

Evaluating Quality Of Life of parents having a child with disability

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Abstract— Few studies have evaluated the quality of life for families of disabled children and none has been done in Arab countries. This study aimed at exploring the quality of life for parents of disabled children. A total number of families having children with disabilities (n=306) were participated in the study who divided into four groups; parents having a child with mental retardation (n=86), parents having a child with learning disability (n=90), parents having a child with physical disability (n= 72), and parents having a child with autism (n=58). The Arabic version of World Health Organization Quality of Life (WHOQOL) measurement was used to collect data around the research questions. The results revealed that the the (Environment) domain had the highest score (M=71.49 SD=14.21), whereas the (Spiritual) domain had the lowest score (M=11.66 SD=4.72). Facets scores results indicated that the 25th facet (Overall quality of life and general health – Overall) had the highest score (M=11.96 SD=4.56), meanwhile the 14th facet (Social support) had the lowest score (M=7.39 SD=2). A multiple regression analysis was employed to identify the domains and facets which made a significant contribution to explain the observed variance in the "Total" facet score. The "independence" domain contributed most highly ($\beta = .336$, $P = 0.00$), followed by the "psychological" domain ($\beta = .237$, $P = 0.00$), whereas the "spiritual" domain ($\beta = .094$, $P = 0.01$) had the least contribution in the total facet score. the results of the study postulated that there were significant differences in the QOL of parents having a child with disability depending on the type of disability variable, favoring parents having a child with learning disability who had the highest QOL scores (most positive), followed by parents having a child with physical disability, then parents having a child with mental retardation, and finally, parents having a child with Autism who had the lowest degree of QOL (most negative). However, further research is recommended to explore other aspects of life quality for families with disabled children.

Keywords— Quality of life, Children with disabilities, Autism, Mental retardation, Physical disability, Learning disability

I. INTRODUCTION

TYPES of children illnesses have changed dramatically during the past century. Until recently, tremendous improvements in medicine were found in children health care on probing at many of serious diseases faced by children in third world countries. Those diseases were either chronic or disabling conditions. And because of the medical technological and health care advancements, lifespan of many children with disabilities increased as well. Notably, growing number of parents and other caregivers have initiated ways to how effectively raise their children with

disabilities at home and in the community. However, while providing care to the child is considered as a normal part of being a parent of any child, providing higher levels of care necessary to a child with long-term functional limitations can become a strain and may result into impacts that affect the quality of life of the parents. Consequently, greater financial stress, more frequent disruption of family routine, and reduced social activities outside the family are basic symptoms that a family has to deal and cope with.

Recently, researchers have shown in psychological adaptation of parents who have children suffering from disabilities that those families face number of challenges much greater than those faced by parents of normal children, in particular when a child with a disability has more than one disability at the same time [1].

Remarkably, the unique experiences of parents of children with ID encounter many experiences and future challenges based on coping mechanisms that they utilize, and their perception of direct impacts of those challenges on their quality of life. Crnic, et. al. [2] reported that having a child with mental retardation involves continuous stress that incorporates many minor and major crises. The model they proposed succinctly illustrates constructs of stress, coping resources, and family ecology. Furthermore, Frey et. al, [3] found that child characteristics (e.g., severity of the disability, level of communication skills), parents beliefs, social network, and coping styles can mediate the influence of parenting stress, family adjustment, and psychological distress of parents of handicapped children.

Westbom [4] investigated the impact of children with physical and mental disabilities on parental conditions, including health and sickness absence. He found that mothers of children with disabilities had more health problems and days on sick leave than did control mothers. Recent evidence suggests that the presence of a family member with Down's syndrome might have a negative impact on maternal quality of life [5].

A. Literature review

To date there has been limited number of studies on the Quality Of Life (QOL) applications to individuals with disabilities as well as their families. Preliminary work on

QOL was undertaken by [6] to examine the impact of respite care on the quality of life of parent's caring for a child with a disability. They developed a new and convenient synthetic measurement comprises 15 items to assess the areas of (QOL) including: social activities, family relations, emotional and physical strains.

Interestingly, the results showed that respite care improved both family relations and social activities, in contrary, respite care had decreased emotional and physical strains. In another major study, [7] investigated stress and the Quality Of Life (QOL) in the parents of young people with intellectual disabilities. The initial sample consisted of 102 parents of young people with (44) and without (58) an intellectual disability. They used two questionnaires (stress questionnaire, and (QOL) questionnaire). The results showed that the families with a member with disabilities reported significantly greater stress than the families in the control group. Additionally, the results revealed that as stress increases the quality of life decreases.

Detailed examination of parental coping by [8] provided clear distinctions in parental coping across the lifespan of the child with Intellectual Disability (ID), specifically in pre-school children, young school age adults, and adults. They found that parents of school age children with (ID) had less confidence in their abilities to handle situations. They often utilize many coping mechanisms to alleviate their stress such as (crying, eating, and smoking). On the other side, parents of young adults with (ID) focused more on problem solving techniques, and were more comfortable dealing with the daily life demands. Costigan et. al. [9] draw our attention to distinctive categories of problem-Solving interactions. The sample consisted of 165 families with a Mentally Retarded child (MR) compared with 52 families without a (MR) child. They found that single mothers, to a large degree, had more difficult experiences with problem solving and misbehaviour by other children in the family.

The relationship between parent-child relationship quality and parental well-being in mothers of children with autism has been investigated by [10]. A total of 45 parents, including 18 parents of autistic children, and 27 parents of typically developing children between the ages 3-6 years completed number of related checklists. The results showed that parents of autistic children reported lower quality of parent-child relationship as well as higher levels of stress and lower levels of well-being as compared with parents of typically developed children.

Recent evidence by [11] aims to analyze the Quality Of Life (QOL) of parents having a child with newly diagnosed Specific Learning Disability (SpLD) and the impact of

clinical and socio-demographic characteristics on their (QOL). 150 parents (either mother or father) of children consecutively diagnosed as having (SpLD) were enrolled. Parent's (QOL) were measured by (WHO) Quality Of Life instrument which contains 25 facets of (QOL) organized in six domains (physical, psychological, level of independence, social relationships, environment, and spiritual). The results revealed that only four of (WHOQOL) domains (psychological, social relationships, environment, and spiritual) contributed significantly to the overall (QOL). The current interest scene needs to address these domains by councillors in order to improve the (QOL) of parents of children with (SpLD).

B. Problem statement

Far too little attention has been paid to investigate the Quality Of Life (QOL) of families of children with disabilities in Arab countries, specifically in Saudi Arabia. Said sadly that the birth of the child with disability is commonly viewed as a tragedy and the notion persists that a family with a child with disability is a family with disability diseases. Thus, some preliminary attempts to establish theoretical approaches that contribute to an understanding of Quality Of Life (QOL) have been made. Some researchers attempted to quantify (QOL), while others believed that (QOL) by its nature is individual and unique, and at this stage cannot be measured using quantitative approaches. One major issue in early QOL research concerned two main indicators of (QOL): objective indicators or social indicators refer to social norms. The term Subjective indicators or measurement of well-being has come to be used to refer to the individual's point of view. A quantitative approach was employed to examine the (QOL) of families with a child with disability.

C. Research questions

The current research questions are directed toward investigating the (QOL) of parents having a child with disability. Therefore, the following research questions were formulated to guide and investigate:

1. Which domains of the (WHO) quality of life measurement do the parents having a child with disability were significantly the lowest?
2. Are there any significant differences in the (QOL) of parents having a child with disability depending on the type of disability variable?

D. Significance of the Study

The present study is significant insofar as it:

1. Directs the programs of family counselling concerning the importance of taking the Quality Of Life for the families of individuals with disabilities

seriously because of their significant impact on the services quality provided to individuals with disabilities.

2. Highlights the interplay between families and their role in network supporting of children with disabilities lives.
3. Acknowledges the types of disabilities that have the most negative impact on the (QOL) of families having a child with disability.
4. Directs governmental policies toward bringing in further legislation to support family in regard to healthcare for family members with a disability.

E. Definition of terms

Quality of life: defined by the World Health Organization (WHO) as an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns.

Children with disability: Children who have mental or physical incapacity either congenital or caused by injury, disease, etc. In this study it refers to (physical, mental, behavioural, and sensory) impairments such as (mental disability, learning disability, and physical disability).

II. METHODS

A. Subjects

The study population consists of a group of families having children with disabilities (n=306) divided into four groups; parents having a child with mental retardation (n=86), parents having a child with learning disability (n=90), parents having a child with physical disability (n=72), and parents having a child with autism (n=58). This study conducted in three cities in Saudi Arabia, (Jeddah, Al-Baha, and Dammam). Children with disabilities in Saudi Arabia receive special education services either in special education centers or joining classes within regular schooling. Accordingly, the sample of this study was selected from this population.

B. Instrument

This study utilized (WHOQOL-100) measurement tool which is a generic multi-dimensional QOL instrument. This tool has been developed across 15 international field centres. It is designed for cross-cultural subjective assessment, and it can be used in any country where people can read and understand English language. This study was applied in an Arab country, and therefore we used the Arabic translated form of this measurement tool. According to [11] the original form (English language) of the (WHOQOL-100)

measures 100 items, and it is possible to derive six domains (areas) scores, 24 specific facets (features) scores, and one facet score that measures "overall QOL and general health". As shown in Table III each facet is represented by four items with a 5-point Likert-type response scale. Domains and facets scores range from 0 to 100, with higher scores indicating better QOL. According to the WHOQOL user manual [12], and the WHOQOL-Group [13], the WHOQOL-100 demonstrates good reliability and validity. Internal reliabilities (as measured by Cronbach alpha) of the 6 domains range from 0.71 to 0.86; and of the 25 facets range from 0.67 to 0.93; demonstrating good internal consistency. The discriminant validity (as determined via t-tests by distinguishing differences between mean scores of ill and well subjects) of the six domains range from 5 to 18.5% (P = 0.001); and of the 25 facets range from 2 to 19.3% (P = 0.001). All six WHOQOL-100 domains scores make a significant contribution to explaining variance observed in the general facet relating to 'overall QOL and general health'.

D. Procedures

In this study the (WHOQOL-100) measurement tool was prepared by the researchers in Arabic language in order to achieve the goal of this study. After visiting special education centres and public schools in which disabled children receive special education services, we obtain necessary permissions from parents to take part in the study. Necessary permissions were also obtained from families having a normally developed child to participate in the study. Total of (112) responses were adopted after eliminating 13 responses for a lack of scientific criteria.

III. RESULTS

This study aimed to investigate the (QOL) of parents having a child with disability using the (WHOQOL-100) measurement tool. Table I shows the mean scores and standard deviation for each domain (six domains) and facet (25 facets) of parents having a child with disability on the (WHOQOL-100) measurement. Regarding the domains scores, we found that the (Environment) domain had the highest score (M=71.49 SD=14.21), whereas the (Spiritual) domain had the lowest score (M=11.66 SD=4.72). Facets scores results indicated that the 25th facet (Overall quality of life and general health -Overall-) had the highest score (M=11.96 SD=4.56), meanwhile the 14th facet (Social support) had the lowest score (M=7.39 SD=2).

TABLE I
WHOQOL-100 DOMAIN AND FACET SCORES OF STUDY PARENTS (N = 306)

Domain	Facet (abbreviation)	Mean	Std. Deviation
I Physical		28.2810	6.36533
	1 Pain and discomfort*	8.1471	2.01175
	2 Energy and fatigue	9.6340	2.97807
	3 Sleep and rest	10.5000	2.80894
II Psychological		41.7680	9.19525
	4 Positive feelings	7.9052	1.94368
	5 Thinking, learning, memory, and concentration	8.0817	2.25211
	6 Self-esteem	8.0719	2.19120
	7 Bodily image and appearance	8.7680	2.66029
	8 Negative feelings*	8.9412	2.33641
III Level of independence		45.0654	12.76094
	9 Mobility	11.6078	4.17445
	10 Activities of daily living	10.4706	2.51568
	11 Dependence on medicinal substances and medical aid*	11.3170	3.71009
	12 Work capacity	11.6699	4.72096
IV Social relationships		26.3922	5.64959
	13 Personal relationships	9.4412	2.43030
	14 Social support	7.3856	1.99713
	15 Sexual activity	9.5654	3.03811
V Environment		71.4935	14.20742
	16 Physical safety and security	9.5327	2.47888
	17 Home environment	8.5490	2.30592
	18 Financial resources	8.7941	2.84232
	19 Health and social care: accessibility and quality	8.9052	2.37628
	20 Opportunities for acquiring new information and skills	8.9837	2.26370
	21 Participation in and opportunities for recreation/ leisure activities	8.9608	2.58719
	22 Physical environment: pollution /noise /traffic /climate	8.4510	2.49180
	23 Transportation	9.3170	1.93013
VI Spiritual	24 Spirituality/religion/personal beliefs	11.6569	4.72280
Additional	25 Overall quality of life and general health	11.9608	4.55766

A multiple regression analysis was employed to identify the domains and facets which made a significant contribution to explain the observed variance in the "Total" facet score. Regarding the analysis of WHOQOL-100 domain scores of parents study as shown in Table II, the model had an adjusted R2 score=0.635; meaning that 63.5% of variance in the overall facet was explained by six domains. The whole six domains scores made a "significant" contribution to explain observed variance in the "Total" facet score. Higher domain score leads to

higher "Total" facet score, and so more "positive" contribution to "Total" facet scores. Lower domain score leads to lower "Total" facet score, and so more "negative" contribution to the Total facet scores. Accordingly, the "independence" domain contributed most highly ($\beta = .336$, $P = 0.00$), followed by the "psychological" domain ($\beta = .237$, $P = 0.00$), whereas the "spiritual" domain ($\beta = .094$, $P = 0.01$) had the least contribution in the "Total" facet score.

TABLE II
MULTIPLE REGRESSION MODEL USING OVERALL QOL FACET AS DEPENDENT VARIABLE AND DOMAINS AS PREDICTOR (INDEPENDENT) VARIABLES

Model	Unstandardized Coefficients		Standardized Coefficients	T	P value*
	B	Std. Error	β .		
(Constant)	-2.781	3.069		-.906	.366
Physical	1.263	.194	.152	6.506	.000
psychological	1.364	.167	.237	8.166	.000
independence	1.395	.142	.336	9.839	.000
Social	1.113	.245	.119	4.551	.000
Environment	.606	.132	.162	4.586	.000
Spiritual	1.057	.319	.094	3.313	.001

a. Dependent Variable: total; B - Regression coefficient; SE - Standard error; β - Standardized coefficient; CI - Confidence interval; Adjusted R Square = 0.635; *P < 0.05 significant (two-tailed)

Analysis of WHOQOL-100 facet scores of parents study reveals that 71.3% of variance in the total facet was explained by the other 25 predictor facets. Multiple regression analysis revealed that 13 facets scores made a "significant" (either positive or negative) contribution to explain the variance in the "Total" facet score. Those facets as shown in Table III were in order as follows

(2,4,5,6,7,9,11,13,16,18,20,22,23). Of these, the 9th facet "mobility" contributed highly positive ($\beta = .233$, $P = 0.002$) in the "Total" QOL of parents study, and the 18th facet "financial" contributed highly negative ($\beta = -2.137$, $P = 0.023$) in the "Total" QOL of parents study.

TABLE III
MULTIPLE REGRESSION MODEL USING TOTAL QOL FACET SCORE AS DEPENDENT VARIABLE AND OTHER 25 FACETS AS PREDICTOR VARIABLES

Model	Unstandardized Coefficients		Standardized Coefficient	T	P value*
	B	Std. Error	β .		
(Constant)	-8.820	3.737		360	.019
pain1	1.210	.673	.046	1.800	.073
energy2	1.309	.499	.074	2.623	.009
sleep3	.574	.628	.030	.914	.362
positive4	3.383	.968	.124	3.495	.001
thinking5	2.082	.580	.089	3.589	.000
selfesteem6	3.058	.672	.126	4.551	.000
bodilyimage7	4.186	.849	.210	4.933	.000
negative8	.387	.828	.017	.467	.641
mobility9	2.828	.896	.223	3.154	.002
activities10	.022	.422	.001	.051	.959
dependence11	2.027	.489	.142	4.140	.000
work12	1.608	2.443	.143	.658	.511
personal13	2.097	.450	.096	4.659	.000
socialsupport14	-.846	.765	-.032	-1.105	.270
sexual15	-.974	1.017	-.056	-.957	.339
physicalsaf16	-2.406	1.173	-.113	-2.051	.041
home17	-.085	.662	-.004	-.128	.898
financial18	-2.137	.935	-.115	-2.286	.023
health19	1.005	.557	.045	1.804	.072
opportunities20	.994	.474	.042	2.098	.037
participation21	.428	.661	.021	.647	.518
physicalenv22	3.036	.803	.143	3.779	.000
transportation23	1.288	.528	.047	2.440	.015
spirituality24	.812	2.436	.072	.333	.739
ginral25	.364	.519	.031	.700	.484

a. Dependent Variable: total

In order to answer the second question the mean and standard deviation have been extracted of parents' "Total" scores on the WHOQOL-100 measurement. The results revealed that the mean number for parents having a child with mental retardation was 214.96 (SD=32.7), and 288.7 for parents having a child with learning disability (SD=26.9), and 170.79 for parents having a child with Autism (SD=32.15), and 255.43 for parents having a child with Physical disability (SD=52.98) see Table IV.

TABLE IV
QOL OF PARENTS HAVING A CHILD WITH DISABILITY DEPENDING ON THE TYPE OF DISABILITY VARIABLE

Types of Disability	N	Mean	Std. Deviation
Mental retardation	86	214.9535	32.71442
Learning disability	90	288.7111	26.90150
Autism	58	170.7931	32.14592
Physical disability	72	255.4306	33.73878
Total	306	237.8007	52.97877

When comparing the dependent variable (QOL of parents having children with disability) and the type of disability their children had, the ANOVA results indicated that there were statistically significant differences in the mean scores. Table V shows that there are statistically significant differences at ($\alpha = 0.05$) in the QOL of parents having a child with disability since calculated (f) amounted to 191.359 and significance level of *.000.

TABLE V
ONE WAY ANOVA ANALYSIS OF QOL OF PARENTS HAVING A CHILD WITH DISABILITY DEPENDING ON THE TYPE OF DISABILITY VARIABLE

Source	Sum of Squares	df	Mean Square	F	Sig.	Tukey's Summary
Between Groups	560959.367	3	186986.456	191.359	.000	
Within Groups	295099.473	302	977.151			learning disability
Total	856058.840	305				

IV. DISCUSSION AND CONCLUSION

A multiple comparison between different types of disabilities of parents having a child with disability using (Tukey HSD) test was carried out to define which differences between the means of types of disabilities were considered statistically significant as shown in Table V. Regarding the QOL of parents having a child with disability, there was a significant difference located between parents having a child with mental retardation (mean=214.96, SD=32.7) and parents having a child with learning disability (mean=288.7, SD=26.9), since the mean difference between them accounted for (73.76) favouring parents having a child with learning disability, and significance level of (*.000). Moreover, there was a significant difference found between parents having a child with mental retardation (mean=214.96, SD=32.7) and parents having a child with Autism (mean=170.79, SD=32.15), since the mean difference between them accounted for (44.16) favouring parents having a child with mental retardation, and significance level of (*.000).

Additionally, there was a significant difference found between parents having a child with mental retardation (mean=214.96, SD=32.7) and parents having a child with physical disability (mean=255, 43, SD=52.98), since the mean difference between them accounted for (40.48) favouring parents having a child with mental retardation, and significance level of (*.000). And there was a significant difference located between parents having a child with learning disability (mean=288.7, SD=26.9) and parents having a child with Autism (mean=170.79, SD=32.15), since the mean difference between them accounted for (117, 91) favouring parents having a child with learning disability, and significance level of (*.000). The analysis products reveal there was a significant difference located between parents having a child with learning disability (mean=288.7, SD=26.9) and parents having a child with physical disability (mean=255,43, SD=52,98), since the mean difference between them accounted for(33,28) favouring parents having a child with learning disability, and significance level of *.000. The results indicate there was a significant difference to be found between parents having a child with Autism

(mean=170.79, SD=32.15) and parents having a child with physical disability (mean=255, 43, SD=52.98), since the mean difference between them accounted for (84.64) favouring parents having a child with physical disability, and significance level of (*.000).

In conclusion, the results of the study postulated that there were significant differences in the QOL of parents having a child with disability depending on the type of disability variable, favouring parents having a child with learning disability who had the highest QOL scores (most positive), followed by parents having a child with physical disability, then parents having a child with mental retardation, and finally, parents having a child with Autism who had the lowest degree of QOL (most negative).

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