AL Jabery, 2011), and (2) studies aimed at measuring the individual or family QOL (Dardas & Ahmad, 2014a; Dardas & Ahmad, 2013a; Arabiat & AL Jabery, 2013; Arabiat, AL Jabery, Abed-alqader, & Mahadeen, 2013; Ohaeri & Awadalla, 2009; Haimour & Abu-Wawwash, 2012; Al-Krenawi, Graham, & Al Gharaibeh, 2011).

Results of the first research category have provided culturally adapted and appropriate measures (e.g., WHOQOL-100; PedQOL; WHOQOL-BREF) of QOL. In addition, results of the second category indicated similar results as do the international research studies, in which parenting a child with disability impacts the family's overall QOL and that impact is varied depending on the type of child's disability, type of coping strategies, level of provided support, and the overall cultural context. Based on the above, the current study aimed at investigating the QOL perceptions of parents of children with disabilities in the State of Kuwait.

Aim of the Study

The main aim of the present study was to measure parents of children with disabilities perceptions of their Quality of Life (QOL) in the State of Kuwait by using the Arabic translated version of WHOQOL-BREF.

Research Questions

The present study tried to answer the following questions:

- 1) What are the perceptions of Kuwaiti parents' of children with disabilities on the WHOQOL-BREF and its domains?

- 2) Do the perceptions of QOL among parents significantly differ according to their variables and/or their children's variables?

Significance of the Study

The current study contributes to the current regional and international literature in several ways. First, it is the first study that targets families of children with disabilities QOL in Kuwait. Second it provides a valid, adapted, and culturally appropriate measure of families QOL that is appropriate to the culture of Kuwait. Third, it investigates the association between QOL perceptions and their characteristics as well as their children's characteristics to either concur or contradict the results of other studies.

Definitions of Concepts

Quality of Life (QOL) is defined as the individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (WHOQOL Group, 1996, p. 4).

Family Quality of Life (FQOL) is defined as the extents to which (1) the families' needs are met, (2) family members enjoy their life together, and (3) family members have a chance to do the things that are important to them (Turnbull, Turnbull, Wehmeyer, & Shogren, 2013, p. 84).

The World Health Organization Quality of Life Brief (WHOQOL-BREF) is defined as an abbreviated version of the WHOQOL-100 scale that includes 26-self administered questions distributed into four domains; physical health, psychological health, social relations, and environment.

Method

Participants

A convenient sample of 140 parents of children with disabilities participated in the study. 32.1% (n = 45; mean age = 38 years, *SD* = 11.47; range 22-75 years) were fathers and 67.9% (n = 95; mean age = 33 years; *SD* = 7.93; range 21-54 years) were mothers. The overall mean of age was 35.2 years (*SD* = 9.38; range 21-75 years) for the entire sample. The vast majority of them were married (70%; n = 98), had a bachelor degree (59.3%; n = 83), ranked themselves as the middle class in their socioeconomic status (69.3 %; n = 97) (see Table 1).

In term of children's characteristics, 65.4 % (n = 79) were males and 43.6 % (n = 61) were females. The overall mean was 9 years (*SD* = 3.19; range 5-16 years) old. In addition, 31.4% (n = 44) were diagnosed with Intellectual Disabilities-IDD; 27.9% (n = 39) with Autism Spectrum Disorders-ASD; 25% (n = 35) with Sensory (hearing or visual) Impairments; and 15.7% (n = 22) with Physical and Other Health Impairments.

From this perspective, studies have investigated the positive and negative impact of the disability on the Individuals' Quality of Life (IQOL) and Families' Quality of Life (FQOL). However, recently, the direction in studying the impact of disability has shifted from focusing exclusively on the individual quality of life into a broadened examination of perceptions held by the entire family (Gardiner & Iarocci, 2012). According to Gardiner and Iarocci, the cause of this shift in attention toward family was due to the emergence of theoretical knowledge about family system (as dynamic, interconnected, and self-regulating system), the deinstitutionalization movement, and the medical advancements that led to a longer life for individuals with disabilities (p. 2179). Accordingly, the concept of Family Quality of Life (FQOL) has been introduced in the field as a crucial measurement of service outcomes, an important predictor of family's satisfaction, and a method for enhancing family's abilities to cope and adjust with their children's disabilities (Samuel, Rillotta, & Brown, 2012; Giné, Gràcia, Vilaseca, & Balcells, 2010; Zuna, Turnbull, & Summers, 2009; Werner et al., 2009; Poston et al., 2003).

The concept of FQOL refers to "*the extents to which (1) the families' needs are met, (2) family members enjoy their life together, and (3) family members have a chance to do the things that are important to them*" (Turnbull, Turnbull, Wehmeyer, & Shogren, 2013, p. 84). Closely to this definition, is the definition provided by Zuna, Summers, Turnbull, Xiaoyi, and Xu, in which FQOL is defined as "*a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact.*" This proposed definition was based on a literature review of 24 studies and led to the identification of three common themes related to the FQOL definition and its measurement. These themes included: (1) satisfaction, (2) meeting individual family needs, and (3) considering family as a unit instead of describing and assessing the satisfaction of its individual members (Zuna et al., 2010).

Measuring FQOL

As the shift was directed in the field toward studying the impact of having a child with disability in the family, researchers varied in their view about what domains should be included to measure the concept of FQOL. In line with that, two major projects have set the foundation for the conceptualization and measurement of the term FQOL. The first was a project initiated at the University of Kansas by the Beach Center on Disability (Park et al., 2003; Poston et al., 2003; Summers et al., 2005; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006), and the other one is the International Family Quality of Life Project (Isaacs et al., 2007; Brown, Anand, Fung, Isaacs, & Baum, 2003; Brown, Isaacs, McCormack, Baum, & Renwick, 2004; Neikrug,

Judes, Roth, & Krauss, 2004). Both of these projects have provided a conceptual framework of what the term FQOL means and how it could be measured (Werner et al., 2009).

As a result of the above mentioned projects, two measures of FQOL with convenient psychometric properties were developed. The first one was the Beach Center FQOL Scale (Park et al., 2003). This scale measures family quality of life through five sub-scales including: family interaction, parenting, emotional well-being, physical/material, and disability-related support (Turnbull, Turnbull, Wehmeyer, & Shogren, 2010; Wang et al., 2006). The other one was the Family Quality of Life Survey (FQoL-2000 and the updated version the FQoL-2006). In the updated version (FQoL-2006), nine areas of family life were the focus and included: health, finances, family relationships, support from other people, support from disability-related services, influence of values, careers and planning for careers, leisure and recreation, and community interaction (Werner et al., 2009, p. 177).

Additionally, two rigorous and widely used measures of QOL have also been utilized in studies targeting FQOL. These two measures were: (1) The World Health Quality of Life-100 Scale (WHOQOL-100) and (2) The Abbreviated Version of The World Health Organization Quality of Life- BREF (WHOQOL-BREF) (WHOQOL Group, 1996, 1998). The WHOQOL-100 is a QOL assessment that was developed by the WHOQOL Group with fifteen international field centers in attempt to develop a QOL measure that would be applicably used cross culturally (WHOQOL Group, 1996, p. 4). On the other hand, the WHOQOL-BREF is an abbreviated version of the WHOQOL-100 with a 24-item that covers four major domains; physical health, psychological health, social relations, and environment (WHOQOL Group, 1996, 1998).

The availability of the above mentioned measures have supported the endeavor of measuring FQOL. Hence, several international studies have initiated to measure the QOL of families of children with disabilities. These studies have used: (1) the Beach Center FQOL Scale (e.g., Meral, Cavkaytar, Turnbull, & Wang, 2013; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006), (2) the Family Quality of Life- Survey -FQoL Survey (e.g., Brown et al., 2003), and (3) the WHOQOL – 100 and WHOQOL BREF (e.g., Gomez & Gomez, 2013; Malhotra, Khan, & Bhatia, 2012) in its original form. However, other studies have either adapted to the above mentioned measures for cultural, or developed their own culturally appropriate measures using qualitative or/and quantitative methodologies (e.g., Schippers & van Boheemen, 2009; Werner, Edwards, & Baum, 2009; Dunst, Trivette, Hamby, & Bruder, 2006).

Measuring Quality of Life (QOL) of Parents of Children with Disabilities in the State of Kuwait: An Exploratory Study of Parents' Perceptions

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Abstract: A great recognition is recently devoted to the importance of measuring (QOL) of children with disabilities Quality of Life (QOL). This recognition is considered essential in the Arab world. The purpose of the current study was to measure the concept of QOL of parents of children with disabilities in the State of Kuwait. A convenient sample of 140 parents participated in the study. Their perceptions of QOL were measured using the Arabic translated version of World Health Organization Quality of Life Brief (WHOQOL-BREF). Results of the study revealed that parents' perceptions or evaluations of their QOL levels for each of the four domains and the total score of the WHOQOL-BREF were in the range of medium to high levels. Results of independent sample t. test and One-way ANOVA revealed no statistically significant differences were found and attributed to any variable related to parents' variables or children's variables. Although, parents of children with Autism and parents of children with Intellectual Disabilities had the lower mean scores of QOL in comparison with parents' of children with Sensory and Physical and Health impairments; however, these differences in means were not significant. Results of the study warrant for future investigations by other research studies. Further explanations and recommendations are presented in the study.

Keywords: QOL, Parents of children with disabilities, WHOQOL-BREF, measuring of QOL.

Introduction

A great recognition is recently devoted to the importance of extending services and support to not only to focus on children with disabilities, but also to include the entire family in the process (Samuel, Rillotta, & Brown, 2012). As a matter of fact, we understand that disability impacts the entire family (Summers et al., 2005). Families of children with disabilities are confronted with ongoing challenges that impact various aspects of their lives (Davis & Gavidia-Payne, 2009, p. 153). Further, Studies in the field have documented both negative (e.g., depression) and positive effects (e.g., empowerment and problem solving) of disability on family functioning (Meadan, Halle, & Ebata, 2010; Bayat, 2007).

تقييم "جودة الحياة" لدى أسر الأطفال ذوي الإعاقة في دولة الكويت:

دراسة استكشافية لتصورات الوالدين

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ملخص: يشهد الميدان في الآونة الأخيرة اهتماماً منقطع النظير بمفهوم جودة الحياة (Quality of Life-QOL) وآليات تقييمه لدى أسر الأطفال ذوي الإعاقة. حيث يعتبر استقصاء هذا المفهوم وتقييمه هاماً لمنطقتنا العربية. هدفت الدراسة الحالية إلى تقييم تصورات مفهوم جودة الحياة لدى أسر الأطفال ذوي الإعاقة في دولة الكويت. حيث تضمنت عينة الدراسة 140 من آباء وأمهات الأطفال ذوي الإعاقة في دولة الكويت تم انتقاؤهم وفقاً لمنهجية العينة المتيسرة. ولتقييم تصورات الآباء، فقد تم استخدام النسخة المعربة لمقياس منظمة الصحة العالمية لجودة الحياة -النسخة المختصرة (WHOQOL-BREF). أشارت نتائج الدراسة إلى أن تصورات الأسر لتقييم مفهوم جودة الحياة لديهم تراوحت ما بين المستوى المتوسط إلى المرتفع وذلك لكل بعد من أبعاد المقياس الأربعة وللدرجة الكلية على حد سواء. كما وأشارت نتائج التحليل الاحصائي المحسوبة باستخدام اختبار "ت" للعينات المستقلة و تحليل التباين الأحادي "ANOVA" إلى عدم وجود فروق ذات دلالة احصائية في مستوى تقييم الأسر لمفهوم جودة الحياة يمكن أن تعزى إلى المتغيرات المرتبطة بهم (مثل الجنس و العمر الزمني والمستوى الاجتماعي والاقتصادي و المستوى التربوي وغيرها) أو تلك المرتبطة بأطفالهم (مثل الجنس والعمر الزمني ونوع الإعاقة وغيرها). وبالرغم من أن الدرجات الفرعية والدرجة الكلية على المقياس لدى أسر الأطفال ذوي اضطرابات طيف التوحد وآباء الأطفال ذوي الصعوبات العقلية والنمائية (الإعاقة العقلية قديماً) كانت منخفضة مقارنة بأسر الأطفال ذوي الإعاقات الحسية والإعاقات الجسمية والصحية إلا أن تلك الدرجات لم تكن ذات دلالة احصائية. وبشكل عام، تلتفت نتائج الدراسة الحالية إلى أهمية إجراء المزيد من الاستقصاءات من قبل الباحثين الآخرين لتصورات تقييم آباء الأطفال ذوي الإعاقة لمفهوم جودة الحياة لديهم. كما وتتضمن الدراسة أيضاً مزيداً من الإيضاحات والتوصيات المرتبطة بمشكلة الدراسة.

الكلمات المفتاحية: مفهوم جودة الحياة، آباء الأطفال ذوي الإعاقة، مقياس منظمة الصحة العالمية لجودة الحياة، تقييم مفهوم جودة الحياة.

The concept of Quality of Life (QOL) became a notion in the field during the 1960s and 1970s, and influenced the field of intellectual and developmental disabilities in the 1980s (Schalock, Keith, Verdugo, & Gómez, 2010, p. 20). According to the World Health Organization-Quality of Life (WHOQOL) Group, the concept of QOL is defined as "individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (WHOQOL Group, 1996, p. 4).

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