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IMPACTS OF INTELLECTUAL DISABILITY CHILDREN UPON PARENT'S QUALITY OF LIFE

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ABSTRACT

This study aimed to assess the quality of life of parents having child with intellectual disability. A descriptive study was conducted in Awat institute center of brain rehabilitation in Erbil city – Kurdistan region - Iraq, between 15th of February to 20th May, 2015. A standardized questionnaire (WHO - QoL, 1998) was used to assess the parent's quality of life. Fourteen related experts were validated on the questionnaire with reliability 0.918. The data collected was conducted through a direct interview, and analyzed by SPSS version 20, using frequencies, percentages, chi-square, Mann-Whitney U Test. The finding of the study found that fathers felt sensory dysfunction and pain and discomfort, but mothers were feeling low self-esteem because of their age, level of education, occupation, and body mass index. The fathers complained of social support because of their age while mothers complained of social support because of their body mass index. Overall the study found that both parents were under the burden, in addition to that the mothers were affected more than the father. The finding indicated that most mothers complained of psychosocial problems while fathers complained of the physical and social problem. But the study indicated that overall there was a significant difference between parent's quality of life.

Key words: Child, Humans, Intellectual Disability, Parents, Quality of Life

INTRODUCTION

Parents of children with various developmental disabilities experience heightened stress, overburden and marginalization in society with a sense of self blame, and tiredness. Intellectual disability (ID) can be defined as a significant limitation in both intellectual functioning and behavior, which refers to general mental disabilities, such as learning, problem solving, interpersonal skills, social responsibility, daily activities, and practical skills (AAIDD, 2013). Many people with ID, even those with known brain-based syndromes, may fall in the upper end of the ID spectrum (IQ in the 60s or low 70s) (McConnell & Llewelly, 2000). Mothers indicated that after having a disabled child, their social life, working life, and family relationships were all affected. They felt severe sadness, and the families also have financial problems (Sen, Yurtsever, 2007). Many of these children are below normal in intellectual development, have poorer language development and less developed reading skills, attain lower social maturity, and have a higher incidence of behavioral disturbances (Sen & Yurtsever, 2007; Hockenberry & Wilson, 2009). Children with ID manifested suffer from impaired social behavior, communication, language, deficit in delay milestones developmental, aggression, self-injury, and mood disorders, self-care skills, failure to grow intellectually, infantile behavior, incuriosity, unable to keep-up in school, failure to adapt, abnormal eye movement during contact, dysmorphic feature, feeding difficulty, irritable or non-responsiveness to contact (McConnell & Llewelly, 2000); Hockenberry & Wilson, 2009). Researchers focused on prenatal factors such as genetic and congenital malformations; exposure to toxins; intrauterine trauma or exposure to alcohol,

cocaine, amphetamines; biological and environmental factors such as fetal alcohol syndrome, fragile X syndrome, birth defects, infections before birth or soon after birth and hypothyroidism, low birth weight, prematurity, birth injuries, or birth asphyxia, hyperbilirubinemia, and nutritional abnormality gestational disorders. These are considered trauma causesing ID among children (Hockenberry & Wilson, (2009); Malhotra, Khan & Bhatia, 2012). A child with ID needs high level of daily care as this permanent disability may become a burden on the family that may affect both physical and psychosocial health of parents (Preece *et al.*, 2016). In a study the effects of religion and spiritual well being of parents was found to be affected due to the disabled child which have significant difference in the Quality of life (QoL) than other type of disabilities (Poston & Turnbull, 2004). Parents having chronic disabilities had reported impaired physical activity, and social relationships, and worse overall perception of their QoL (Motamedi *et al.*, 2007; Sen & Yurtsever, 2007). The nurses can play a major role in developing, and implementing the individualized education plan for each child with special needs in the school system and the individualized family service plan designed for the family and ID child in an early intervention program (Hockenberry & Wilson, 2009). Based on our knowledge this is the first study which assesses the QoL of parents having ID children in Kurdistan region- Iraq.

METHODOLOGY

Study design

A descriptive cross sectional study was carried out.

Setting and samples

Awat institute for brain training of ID children in Erbil city- Kurdistan Region /Iraq, was selected for the study. This center it is the only governmental institute which is providing functional teaching for ID children, taken care by their family, school teachers and diagnosed by the pediatrician as ID children. Non–probabilistic (purposive) samples of 165 parents (86 mothers and 79 fathers) were asked respectfully to participate in this study. These parents were providing daily care for their ID children and who attended the center daily for transportation of their children. Seven of the fathers dropped out because; three fathers of ID children were dead, two fathers were living outside of Iraq, and two other fathers were refusing to participate in the study. The parents who complained of mental ID children aged between 6-18 year old, and those attending Awat institutes, of both genders, and both parents were included in the study. The parents who complained of mental retardation with difficulty in speech and listening, ID children aged 6 years and > 18 years old, if both the parents of child is dead then they were excluded from the study.

Ethical consideration

Before participating in the study, the ethical approval was taken from the College of Nursing (CoN) / Hawler Medical University (HMU) (IRB- N0. 4 dated 11.10.2015/CoN/HMU). Before data collection the purpose of the study was clearly explained to the participants and their informed verbal consent was obtained. During the entire study period, the participants had the right to terminate their participation at any time. To avoid harming the participants during the interviews, data collectors were asked to stop an interview if a participant had a negative emotional reaction. The instrument was designed without asking any personal information such as phone number, address, and other related information. All information about the participants was kept confidential. The data collection started from 15th of February and continued till 20th May 2015.

Measurement / Instrument

A validated questionnaire was structured for those who were kindly accepted to participate in the study. The study was carried out through a series of meeting with parents; an open-ended question was introduced concerning the impact of children with ID upon their parents QoL. The study questionnaire format consisted of two parts; the first part was divided into two sections: first sections included the parents' socio-demographic characteristics which include; age, level of education, occupation, and parent's anthropometric measurements, residential area, type of family. The second section was to assess the socio-demographic characteristics of the child with ID, which consisted of age, gender, school grade and other disabilities associated with ID children. A standardized tool (WHO-QoL, 1998) was used to assess the parent's QoL, in the second part; which

adapted from World Health Organization (WHO), and consisted of three domains as follows: Physical domain: this domain consisted of 16 items namely, pain and discomfort (4 items), energy and fatigue (3 items), rest and sleep (4 items) and sensory function (5 items). Psychological domain consisted of 21 items, it was classified into six items as follows appearance and body image (4 items), thought (3 items), concentration and memory and learning (4 items), negative feeling (5 items), positive feeling (2 items) and self-esteem (3 items). Finally the social domain consisted of 11 items like interpersonal relationship (5 items), social support (4 items) and sexual activity (2 items). The tool was scored with the three alternative answers (Likert scale) 3 score for always, 2 for sometimes, and 1 for never. The higher scores of the questionnaire indicated greater effects, and lower scores referred into lower impacts on ID children upon parent's QoL. The validity of the study instrument were initially assessed through the panel of 14 experts of specialty related to the field of the present study, the alpha correlation coefficient was 0.918. The tool has been translated into Kurdish language by an official translator and two Kurdish-speaking researchers participated in the data collection. Direct interview was dependable for data collection; the data were collected and filled out by the researcher. Each interview took approximately 30–45 minutes. In the form of data collection was done without mentioning the name of the parents, their address, or any other secured information.

Data analysis

Data was prepared, organized, and interpreted by computer using Statistical Package for Social Science (SPSS, version 20) and data were an analyzed using basic descriptive statistics data analysis. Chi – square with the level of significance at 5, was considered as significant level of association. And Mann-Whitney U Test was used to detect the difference between QoL of parents.

RESULTS

Parent's profile

The result showed that less than half (43.0%) and (39.2%) of the parents aged between 37- 48 years old respectively; 44.2% of mothers were illiterate, the majority (83.7%) of mothers were housewife, while more than half (58.2%) of fathers were working as a government employee, the result showed that 38.4% of mothers were obese (Table 1). The current study showed that the majorities (98.2%) of parents were married, more than half (63.1%) parents were living with low SES, and most (75.8%) were living with the traditional nuclear family (Table 1).

Table 1: General characteristics of the subjects: (Mother (n=86) Father (n=79)

Variables	n(%)*	n(%)
Age		
28 – 37	19 (22.1)	11 (13.9)
38 -47	37 (43.0)	31 (39.2)
≥ 48	30 (34.9)	35 (46.8)
M± SD	**43.88 ± 8.29**	**46.57 ± 10.44**
Occupation		
Employee	14 (16.3)	76 (96,2)
Retired	0 (0.0)	3 (3.8)
Housewife	72 (83.7)	0 (0.0)
BMI classification		
18.5 - 24.9 (normal weight)	12 (14.0)	29 (36.7)
25 -29.9 (over weight)	32 (37.2)	26 (32.9)
30 -34.9 (obese)	33 (38.4)	17 (21.5)
More than 35 (severely obese)	9 (10.5)	7 (8.9)
M± SD	**29.43 ± 4.15**	**27.67 ± 5.07**
Type of Family		
Tradition nuclear	125 (75.8)	
Blended	19 (11.5)	
Single-Parent	3 (1.8)	
Communal	18 (10.9)	

n= number and frequency M± SD=mean and standard deviation

Intellectual disability's profile

The study found that more than half (52.3%) of ID children were at the school and at developmental age, most (69.8%) were male, and 43.0% of them were irregular in attendance to school Table 2.

Table 2: General characteristics of the ID children

Variables	n(%)
Childs Age	
6-12	45(52.3)
12-18	41(47.7)
M± SD 12.55 ± 3.29	
Gender	
Male	60(69.8)
Female	26(30.2)
Attendance to school	22(25.6)
Regular attendance	37(43.0)
Irregular	27 (31.4)
Not at tendency	
Achievement in the school	22(25.6)
Excellent	39(45.3)
Good	25(29.1)
Bad	

Quality of life domains of parent

Physical problems among parents

The study showed highly significant association between father's sensory function and their age, and a significant association between father's pain and types of family at *p*-value 0.004, 0.042 respectively (Table 3a).

Table 3a: Association between subjects profile and physical domain (Mother (n=86) Father (n=79).

Items	Mother			Father		
3.a. Physical domain Sensory dysfunction	**Always**	**Sometimes**	**Never**	**Always**	**Sometimes**	**Never**
Age						
28 – 37	15	2	2	1	1	9
38 -47	33	3	1	1	3	27
≥ 57	24	4	2	3	6	28
χ^2 **(*P*-value)**	3.40	0.757			22.364	**< 0.001**
Pain and Discomfort						
Types of family						
Traditional-nuclear	31	18	15	2	12	47
Blended	6	1	3	1	0	8
Communal	6	6	0	0	5	4
χ^2 **(*P*-value)**		7.918	0.441		9.922	**< 0.042**

n=Number of participants 2=chi-square tests p-value P ≤ 0.01

Psychological problems among parents

The finding of the study showed that there was a significant association between mother's self-esteem and the age, year of education of mothers and thought process, also there is a highly significant association between father's occupation and their thought, and there is a highly significant association between mother's appearance and BMI at *p*-value 0.001, 0.00, 0.003 respectively (Table 3b).

Table 3b: Association between subjects profile and psychological domain (self esteem) (Mother (n=86) Father (n=79)

Items	Mother			Father		
Self-esteem	**Always**	**Sometimes**	**Never**	**Always**	**Sometimes**	**Never**
Age						
28 – 37	7	7	5	2	4	5
38 -47	26	2	9	7	5	19
≥ 48	16	9	5	12	5	20
χ^2 *P*-value	16.640	**< 0.011**			11.027	0.200
Level of education						
Illiterate	34	3	0	4	1	7
Literate	33	1	2	31	7	11
High education	13	1	1	14	1	3
χ_2 *P*-value	33.839	**0.001<**			13.822	0.181
Occupation						
Employee	11	1	2	47	8	21
Retired	0	0	0	2	1	0
House wife	67	4	1	0	0	0
χ^2 *P*-value	8.673	**0.070**			15.724	< 0.001
BMI						
Less than 18.5	15	19	5	2	11	24
18.5 - 24.9	18	7	3	2	8	13
25 -29.9	1	5	2	0	5	3
30 -34.9	1	1	4	2	3	1
More than 35.9	1	4	0	0	1	4
χ^2 -value	23.765	**< 0.003**			12.297	0.138

n=Number of participants c²=chi-square tests BMI= body mass index *p*-value *P* ≤ 0.01

Social problems among parents

Current study found that there was a highly significant association between father's age and the social support. There is a highly significant association between mother's social support and BMI at *p*-value 0.002, and 0.000 respectively (Table 3c).

Table 3c: Association between subjects profile and social domain (Mother (n=86) Father (n=79).

Items	Mother			Father		
Social aspects	**Always**	**Sometimes**	**Never**	**Always**	**Sometimes**	**Never**
3.c. Social support	**f.**	**f.**	**f.**	**f.**	**f.**	**f.**
Age						
28 – 37	16	1	2	8	0	3
38 -47	25	9	3	19	3	9
≥ 48	20	8	2	7	6	24
χ^2 **(*P*-value)**	4.028	0.673			23.967	**< 0.002**
Pain and Discomfort						
BMI						
Less than 18.5	32	6	1	17	3	17
18.5 - 24.9	20	3	2	11	3	9
25 -29.9	5	1	0	2	1	5
30 -34.9	1	2	4	2	1	3
More than 35.9	3	0	0	2	1	2
χ^2 **(*P*-value)**	33.715	**< 0.000**			2.601	0.957

n=Number of participants ,2=chi-square tests BMI= body mass index *p*-value *P* ≤ 0.01

Difference between quality of life of parents

A current study indicated that there were highly significant differences between parent's QoL within over all domains (physical, psychological, and social) at *p*-value (0.000) respectively, and showed that the mean scores of mother were higher than fathers mean score (Table 4).

Table 4: A difference between parent's quality of life using Mann-Whitney (U-Test) *

Domains	Mothers (Mean score)	Fathers (Mean score)	***P*-value
Physical	2.4767	1.6203	<0.001
Psychology	2.3721	1.6456	<0.001
Social	2.6628	1.9367	<0.001
QoL	2.1744	1.6835	<0.001

*Obtained by Mann-Whitney (U-Test) ***p* ≤ 0.01

DISCUSSION

Parent's of intellectual disability profile information.

Regarding the age of the parents, the present result showed that the majority of parent's ages were between 38-47 years old. A similar study which found that 42.9% of the mother's aged was between about 32-37 years (Mugno & Rutat, 2007). The researchers found that the parents aged were between 30-40 years old (Ergun & Ertem, 2012; Hasan, 2014). With the respects to the level of education, the present study found that the half of mother's was illiterate, and one quarter of fathers were secondary school graduated. This result was supported

by a cross-sectional study, which found that the 44.2% of Iranian mothers who had ID children were illiterate (Mbugua *et al.*, 2011). Mugno & Rutat (2007) found that 43% of parents were secondary school graduated, but Ergün, & Ertem (2012) found that 72.6% of participants were primary school graduate.

Concerning their occupation, the current study found that the highest percentages (83.7%) of mother's were housewives and 58.2% of fathers were government employees. A study done by Hasan in 2014, on cerebral palsy (CP) in Kurdistan region- Iraq emphasized that overall 88% of caregivers in Erbil city were housewives, and their husbands were employed. Mbugua, Kuria & Ndetei (2011) stated that 73.7% of parents were not employed and 15.8% were businessman. In contrast, of the current result, Dardas & Ahmad (2014) and Seltzer *et al.*, (2011) emphasized that the most percentage of mother's were unskilled workers, while 80% of parent's were government employee (Seltzer *et al.*, 2011; Dardas & Ahmad, 2014). Mother's in the families who have had chronic disabilities were illiterate, and housewife; most of them complained of deficit homecare management and most of them were caregivers (Schmidt *et al.*, 2010; McConnell & Savage, 2015)

Concerning their body mass index (BMI) score, our result revealed that mother's BMI showed that they were obese and fathers were normal weight, because in the Middle East cultures the men have more time than women for walking and for other movement. Fornieles *et al.*, in 2013 who found that 76.5% of mother's having child with ID were obese and overweight. Others emphasized that the mother's having ID children with developmental disability were obese (Seltzer *et al.*, 2011). McConnell & Savage (2015) found that the parents having ID were overweight. Similar study found that the parents caring for children with ID especially mothers, were more likely to be overweight, and compared to control parents. However, evidence showed that older parents were at risk of ill-health as they consumed more saturated fat with greater BMIs (Gallagher *et al.*, 2008).

Regarding the marital status of parents, majority of study individuals were married. Another study in Jordan indicated that 98.2% of parents were living together and were married (Dardas & Ahmad, 2014). According to Mugno *et al.*, (2007) in Italy, it was found that 77% of parents are living together. Likewise, similar study was done in Kenya and mentioned by Hasan, (2014) emphasized that 63% of caregivers were married in contrast with Denise and others in the USA found that only 47% of parents were living together (Ergun & Ertem, 2012).

With regard to their SES the present study found that the most (63.0%) parents lived with low SES. Ergun *et al.*, in Turkey found that most families live in low SES. A Canadian researcher named Law *et al.*, (2014), found that most of the parents were living in low SES. Concerning the types of family, most of the parents were living within the traditional nuclear family, our present study agreed to a study which was done in the USA and found that half (51%) of parents were biologically interacted and living within traditional family (Ergun & Ertem, 2012). Also supported by a Turkish study, which found that 86.3% of parents were belong nuclear family (Mugno & Rutat, 2007). This result disagreed with a study was done in Canada and found that the majority (83%) of children lived in blended family.

Intellectual disability's profile

Regarding the child's age, more than half (52.3%) of ID children samples were male at the school level and were at developmental stage. The finding was similar to Ergun *et al.*, (2012) among Turkish people who found that 59.5% of children were aged between 7-12 years (Ergun & Ertem, 2012). A study in a Rural Setting in Kenya and indicated that 51% of the ID children were 6-9 years old (Mbugua, Kuria, & Ndetei, 2011). Law *et al.*, in Canada found that ID children were in adolescent stage, which is in contrasted with current result. Rimmer and colleagues (2011) reported that the age of children with disability was between 15-18 years. Concerning the gender of children, the findings of the present study showed that most of the ID children were male. Motamedi *et al.*, in Tehran (Iran) (2007) found that 67% of the ID children were boys. Researchers found that male were more in number than females (Mugno & Rutat, 2007; Boyd *et al.*, 2010; Fornieles *et al.*, 2013).

Association between parent's profile QoL domains and physical domain

The result showed that there is a highly significant association between father's sensory function and their age, while there is no significant association between mother's sensory function and their age. Current study

found that there was a significant association between types of family and fathers' pain. Boyd *et al.*, (2011) found that the parent's sensory functions are affected by their children who had developmental delay and their behaviors. Emerson (2003) found that the parents of children with ID experience impairment, physical functioning, tiredness or exhaustion. Most of Muslim cultures depend on father as the source of economy, their efforts affects on their rest and comfort. Furthermore, the ID fathers were significantly more affected, than mothers. Dardas & Ahmad (2014) emphasized that family members are considered reasonable predictors of pain and discomfort. It would seem that the fathers' expectations are harder to fulfill than the mother's (Emerson, 2003). The fathers' expectations are attuned to the outer world; the actual day-to-day tasks related to the child's care cause pain, but the mothers are less demanding and their expectations are more self-focused (Pelchat & Lefebvre, 2004).

Association between parents profile and psychology domain

Current study showed that there is a significant association between the mother's age and their self-esteem. There was a highly significant association between mother's thought and their year of education. There is significant association between fathers' occupation and their thought. Regarding child's BMI the result of the present study found high significant association between BMI and mother's appearance. The present study showed that the mothers were worried because living with a disabled child can have profound effects on the entire family, other siblings, and extended family members. It is a unique shared experience for families and can affect all aspects of family functioning. Self-esteem is a part of an individual's personality; this may reflect on the general self-esteem of women. Another study found that the mother's tended to have a lower self-esteem compared with fathers. The women's education effects on their thought (Yamada *et al.*, 2012).

Association between parents profile and social domain

The current study found that there was a significant association between father's age and social support, while there was no significant association between mother's age and social support. Ergun and Ertem, (2012) stated that the society plays an important role in sharing the values, feeling and happiness which is leading to acceptance also help to overcome new roles and identification. Fathers of the children with ID suffered from impaired social relationship (Preece *et al.*, 2016).

A comparison between parents quality of life within overall domains

The present study found, highly significant difference between parents QoL in overall domains (physical, psychological, and social), mothers were recorded high mean scores than fathers. Malhotra *et al.*, (2012) in Delhi, suggested that the parents of children with ID experienced grater stress and poorer QoL than parents of children without ID. The result indicated that there were significant differences in the QoL of parents having a child with a disability depending on the type of disability (Poston & Turnbull, 2004).

More specifically, mothers of children with ID displayed lower physical health, impairment in social relationships, in their psychological status and poorer perception of their environment, While Fathers complained of their psychological status and impairment in social relationships (Malhotra, Khan & Bhatia, 2012). Parents in the delay, developmental group reported impaired physical activity and social relationships with worse overall perception of their QOL and health status (Motamedi *et al.*, 2007).

LIMITATION

Some of the parents were excluded from the study because they didn't attend Awat institute especially fathers. It was difficult to find funding support to bring parents from their home to the institute for filling out the questionnaire because of their low Socioeconomic Status. The present study clearly indicated that finally the lack of official and accurate statistic which clearly refers to the number of ID in Erbil city.

CONCLUSION

The majority of mothers suffered from Physical, Psychological, Social, while the majority of the fathers suffered from Psychological factors. Overall the study found that both parents were under burden, but the study realized that mothers complained of a poorer quality of life compared with the fathers.

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