

**NEAR EAST UNIVERSITY
GRDUATED SCHOOL OF SOCIAL SCIENCES
GENRAL PSYCHOLOGY MASTER PROGRAM**

MASTER THESIS

**LIFE QUALITY OF FAMILIES HAVING A CHILD WITH
AUTISM SPECTRUM DISORDER IN KURDISTAN REGION
OF IRAQ**

GORAN KAMERAN ABDULLAH

20135373

SUPERVISOR: ASSIST.PROF.DR.ZIHNIYE

NICOSIA – 2015

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Özet

Irak’ın Kürdistan Bölgesinde Otistik Spektrum Bozukluğu olan Ailelerin Yaşam Kaliteleri

Hazırlayan, Goran Kameran

Haziran, 2015

Bu çalışmanın amacı otistik spectrum bozukluğu tanısı almış çocuğa sahip olan ailelerin yaşam kalitelerini ve bazı değişkenlerle ilişkilerini tesbit etmektir. Irak’ın Kürdistan Bölgesi’nin başkenti olan Erbil kentinde bu araştırma yürütülmüştür. Toplam olarak 76 katılımcı soru formlarını doldurmuştur. Yaşam kalitesi Dünya Sağlık Örgütü Yaşam Kalitesi Ölçeği (WHOQOL-BREF) ile ölçülmüş ve uygun istatistik yöntemlerle değerlendirilmiştir.

Bulgular doğrultusunda annelerin otistik çocuğa bakım veren temel kişiler olduğu, yaş grubu ikide olan anne-babaların diğer yaş gruplarına göre daha fazla otistik çocuğa sahip oldukları görülmüştür. Bunların yanı sıra, birçok ailenin orta okul mezunu, orta düzeyde gelire sahip ve kırsal kesimde yaşadıkları da görülmüştür. Çocuklara bakıldığında ise otistik spectrum bozukluğu olan çocukların çoğu erkek ve tanı alma yaşı olarak da 4-8 yaş aralığında olanların daha çok olduğu görülmüştür. Bunlara ek olarak, bulgular doğrultusunda dünya ile kıyaslandığında Irak’ın Kürdistan Bölgesinde otizm tanısı daha geç konmaktadır.

Sonuç olarak, genel sonuçların Yaşam Kalitesi ölçeğinin en az bir alt ölçeğinde ailelerin yaşları, eğitim durumları, ekonomik durumları, yaşanan bölge ve çocuğun doğum sırası gibi değişkenlerin farklılık yarattığı bulunmuştur. Bunların yanı sıra, Yaşam Kalitesi Ölçeği alt ölçeklerinden hiçbirisi medeni durum, ailenin işi ve çocuğun eğitim durumuyla ilişkili fark tesbit edilmemiştir.

Anahtar kelimeler: Otizm, Ailelerin yaşam kalitesi

Abstract

Life Quality of Families Having A Child Autism with Spectrum Disorder in Kurdistan Region of Iraq

Prepared by: **Goran Kameran**

June,2015

The purpose of this study is to explore the quality of life of parents having a child autism spectrum disorder and its association with some related variables. It has been conducted in Erbil, the capital of Kurdistan Region of Iraq. A total of 76 participants completed the questionnaires. Quality of life was measured by a standardized questionnaire of the World Health organization (WHOQOL-BREF) instrument and analysed using an appropriate statistical method.

The overall results indicated that mothers are the main care-giver of a child with autism, the parents with the group age of giving birth (2) were more likely to have autistic children than other group ages. Furthermore, most parents graduated from secondary school, had a medium socio economical level and live in urban areas. In regards to the child, the results showed that most of children with autism spectrum disorder are male and children within the age of 4 to 8 years were more likely to get autism disorder diagnosis than others. In addition, the results indicated that children with autism usually get late diagnosis in Kurdistan compared to the rest of the world.

Finally, the overall results showed that there is significance difference between at least one domain of the QOL and age group of the parents, level of education of the parents, economic status, residential area and the birth order of the child. However, the research found no correlations between any domain of the QOL and marital status of the parents, parent's occupation, and age and education level of the child.

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Key words: Autism, Life Quality of families

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The work presented in this Thesis is, to the best of my knowledge and belief original, except as acknowledged in the text, and has not been submitted either in whole or in part, for a degree at this or any other university.

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Goran Kameran

2015

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List of Abbreviations

ASD	Autism spectrum disorder
APA	Psychiatric Association
PDD	Pervasive developmental disorder
WHO	World health organization
QOL	Quality of life
SPSS	Statistical package social sciences
QOLWHO- BREF	Quality of life world health organization- Brief
DSM-IV	Diagnostic and Statistical Manual of Mental Disorder.4th edition
KRI	Kurdistan region of Iraq

Introduction

1.1 Description of Autism

The autism society of America at 2005 defined autism such as growing disorderly and it will be appear on the first third years of the childhood. At the result of the damaging nerves which affects to the brain orders and eventually that also causing the mental development delay. Which the shortage of the social communication will happen in both oral and writing ways. And those children they have more answers for the things than for the human beings and their circumstances will be soon changing when something happen in their lives. They continually repeat some special behaviours and words in their lives (Suleiman, 2007, p.17)

According to Gillham (2000, p. 269) autism can be identified as an organic developmental and mental disorder which manifests itself in the form of atypical behaviours, strain social functioning and disturbances in communication (Volkmar & Pauls 2003).

Autistic disorder is the most common pervasive developmental disorders with early childhood onset (Murphy et al, 2007, p. 47-48)

Autism is also defined as the presence of a marked impairment in development of social interaction and communication with restrictions in activity and interest. Autism affects between 2 and 20 people per 10,000 in general populations, it occurs in boys more than girls, with the ratio ranging from 2:1 to 5:1. However, when girls are affected, they tend to be more severely impaired and have poorer outcomes. About half of children with autism are mentally retarded, and about 25% have seizure disorders (Boyd, 2004, P. 608).

Autistic spectrum disorder (ASD) is a neurological pervasive developmental disorder that cripples an infant's ability to communicate and interact with others in social settings. ASD is a problem for individuals from all the diverse ethnic groups and is also not subject to socioeconomic status. The centre for disease control and prevention (Ibrahim&Nuree, 2008, p.10) ranked ASD as the third most dominant developmental disorder after cerebral palsy and intellectual retardation or disability.

ASD can be described as an intricate combination of both neurobiological and developmental disabilities. These disabilities take form within the child's three years. However more than 50 percent of autistic children are only diagnosed during their schooling years. The neurological development and functioning of children afflicted with ASD is stranded in activities involving communication and interaction with others. These infant exhibit complications in social interactions and communication. Children with autism typically have difficulties in verbal and nonverbal communication as well as general play and gaming activities (Varcarolis & Halter, 2010, P.639).

Children afflicted with ASD frequently exhibit complicated behaviour patterns that disturb both family and parental functioning significantly. Parents of autistic children usually have limited time for themselves and their health because of the overwhelming burden poised by caring for these disabled children. These caregivers are considered to be predisposed to significantly diminished satisfaction in several domains of their wellbeing. (Davis and Carter ,2008, P.531) postulated that these parents typical experience heightened stress levels, deteriorating mental health, difficulty navigating social functioning (Hartley et al, 2010), diminished general health and rigid functioning within the family unit. A gestalt view is required to fully comprehend the psychological tools of parents of autistic children and factor affecting their health and general quality of life. Statistics in America estimate that half a million children suffer from ASD, such that 1 in very 150 children is afflicted (Reserved. 2012).

Providing for a child suffering from ASD can prove to be financially draining and one parent may feel incapacitated because they may have to stay at home to take care of the child and not go to work. This has negative impacts on the family structure and financial status. The result situation may be positive or negative to different members of the family and also produces varying anxiety and depression levels which are subject to the member's interaction with the autistic child (Gundogar, 2010,p.1917-18).

Autism is kind of paralyse that happen to the human and this will cause them they cannot control then mind to escape from reality Those child will demonstrate they don't care about family and by so they will lose the feeling of pain and they will care about other things that they aren't important with normal people and that's why they love to look out the sky because the lost communication with community (Zalhay, 2005, p.21).

1.2 History of Autism

A word of autism is a Latin (contain 2 parts the first is (Aut) which means (self) and the second is (Ism) which means (state) and for that word means (self-state) also autism is considered a psychiatric disease because it belong to psychiatric disease and this is developing to their important categories (communication ,social ,thinking)the autism thinking is called self-destruction thinking because it's really goes into action this malfunction is appears in first year of the second year (Ali, 2013,p.31)

Its background to the 16th century (Johannes mathesius) in 1504-1565in the reclaim of a child 12 years old which had most of symptoms of autistics and he thought that this child is a realness and he cannot control himself and it needed for this symptoms should be illuminated to kill that devil in his soul(saleh,2012,p18).after that the French doctor (Jean- Marc- Gaspard Itard) in (1775- 1838) who worked as a doctor in French army and he was specified in ear disease and teaching child's with special recurrent he had an experiment of a child of the child named (victor) which called mad a violent child . he wrote the life of victor begins at the time that his wife dispose him in one of France woods and they leave him for Many years without any control and this child was left for many years without any terms of life. And (Jean- Marc)at the age of 12 he found (victor)and he prepare him to move civilized environment and new life in France and he tried to teach victor some basics things and teach him in simple way so he can have the ability to react far simple things and so victor had a difficult in region the society(Talar, 2005, p.27).

The thought of autism have been seen by the German doctor (Hugh Blair) in 1911and he decided to more explain more symptoms of autism. He found that autism is disease of coughing arrowed with thing born with the child that not Easley observed. (Walter, 2011, p.513)

After that in 1938 Hans Asperger at Vienna College at Austria he used crystal word to explain autism mal Function of community acts by the children. At this pain on the hand of scientist (Lora wench and yeti frays) started this made a lot of experiment at autism at the national autism at UK at 1962 the wrote a important stake like a book theory of reason that baron took apart in this society they figure out that people with autism are having difficulty with getting in many ways lack of mind. To stand the investigation on autism they established had quarter with (Baron) 1962 and (Metlar) 1966 (Kemal, 2005, p.18-19)

In 1943 (Kanner) he used autism and established a list for children who has autism but (Hans Asperger) found another type of autism (Asperger) and in another way the communication of child with their people. Those children with autism they barely recognize people in and out and he said that children who learn language in new letter they won't be successful (Hassan, 2009, p158)

At (1960 -1970) the treatment of hate also included so teaching and training people for autism to deal with it more. Those people who have child with autism shall deal normally with him and away from punishment or to use autism drug when autism growth to use more drug (Ali, 2013, p.33).

At the (1980-1990) of second century the advanced autism research begins at this time autism was scientific known. Because at the ear low was all research only and primary report that cannot be depend on that why a lot of autism report was there on at that time .at the same time the research gives hope to the accuracy of autism in the research of (ASKANDANAFI and UK) countries there was a difference in marriage of one a part done from that marriage two part done till now this way their children no autism. (Zand .et al.,2006 p.27)

1.3 Diagnostic and Statistical Manual of Mental Disorders

Throughout many years, the diagnostic criteria has been unfolded and elaborated, along with during the time frame of the DSMIV. (Ben-Zeev & Corrigan 2010). While the main characteristics' of ASDs have included a simple triad of impairments closely linked to social interactions, communication deficits and restrictive/repetitive behaviours and interests. At this moment of time, research has been significantly inclined of the new proposed Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V), along with this new edition; symbolic effects will markedly adjust the current diagnosis of ASDs (Autism Genetic Research Exchange, 2008). In the current draft, the triumvirate is significantly lowered to two core features, those being the social interactions/communication and restrictive behaviour (Ben-Zeev & Corrigan 2010, p. 318-327).

Alterations to the current ASD symptomatic criteria have been made a few times through the years, most as of late in May of 2013, alongside the distribution of the fifth version of the (DSM- V). (Catherine & Ann, 1994, pp. 653-682). Significant changes to analytic criteria in

which including the widening or making criteria stricter are thought to straightforwardly affect commonness. (Glorisa, Patrick, Ligia, Pedro, Milagros, Ann, 2004).

The most up to date recent changes incorporate a disintegration of the diverse sections laid out in the past version of the DSM. While text modifications of the fourth release including Autistic issue, Asperger's disorder, pervasive developmental disorder issue not generally specified (PDD-NOS). Lastly, youth disintegrative anarchy (CDD) into one class called ASD. (Rutter, 1994, pp. 571-593.).

As indicated by the Diagnostic and Statistical Manual of Mental Disorders (DSM-1V), children who are with ASD are less ready and not so able to collaborate with the world and/or connect with society as other kids do. (Community Report on Autism, 2014). They are at same time being confronted with deficits in correspondence both verbal and non-verbal, social mindfulness and connection additionally inventive play (variable hobbies and conduct) or subject to schedules, profoundly delicate to changes in their surroundings. Its influences (1-2500) with a male to female ratio of pretty nearly four to one in this sense of case. (Holmes& River, 1999, pp. 231–239.).

Utilizing DSM-IV, patients could be diagnosed with as many as four different disorders: autistic disorder, Asperger's disorder, childhood disintegrative disorder, or the catch-all diagnosis of pervasive developmental disorder not otherwise not generally indicated. (Holmes& River, 1999, pp. 231–239.). Research has been found that these different varieties of judgments were not reliably connected crosswise over distinctive facilities and treatment focuses. (Holme&River, 1999, pp. 231–239). Anyone which is diagnosed with one of the four pervasive formative issue (PDD) from DSM-IV are still to meet the benchmark for ASD in DSM- V, more exact DSM- V conclusion. After all, DSM does not layout accurately and effectively pin point the treatment and administrations for mental disorder. (Michael. 1995, pp. 457-679.). Lastly, making judgment in deciding a precise judgment is a first venture for a clinician in characterizing a treatment arrangement for a patient. The American Psychiatric Association (APA) will distribute DSM-V in 2013, in an ultimate 14-year modification process. (Marcos, 2010, pp. 10–11).

Senior investigator, Susan Swedo, MD, is currently leading the Neurodevelopmental Work Group at the National Institute of Mental Health. (Fred, 2000, pp. 124-163). This is work group has ultimate great potential in the current present moment of time and in the coming years. As highly suggested and regarded the DSM- V benchmark for ASD to a more grateful

and affective reflection of the state of ability and awareness about the significance of autism. (Marcos, 2010, pp. 10–11). The Work Group accepts a solitary umbrella disorder will enhance and efficiently improve the conclusion and final stages of ASD without constraining the affectability of the benchmark, or considerably making significant changes to the quantity of children being diagnosed. (Fred, 2000, pp. 124-163).

While the DSM-V has been scientifically tested in real-life clinical settings as a feature of DSM-V field trials, and investigation has been obtained from testing indicated and demonstrated that there were no critical alterations in the commonness of the disorder. (Kelsey, 1996). All the more as of late, the most biggest and most exceptional study, distributed by Huerta, et al, in October 2012 issue of American Journal of Psychiatry, contributed the most complete and comprehensive evaluation of the DSM-V criteria for ASD taking into account the extraction from beforehand obtained information. (Catherine&Ann, 1994, pp. 653-682.). As the study continued to make significant progress, it had found the that the DSM-V criteria identified 91 percent of children with clinical DSM-IV PDD diagnosis, providing a reasonably fair statement that most children with DSM-IV PDD diagnoses will retain their diagnosis of ASD utilizing the new criteria. Few various studies, using methodologies, have been conflicting in their discoveries. (Catherine & Ann, 1994, pp. 653-682.).

Evaluating this significant issue, Huerta et al. embarked a journey of discoveries to focus the affectability and specificity of the contemplated DSM-V criteria relative to the DSM-IV criteria. (Catherine & Ann, 1994, pp. 653-682.). It has applied three data sets incorporating 4,453 children with a DSM-IV clinical analysis of pervasive formative disorder (PDD) and 690 with non-PDD findings (e.g., dialect issue). (Sirey, et al, 2001, pp. 479–481). It was reported a general affectivity of 0.91 and a particularity of 0.53 for the recommended DSM-V criteria. (David, 2005).

The schemed modification for (ASD) in the DSM V has established a debates lately, most strikingly in the connection to the likelihood that a few people who at present meet criteria under the DSM-IV-TR, but would no longer meet the criteria under the proposed DSM-V. (David, 2005).

Lastly, in addition to a proposed change in the DSM-V is decreasing the areas of disability from three to two by consolidating the social connection and correspondence spaces into a single solitary area. While the adequately implies that the current present situation eight

criteria in these ranges will be decreased into the three criteria categories. (Kim, et al, 2011, p. 904-12). RRBs will be the second DSM-V area and will comprise of four criteria categories, which significantly incorporate astonishing and extraordinary sensory behaviours. While in order to meet the criteria for Autism range issue under the proposed DSM-V amendment, the child must meet each of the three of the social correspondence debilitations and no less than two of the RRBs. After all as indicated by the DSM-V Neurodevelopmental Workgroup, the reason for demanding no less than two indication symptom manifestations from RRBs is to enhance specificity.

As indicated by the DSM-V Neurodevelopmental Workgroup, the reason for needing no less than two indication appearances from RRBs is to enhance specificity. (Williams, 2008).

1.4 Families with a Child Diagnosed as Autism Spectrum Disorder

Caregiver of infants suffering from autism spectrum disorders (ASD) experience daunting hardships and their lives are plagued with endless expectations and obligations. Their stress levels are higher than those of parents of children with other disabilities or normal children (Zalhay.2005, p.23). According to Baxter (2002), parents of autistic infants are also more susceptible to anxiety and depression than both the mentioned groups (Baxter et al. 2000, P. 105–118). In most families where there is an autistic member, parents feel constricted and unable to plan or initiate career development (Brown et al. 2006, p. 238–245).

A review of the psychological adaptation studies on parents of autistic children revealed that most of these researches employed partial analysis of variables to predict adaptation. However, a multidimensional and holistic approach must be adopted to simultaneously examine the influence of different factors. Only a limited number of studies have used this approach in the investigation on the adaptation tools for parents of children afflicted with ASD (Pozo et al. 2006, p. 342–7).

In comparison with the rest of the nation, mothers of children with autism have the greatest mental health problems. They harbor negative emotions and are more predisposed to burnout because of the burden of caring for autistic children. The mothers are requiring to be stronger and more sensitive than the fathers. The strength of the mother-child bond is subject to the extent of the child's maladaptive behaviours, the extend of social impairment of the child and the attitude of the mother toward the child's disability. The strongest bond is created when

the child exhibits less severe maladaptive behaviour, has less social impairments and the mother has a positive attitude and sensitivity towards the child's disability. Relationships fostering warm affection are associated with greater care giving benefits for the mother. These benefits are closely related with quality of life and families that experience difficulties adapting and communicating are predicted to have elevated anxiety and depression (Ghanizadeh et al, 2009, p. 478 – 482).

Parents have a pivotal role in the development of their children's psychological, academic and social life. Parents are considered of utmost importance in all transitions in life as symbols of stability and consistence. According to Hart and Kelley (2006) the welfare and development of infants with chronic disabilities is highly dependent on their parent's mental health (Pesonen et al., 2008).

Parents of children afflicted with ASD were found to experience diminished satisfaction with their quality of life than parents of Down syndrome plagued with Down syndrome on eight of nine of the measured domains. Their dissatisfaction lay in their finances, health, family coordination and outsider support. Preparation, leisure, general pleasure from life, support from disability enabling bodies, community and civil involvement were also other domains where the parents of autistic children scored low. However they scored high on satisfaction from spiritual and cultural affiliations. This population also score low on marital satisfaction, family adaptability and high on family cohesion and discord (Mugno et al. 2007).

Turnbull (2004, p. 4) postulates that parental care is imperative to the deinstitutionalization and improvement of the intellectual abilities of children with intellectual impairments

Quality of Life of ASD Families

In an attempt to improve the quality of life, studies have been conducted since the 1970s to treat and manage most chronic disabilities and medical conditions. (QOL) is a crucial measure of benefit of treatment for individuals suffering from mental and physical ailments. Longitudinal studies reveal poor outcomes for individual with autism however limited research has been dedicated to evaluating the results of autism using actual world measures including employability, social support and self-reliance to develop a standardized measure of success. According to Burgess and Gutstein (2007,P. 80–86) setting QOL indicators as the base for creating treatments and assessing outcomes in autism would prove very useful for monitoring progress.

The World health organization defines QOL as the individual's own assessment of their living situation in the context of the culture and value system operating around them additionally accounting for their aspirations, expectations, standards and concerns. QOL is an intricate concept extending to the individual physical status, psychological health, independence, personal beliefs, social interactions and a sustainable relationship with their environment (Mugno, et al, 2007).

ASD is a *neuro-developmental delay* (NDD) whose common features include variations of social and communication difficulties. These individuals exhibit restricting and repetitive behaviours that negatively impact the family's functioning. Families with members plagued with ASD are characterized by elevated stress levels and depression; they also experience diminished marital and family unity (Bundy & Kuncie, 2009, p. 401- 410).

Furthermore families of children with ASD are most typically likely to have unattended health issues or needs, unmet family support needs and unknown service referral needs. According to Kogan (2008) the knowledge of their unmet needs and the high prevalence of ASD an estimated one in sixty-eight (Centres for Disease Control, 2014), serve as the logic behind the assessment and investigation of QOL among families of children afflicted with ASD.

Only in the last decade has research on FQOL surfaced although the impact of raising autistic children had been highlighted well before. The cornerstone for this field is the vast literature on the quality of life of individuals with ID for example Cummins (1997, p. 116-150). Shu (2009) alludes that having a child suffering from ASD disrupts family dynamics and results in financial, physical, social and psychological problems for the other members of the family. These families are in need of extensive external support to neutralize these negative reactions.

It is imperative to take into consideration cultural difference in the designing and implementation of valid and reliable QOL measures. It also ensures accuracy of cross-cultural programs. However most studies dedicated to the QOL of parents of autistic children were based on Western countries or developed middle-eastern countries. Presently there are no such researches carried out among Arabic individuals. Arabic culture and beliefs are markedly different from western one and so are the people. Furthermore Arabs have a common culture shared among different Arabic nationalities (Retso, 2002).

1.5 Literature Review About Quality of Life

This section provides results and discussion of most common researches that have been done, so far, in regards to Quality of Life of families with child Autism Spectrum Disorder (ASD). It will highlight the differing views as well as contributing factors that relate to quality of life within a family.

Falk, Norris, and Quinn (2014) studied the factors predicting stress, anxiety, and depression in the parents of children with Autism using a survey based methodology. A total of 479 parents (250 mothers, 229 fathers) of children with Autism participated in the study and were asked questions in the form of statements, to which the respondents asked quantified their agreeability using a Likert scale ranging from 1-5; 1 being “strongly disagree”, and 5 being “strongly agree”. The questions pertained to things such as aggression of child, financial dependency and economic support, as well as need for support from friends, family and society. The study concluded that traits of Anxiety in parents related to maternal age and the mother’s ability to set behavioural limits, and traits of Depression were linked, or rather predicted, to the child’s aggression towards the adults. Although these two traits differ in predictors, Falk, Norris, and Quinn argue that there is a ‘core theme’ central to both – which they define as the ‘perception of control’. The basis of the ‘perception of control’ is as follows: depression describes a perception of parental influence over the child’s developmental behaviour patterns (in response to depression seen in parents) and anxiety is more specific to a perceived ability to set limits on maladaptive behaviour, however, both these are still measures of parental perception of control, and in both cases if a parent does not perceive any direct influence over their child, it can be a prediction of a form of elevated mental health measure. One parent commented *‘I get very depressed. My three sons are on the spectrum. My youngest doesn’t speak much and has Hypertonia and he seems so unhappy. And I feel so guilty because I should be able to help him. I feel like such a bad mother.’* (pg. 3198)

These findings would suggest that there is somewhat of a cyclical influence of parents and child, that is, autistic children react and/or adapt to projections of mental health of their parents, and thus reflect such emotions onto their parents, and so on in regression. The study by Falk, Norris, and Quinn (2014) used both mothers and fathers, however did not highlight any major differences between the responses of the two.

One study by Dabrowska & Pisula (2010, pg. 266) suggested that mothers have higher levels of stress with regard to Autistic children, and was also found to be more easily demoralized in the behavioural conditions of the child in comparison with the fathers. A similar study by Allen, Bowles, Weber (2013, pg. 5) showed that ASD children who exhibited a greater deficit in sensory and cognitive awareness was positively correlated with fatherly stress. On the other hand mothers would experience relatively more stress than fathers in the same situation. Other studies, such as Hastings (2003, pg. 234) seem to suggest that fathers and mothers experience similar levels of stress in relation to their ASD child.

Although studies vary with respect to stress of mothers and fathers of children with ASD, it is clear that regardless of whether mothers or fathers experience more stress, anxiety, depression and so forth, there is an effect of raising ASD children on the mental health of parents. It is a matter of quality of life. However, we cannot say for certain if these numbers are consistent with parents with children who do not have Autism Spectrum Disorder (ASD) and so this research needs to be cross correlated with a study comparing the two in order for definitive conclusions to be made.

A study compared parents of children with ASD and parents with children without ASD, and found that the parents of children with ASD were much less satisfied with their quality of life (Higgins et al, 2005,p. 125-37).This is an important study as it highlights in direct terms the level of dissatisfaction with quality of life.

This strain on mental stability can, in some cases, cause the parents to divorce, putting the Autistic child in an even further compromising situation. Hartley (2010) studied the rate and likelihood of divorce in parents of children with ASD. It was expected that parents of children with a form of ASD had a extended period of susceptibility to divorce (pg. 450). This vulnerability markedly dropped once the child reached the age of approximately 8 years of age. The study was compared with the general population and was found to be similar in many ways. The risk of marital separation was shown to be similar in the first several years of marriage in parents with young children (without ASD). However, as children grow they become more and more independent and thus rely less and less on their parents. Unfortunately this is not the case with parents with children that have ASD, as there is a perpetual need for parents to shelter and care for them even past what would be the age of maturity in a child that does not suffer from ASD (pg. 455). And thus even though there is a marked drop in divorce risk within the first 8 years, similar to parents with children without

ASD, the stress brought on by taking care of an autistic person continues for much longer than that faced by parents with children who do not suffer from ASD.

Another study by Higgins (2005) used a survey based method to find out more about quality of life of parents with ASD children. 87% of the respondents indicated that they were in a stable relationship with their partner (Higgins, 2005, pg. 131), while acknowledging that there existed high levels of stress, whether physical, emotional, or financial. Of the 134 surveys, only 75.5% of respondents had never been separated or divorced (Higgins, 2005, pg. 128). This strongly suggests that divorce is no more common in parents with children of ASD, and that having a child with autism, although stressful at times, had little effect on the outcome of whether a marriage would end in divorce. However, this is not to be confused with level of satisfaction in a marriage, as in some cases it would be very difficult for the ASD child to cope with divorce, and thus with the child's interest in mind parent's may opt not to divorce or separate. Another thing to note is the disparity of the levels of happiness of parents of ASD children and parents of children without ASD. The study revealed that the former were somewhat less happy than the control group (parents with children that don't have ASD). A limitation to this study is the large difference between respondents dealing with ASD and respondents of non-ASD children.

It can be seen that for parents to be successful in raising a child with ASD they must be quite resilient in order to manage the needs of their child. Bayat (2007) studied the resilience of families with children with Autism. A survey based method was used asking open ended questions to a cohort of 175 parents with a child with Autism aged between 2 and 18. The results showed that there were two necessary factors of resilience within a family; the first being the family's ability to pull resources together and the second being the family members being connected. 62% of the respondents expressed themselves as pulling together and being together in an act of familial resilience to adversity. This came with subsequent effects such as husband and wife becoming closer as a result. One respondent says "My son's autism has made our family life tougher, emotionally and financially.... In some sense, this also makes our family closer, because an individual cannot handle the toughness alone." (Bayat, 2007, pg. 709) There is somewhat of a positive conclusion in this study as it shows how parents of children with autism can persevere, regardless of any perceived inferiority of day to day life.

The study is however limited as 80% of the children with Autism were male (Bayat, 2007, pg. 706), and thus we do not get an evenly distributed gender. The study also uses open ended questions that may be ambiguous in nature and left for the researcher to interpret and

conclude findings, which can be problematic. More empirical method should be sought using even distribution of gender.

Another factor under the umbrella of quality of life when discussing parents, or rather families, with children with autism spectrum disorder is finance. Money, or lack thereof, can put a lot of strain on a families, and thus affects the quality of life. A Canadian study (Brown, 2003) asked families of ASD children about their finances, more specifically how they felt of their total income. An answer ranged from families being either “well off” or “just getting by”, what’s interesting is that no family described themselves to be “struggling” in terms of finances. However, on average, the 34 families that were studied spent \$624.12 per month on care, support, or equipment for the family member with ASD. In the same study it was found that 31 of 34 families indicated that they make a conscious effort to seek activities that are both fun and enjoyable for the whole family, contributing to the overall happiness, and thus quality of life.

The intensity of the burden bore by families raising autistic children was revealed in a study by Lee et al, (2003) who found that the QOL for individuals with autism may be inaccurate. Members of families with children diagnosed with autism experience further reaching effects on the quality of life than others with children suffering from Attention Deficit Hyperactivity Disorder or Attention Deficit Disorder (Lee et al, 2003).

In Japan, Yamada (2012, P.1-9) postulated that physical activity and social relationships retardation were common features in parents of children afflicted with PDDs. In contrast research on such children residing with grandparents showed elevated maternal QOL score in relation to physical activities.

Hayder (2011,p.3-5) studied parents of autistic children in Qatar and reported that such parents were more predisposed to experiences of psychological and physical ill-health in comparison to parents of regular children. This revealed how emotionally and physical demanding raising an autistic child was on the caregiver and their lives. Cumulative QOL scores signified impoverished health among parents while autistic children unlike parents with typically developing infants whose scores suggested both physical and psychological health.

Religious affiliations and community support are imperative to rising the FQOL scores of families with children with ASD (Roxana, 2012, p. 1-8). Studies in Romania revealed the benefits of these affiliation and services. Furthermore the lack of financial, social and career

support produced a trend of significantly low FQOL scores. Opportunities for financial and social support were also revealed to be scarce for this population group. Roxana (2012), asserts that family support, career and financial support were significant predictors of the family's FQOL score.

A comparison between childrearing practices of parents of children afflicted by ASD revealed no significant deviation from the conventional child rearing practices. However infants with ASD like other children with developmental disorders have exaggerated reactions to changes in the environment or family for example upheaval within the family, relocation, new family member or general psychological stressors. They are irritable and sometimes unable to cope with the slightest change in their immediate surroundings or family (Sadock and Sadock, 2008,P.605-611).

1.6 Statement of the Research Problem

According to the Kurdistan Society statistics, the number of children diagnosed with autism in Kurdistan has grown at an alarming rate. In 2010, about 1500 cases have been reported with ASD in all cities in Kurdistan (540 in Erbil, 480 in Sulaimanya and 430 in Duhok). This indicates that the total number of children diagnosed with ASD has been doubled from 2013 to 2014. While only 150 children with ASD were diagnosed and reported in 2010. According to DCD global organization, there were about 67,000,000 cases of children diagnosed with ASD in the world in 2014 (ASK document census, 2012).

This study is to investigate the quality of life for those parents who have children autistic problems in Kurdish society. Unfortunately, most of parents are not familiar with autism and have a little knowledge on how to treat or deal with their children.

1.7 Hypothesis

We expect that those parents, who have autistic children, have high stress interims of psychological conditions. There for according their life they face social problems in comparison with those parents don't have any problems in their daily life.

1.8 Research Question

This study conducted to address certain key question about the life quality of families who have autistic children, the question include, is there high stress interims of psychological conditions among the family members?

Methodology

2.1 Participants

In this research, many useful information (about the parents and the children with autism) have been collected from several rehabilitation centers of autism in Erbil, the capital of Kurdistan Region of Iraq. A sample has been collected randomly from a total of 76 parents with child spectrum disorder. All the parents have interviewed separately and completed all questionnaires freely, without applying special conditions.

2.2 Socio-Demographic Information about Parents

Socio-demographic characteristics of parents is a standard form aimed to collect information about the individual parent with child spectrum disorder. The form, which is shown in Appendix A- English version and Kurdish version, includes various information about the main care-giver, including the age, level of education, occupational status, level-economic status, number of family and residential area.

2.3 Socio-Demographic Information about Autistic Child

Similar to the previous form, this socio-economic form collects useful information about the child diagnosed with autism spectrum disorder. A copy of this form is shown in Appendix B in both languages, English and Kurdish. These information includes gender, age, level of education, year diagnosed, birth order, other autistic in the family and any other disabled individuals.

2.4 WHOQOL-BREF Questionnaires

The World Health Organization Quality of Life (WHOQOL) project was initiated in 1991 to develop an international cross-culturally comparable quality of life assessment instrument. It comprises 26 items, which measure the following broad domains: physical health, psychological health, social relationships, and environment. Each item is rated on 5 point scale ranging from not at all to completely. The questionnaire is to assess general quality of life of parents with autistic children.

The physical dimension of health is probably the easiest to understand. The state of physical health implies the notion of —perfect functioning‖ of the body. It conceptualizes health biologically as a state in which every cell and every organ is functioning at optimum capacity and in perfect harmony with the rest of the body (ALgorany, 2010).

The domain of psychological well-being' is associated with negative feelings of mood, sadness, anxiety, and dissatisfaction with oneself. Both mothers and fathers in the MR and autism groups had highly significantly impaired QOL in this domain (Malhotra et al, 2012, p.173-174.).

The chronic illness frequently affects the quality of client's social relationships and roles, at the same time clients social support affects their quality of life. Likewise, individual's socio-cultural backgrounds and relationships influence their response to illness and nation's quality of life (ALgorany, 2010)

Environmental health is defined by the World Health Organization as those aspects of the human health and disease that are determined by factors in the environment. It also refers to the theory and practice of assessing and controlling factors in the environment that can potentially affect health (WHO, 2007).

A standardized tool for assessment the quality of life adopted from World Health Organization (WHO) was used in data collection, (WHOQOL-BREF). This tool was translated from English language (see both English and Kurdish versions of the form in Appendix C) to Kurdish language by Dr. Redar Mohammed Ameen, who has PhD degree in Psychiatric, to become clear and understandable questionnaire. It was found that Determination of reliability of the total QOL was based on the test-retest method, alpha correlation coefficient was computed and indicated that the correlation coefficient was 0.913. (Ameen,2013,Fatah,2013)

On the other hand, The content validity of the study questionnaire was determined initially through a panel of 25 experts from different related specialties. They were asked respectively to review the draft of the questionnaire for clarity and adequacy in order to achieve the objectives of the present study. The expert's responses were positive towards the study instrument: They recommended some modifications regarding socio-demographic characteristics. They took all the responses into consideration, and some changes have been done in the tool to prepare the version suitable for conducting the study (Mosleh, 2013).

A copy of email that gives permission of using the Kurdish version of the WHOQOL-BREF form is shown in Appendix D.

2.5 Data Analysis

In this study, data will be analyzed by using statistical package for social sciences (SPSS, version 20.0) for Windows which is used to analysis the data. Percentage and frequencies will be used for categorical variables. Furthermore, the analysis of data will include T-test, one way ANOVA and Correlation.

RESULTS

The results are based on data that have been directly collected from 76 families with autistic children in Erbil-Iraq. Useful information about the care-giver and the child are analyzed, using special tools, and organized in tables (Tables 3.1 to 3.2) to indicate the over- all percentage in each case. The differences between each case with QOL subscale, namely, over scale, physical scale, psychological scale, social scale and environment scale, are also shown in Tables 3.3 to 3.13. These records have been computed with one way Anova statistically method.

Table 0.1. Socio-demographical characteristics of parents

Items		n	%
Care-giver	Father	37	48.7
	Mother	39	51.3
Age of parents	24-29	3	3.9
	30-34	15	19.7
	35-39	26	34.2
	40-44	19	25.0
	Older than 44	13	17.1
Marital stats	Married	75	98.7
	Separated	1	1.3
Level of education	Unable to read /write	7	9.2
	Able to read / write	10	13.2
	Primary school graduate	14	18.4
	secondary school graduate	23	30.3
	Bachelor's degree	21	27.6
	Higher degree	1	1.3
Occupation	Unemployed	22	28.9
	Government	29	38.2
	Private Sector	9	11.8
	Self-employed	16	21.1
Residency	Urban	73	96.1
	Rural	3	3.9
Economic Level	Very bad	4	5.3
	Bad	16	21.1
	Medium	39	51.3
	Good	14	18.4
	Very Good	3	3.9

Table 3.1 shows all necessary information about the primary care-giver of the child with autism spectrum disorder. According to the table, one of the parents (either mother or father) is the primary care-giver of the child with the score of 48.7% for the father (n=37) and 51.3% for the mother (n=39). As expected, mothers are the main care-givers of autistic children in Erbil. Regarding the ages of parents, parents with autistic children aged between 35 to 39 years old have the highest percentage 34.2% (n=26) among other group ages. While younger parents with age various from 24 to 29 years have lowest percentage 3.9% (n=3). The percentages for other group ages were 19.7% (n=15) for the age group (30-34) years, 25% (n=19) for the age group (40-44) years and just above 17% (n=13) for those parents aged 44 years and above.

In respect to the parents marital status, majority of the parents with autistic children are married and living together with their child. With percentage of 75% (n=75) of married parents, the child is expected to receive higher care and live in a better environment. The table shows that only 1.3% of parents were separated.

Regarding the level of education of the parents, almost a third of parents (30.3%, n=23) have completed secondary school. Parents who hold bachelor's degree have a percentage of 27.6% (n=21) in total studied sample and Parents who were unable to read/write have a percentage of 9.2% (n=7) of the studied sample. For the remaining cases, 13.2% (n=10) of the parents were just able to read and write and only 1.3% (n=1) holds higher degree education.

The next section of the table shows the occupation of the parents and their percentages. It can be seen that most of them 38.2% (n=29) were government workers, 28.9% (n= 22) were unemployed, 21.1% (n=16) were self-employed and 11.8% (n= 9) worked in private sectors.

Concerning the residential area, the table shows that the highest percentage of the taken sample were from urban area with 96.1% (n=73) and only 3.9% (n=3) were living in rural area.

This research also studied the socioeconomic status of the parents and found that 51.3% (n= 39) of them were with medium socio economical level, 21.1% (n=16) were having a low or bad socio economic status, 5.3% (n=4) were in a very economical situation and only 3.9.7% (n=3) were having a very good socio economic status.

Table 0.2. Background Characteristics of the Autistic Child

Items		N	%
Gender of child	Male	57	75.0
	Female	19	25.0
Age of Child (years)	4	8	10.5
	5	13	17.1
	6	14	18.4
	7	15	19.7
	8	11	14.5
	9	6	7.9
	10	5	6.6
	11	2	2.6
	12	2	2.6
Child Level of education	Unable to read /write	69	90.8
	Able to read / write	4	5.3
	Primary school graduate	3	3.9
Date Diagnosed	2005	1	1.3
	2007	3	3.9
	2008	2	2.6
	2009	6	7.9
	2010	9	11.8
	2011	14	18.4
	2012	12	15.8
	2013	19	25.0
	2014	9	11.8
	2015	1	1.3
Birth Order of Child	First	19	25.0
	Second	24	31.6
	Third	15	19.7
	Fourth	8	10.5
	Fifth	5	6.6
	Sixth	2	2.6
	Seventh	2	2.6
	Ninth	1	1.3
Any Other Autistic Child in the Family?	Yes	4	5.3
	No	72	94.7
Any Other Disabled Child in the Family?	Yes	7	9.2
	No	69	90.8

Table 3.2 shows all information about the child diagnosed with autism disorder. These data have been collected from the studied sample.

Concerning the gender of the child, it can be seen that most of them were males 75.0% (n=59) and only 25.0% (n=19) of them were females. The study also shows that more than 80% of autistic children were aged between 4 to 8 years with 10.5% (n=8) of the participants were 4 years old, 17.1% (n=13) were 5 years old, 18.4% (n=14) were 6 years old, 19.7% (n=15) of the participants were 7 years old and 14.5% (n=11) of the them were 8 years old. According to the studied sample, children with ages various from 9 to 12 years were less

likely to get autism disorder. The percentage for children aged 9-12 years were below 20% with 7.9% (n=6) of them were 9 years old, 6.6% (n=5) were 10 years old, 2.6% (n=2) were 11 years old and 2.6% (n=2) were 12 years old.

Regarding the child level of education, the table shows that a massive percentage of 90.8% (n=69) of the children were unable to read/write, while only 5.3% (n=4) of the children were able to read/ write and 3.9% (n=3) of them were at/or graduated from primary school.

The table also shows a highest percentage of the cases with 25.0% (n=19) have been diagnosed with the autism disorder in 2013, while the lowest percentage of diagnoses occurred in 2005 and in 2015 with 1.5% (n=1) of the total studied cases. In 2007, 3.9% (n=3) of the participant children found to have autism disorder. Similar result has been reported in 2008 with a percentage of 2.6% (n=2) children diagnosed with autism. The number of children diagnosed with autism disorder has dramatically increased to 7.9% (n=6) in 2009, 11.8% (n=9) in 2010, and 18.4% (n=14) in 2011. However, the total number of children found to have autism disorder has decreased slightly to 15.8% (n=12) in 2012 and 11.8% (n=9) in 2014.

The next section of the table shows the birth order of the child in the family with autistic children. It can be seen that most of the families have their second child diagnosed with autism with a percentage of 31.6% (n=24). While 25.0% (n=19) of the families got their first child diagnosed with autism. It can be noted that the percentage of the birth order reduces as the birth order of the child increases from third to ninth with 19.7% (n=15) for the third birth order, 10.5% (n=8) for the fourth birth order, 6.6% (n=5) for the fifth birth order, 2.6% (n=2) for the sixth and the seventh birth orders, and 1.3% (n=1) for ninth birth order child.

The research also studied other cases where the families with autism children having other autistic or disabled child in the family. A percentage of 5.3 % (n=4) of the families reported that they did have another autistic child in the family, meanwhile 94.7% (n=72) of the families did not have other autistic child. The last section of the table shows that the majority of the parents, 90.8% (n=69), do not have any other disabled child in the family. While, 9.2% (n=7) of the families suffer from another disabled child in the family.

Table 0.3. Differences between Age group of parents with QOL domains

QOL domains and Items	Age of Parents	Mean \pm Std. Deviation	F	P
Over Scale	24-29	12.50 \pm 62.50 (n=3)	1.651	0.171
	30-34	15.83 \pm 7.78.50 (n=15)		
	35-39	13.94 \pm 8.53 (n=26)		
	40-44	15.13 \pm 11.28 (n=19)		
	Older than 44	7.69 \pm 9.93 (n=13)		
Physical scale	24-29	118.78 \pm 16.53 (n=3)	2.636	0.041*
	30-34	111.25 \pm 20.34 (n=15)		
	35-39	111.29 \pm 19.04 (n=26)		
	40-44	118.09 \pm 31.72 (n=19)		
	Older than 44	88.46 \pm 37.91 (n=13)		
Psychological scale	24-29	83.33 \pm 21.94 (n=3)	1.974	0.108
	30-34	95.00 \pm 14.21 (n=15)		
	35-39	84.37 \pm 18.13 (n=26)		
	40-44	94.73 \pm 25.19 (n=19)		
	Older than 44	77.88 \pm 23.33 (n=13)		
Social scale	24-29	37.50 \pm 10.82 (n=3)	0.663	0.620
	30-34	43.33 \pm 30.93 (n=15)		
	35-39	36.29 \pm 11.45 (n=26)		
	40-44	39.14 \pm 9.51 (n=19)		
	Older than 44	33.65 \pm 13.91 (n=13)		
Environment scale	24-29	103.33 \pm 28.86 (n=3)	0.961	0.434
	30-34	100.83 \pm 23.12 (n=15)		
	35-39	98.31 \pm 25.59 (n=26)		
	40-44	109.86 \pm 36.52(n=19)		
	Older than 44	37.00 (n=13)		

*P \leq 0.005

Table 3.3 shows the performances of parents' activities for each age group in terms of physical scale, psychological scale, social scale and environment scale. One way anova analysis was used to analysis differences between age group of parents with quality of life domains, as it be seen, no significant differences have been found in the over scale, psychological scale, social scale and environment scale for any age group. The only significant difference found was in the age group 44 years and above in terms of physical scale with a low level score of P=0.041 and mean score of 29, 63 \pm 9.62 (n=13).

Table 0.4. Differences between Marital status of parents with QOL domains

QoL domains and Items	Marital status	Mean ± Std. Deviation	t	P
Over scale	Married	13.41 ± 9.56 (n=75)	0.307	0.581
	Separated	18.75± 0.00 (n=1)		
Physical scale	Married	109.16± 28.01 (n=75)	0.315	0.576
	Separated	125.0000± 0.00 (n=1)		
Psychological scale	Married	88.25± 21.00 (n=75)	1.483	0.227
	Separated	62.50± 0.00 (n=1)		
Social scale	Married	38.0833±17.01 (n=75)	0.159	0.691
	Separated	31.2500± 0.000 (n=1)		
Environment scale	Married	37.99± 30.52 (n=75)	0.949	0.423
	Separated	125.00± 0.00 (n=1)		

*P≤0.005

Table 3.4 reports the effects of marital status on each QOL subscale. One way anova analysis was used to analysis differences between marital status of parents with QOL domains. It can be noticed that no significant differences have been found within the studied sample.

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Table 0.5. Difference between _ Level of educations of parents with QOL domains

QoL domains and Items	Parent Level of Education	Mean \pm Std. Deviation	F	P
Over scale	Unable to read /write	6.25 \pm 14.87 (n=7)	2.003	0.103
	Able to read / write	12.50 \pm 9.77 (n=10)		
	Primary school graduate	11.60 \pm 8.07 (n=17)		
	secondary school graduate	16.84 \pm 9.68 (n=23)		
	Bachelor's degree	13.92 \pm 6.93 (n=22)		
Physical scale	Unable to read /write	72.32 \pm 33.04 (n=7)	5.596	0.001*
	Able to read / write	105.62 \pm 29.08 (n=10)		
	Primary school graduate	102.23 \pm 20.88 (n=14)		
	secondary school graduate	117.66 \pm 26.69 (n=23)		
	Bachelor's degree	118.75 \pm 20.50 (n=22)		
Psychological scale	Unable to read /write	63.39 \pm 24.85 (n=7)	3.624	0.010*
	Able to read / write	85.00 \pm 22.85 (n=10)		
	Primary school graduate	85.26 \pm 17.43 (n=14)		
	secondary school graduate	93.20 \pm 20.63 (n=23)		
	Bachelor's degree	93.18 \pm 16.80 (n=22)		
Social scale	Unable to read /write	30.35 \pm 11.65 (n=7)	0.795	0.532
	Able to read / write	33.12 \pm 11.04 (n=10)		
	Primary school graduate	41.96 \pm 34.09 (n=14)		
	secondary school graduate	39.40 \pm 9.87 (n=23)		
	Bachelor's degree	38.63 \pm 8.10 (n=22)		
Environment scale	Unable to read /write	74.10 \pm 33.74 (n=7)	2.389	0.059
	Able to read / write	91.25 \pm 25.54 (n=10)		
	Primary school graduate	98.66 \pm 22.75 (n=14)		
	secondary school graduate	104.61 \pm 34.75 (n=23)		
	Bachelor's degree	110.22 \pm 26.97 (n=22)		

**P<0.005

Table 3.5 shows the impact of the level of education of parents with autistic children on each QOL subscale. Anova results show that there is a significance difference between physical scale and parents who unable to read/write with P=0.001 and its mean score in this case is 46, 42 \pm 10.84 (n=7). In addition, there is significant difference between psychological scale and parents who unable to read or/and write with P=0.010 and its mean score in this case is 29, 81 \pm 8.52 (n=7).

Table 0.6. Difference between Occupation of parents with QOL domains

QoL domains and Items	Parent Occupation	Mean \pm Std. Deviation	F	P
Over scale	Unemployed	11.36 \pm 10.50 (n=22)	1.360	0.262
	Government	12.50 \pm 8.99 (n=29)		
	Private Sector	17.36 \pm 6.83 (n=9)		
	Self-employed	16.01 \pm 9.93 (n=16)		
Physical scale	Unemployed	99.71 \pm 28.50 (n=22)	2.338	0.181
	Government	110.99 \pm 22.82 (n=29)		
	Private Sector	127.77 \pm 17.98 (n=9)		
	Self-employed	109.37 \pm 35.50 (n=16)		
Psychological scale	Unemployed	80.11 \pm 21.87 (n=22)	1.646	0.186
	Government	90.51 \pm 17.88 (n=29)		
	Private Sector	95.83 \pm 14.65 (n=9)		
	Self-employed	89.45 \pm 26.39 (n=16)		
Social scale	Unemployed	36.93 \pm 27.06 (n=22)	0.236	0.871
	Government	37.93 \pm 9.87 (n=29)		
	Private Sector	42.36 \pm 9.77 (n=9)		
	Self-employed	37.10 \pm 12.59 (n=16)		
Environment scale	Unemployed	90.34 \pm 25.64 (n=22)	1.687	0.177
	Government	103.87 \pm 29.23 (n=29)		
	Private Sector	115.27 \pm 33.52 (n=9)		
	Self-employed	100.39 \pm 34.87 (n=16)		

*P<0.005

Table 3.6 in one way Anova table reports the type of occupation the parents have with respect to each QOL subscale. In the studied sample, no significant differences have been found between the occupation of the parents and the QOL scales.

Table 0.7. Difference between Economic Status with QOL domains

QoL domains and Items	Parent Economic status	Mean \pmStd. Deviation	F	P
Over scale	Bad	-4.68 \pm 5.98 (n=4)	18.901	0.000*
	Very bad	4.68 \pm 8.06 (n=16)		
	Medium	16.50 \pm 5.64 (n=39)		
	Good	18.30 \pm 7.93 (n=14)		
	Very good	22.91 \pm 9.54 (n=3)		
Physical scale	Bad	64.06 \pm 29.91 (n=4)	14.633	0.000*
	Very bad	87.50 \pm 24.04 (n=16)		
	Medium	112.50 \pm 20.57 (n=39)		
	Good	131.69 \pm 18.58 (n=14)		
	Very good	141.66 \pm 3.60 (n=3)		
Psychological scale	Bad	51.56 \pm 13.85 (n=4)	17.851	0.000*
	Very bad	68.35 \pm 15.04 (n=16)		
	Medium	93.26 \pm 15.46 (n=39)		
	Good	100.00 \pm 15.30 (n=14)		
	Very good	114.58 \pm 15.72 (n=3)		
Social scale	Bad	25.00 \pm 5.10 (n=4)	1.076	0.375
	Very bad	40.62 \pm 31.70 (n=16)		
	Medium	36.37 \pm 10.52 (n=39)		
	Good	42.85 \pm 8.07 (n=14)		
	Very good	39.58 \pm 3.60 (n=3)		
Environment scale	Bad	56.25 \pm 15.30 (n=4)	14.993	0.000*
	Very bad	73.43 \pm 25.25 (n=16)		
	Medium	105.12 \pm 20.62 (n=39)		
	Good	124.10 \pm 28.78 (n=14)		
	Very good	135.41 \pm 15.72 (n=3)		

*P<0.005

Table 3.7 One way Anova indicates effect of the economical level on each QOL subscale. It can be seen that more than one significant differences have been recorded for parents with very bad economical level. In over scale, parents with very bad economical level report a strong significant difference with P=0.000 and mean score of 27, 60 \pm 5.20 (n=16). Same significant difference have been reported with P=0.000 and mean score of 77, 60 \pm 16.20 (n=16) for physical scale. In addition, parents with very bad economical level have as low as P=0.000 for psychological and environment scales with mean scores of 46, 22 \pm 9.62 (n=16) and 79, 16 \pm 17.59 (n=16), respectively.

Table 0.8. Difference between the age of the Autistic Child with QOL domains

QoL domains and Items	Age of Child	Mean \pm Std. Deviation	F	P
Over scale	4	11.71 \pm 10.79 (n=8)	0.814	0.593
	5	13.94 \pm 7.71 (n=13)		
	6	10.71 \pm 8.64 (n=14)		
	7	14.16 \pm 10.42 (n=15)		
	8	18.18 \pm 9.03 (n=11)		
	9	9.37 \pm 13.54 (n=6)		
	10	17.50 \pm 5.22 (n=5)		
	11	12.50 \pm 17.67 (n=2)		
	12	9.37 \pm 4.41 (n=2)		
Physical scale	4	110.15 \pm 33.72 (n=8)	0.229	0.984
	5	108.17 \pm 21.10 (n=13)		
	6	112.50 \pm 24.51 (n=14)		
	7	109.58 \pm 28.82 (n=15)		
	8	107.95 \pm 39.14 (n=11)		
	9	97.91 \pm 34.83 (n=6)		
	10	117.50 \pm 17.34 (n=5)		
	11	118.75 \pm 35.35 (n=2)		
	12	103.12 \pm 13.25 (n=2)		
Psychological scale	4	85.93 \pm 21.58 (n=8)	0.810	0.596
	5	89.42 \pm 14.74 (n=13)		
	6	85.26 \pm 16.18 (n=14)		
	7	85.00 \pm 23.59 (n=15)		
	8	96.02 \pm 25.35 (n=11)		
	9	76.04 \pm 29.15 (n=6)		
	10	100.00 \pm 7.65 (n=5)		
	11	96.87 \pm 48.61 (n=2)		
	12	78.12 \pm 4.419 (n=2)		
Social scale	4	39.84 \pm 21.07 (n=8)	0.438	0.894
	5	36.53 \pm 9.83 (n=13)		
	6	38.39 \pm 11.19 (n=14)		
	7	42.91 \pm 31.94 (n=15)		
	8	37.50 \pm 8.83 (n=11)		
	9	34.37 \pm 11.00 (n=6)		
	10	27.5000 \pm 14.38 (n=5)		
	11	37.50 \pm 0.00 (n=2)		
	12	40.62 \pm 4.41 (n=2)		
Environment scale	4	106.25 \pm 34.718 (n=8)	0.629	0.751
	5	102.40 \pm 26.08 (n=13)		
	6	100.00 \pm 27.18 (n=14)		
	7	100.41 \pm 36.63 (n=15)		
	8	99.43 \pm 32.53 (n=11)		
	9	79.16 \pm 28.41 (n=6)		
	10	107.50 \pm 19.96 (n=5)		
	11	96.87 \pm 57.45 (n=2)		
	12	128.12 \pm 13.25 (n=2)		

*P<0.005

Table 3.8 shows that there is no significant differences between the ages of the autistic child with QOL subscales with one way Anova analysis.

Table 0.9. Difference between Education levels of the Autistic child with QOL domains

QoL domains and Items	Child Level of Education	Mean \pm Std. Deviation	F	P
Over scale	Unable to read /write	13.31 \pm 9.81 (n=69)	0.484	0.618
	Able to read / write	12.50 \pm 5.10 (n=4)		
	Primary school graduate	18.75 \pm 6.25 (n=3)		
Physical scale	Unable to read /write	107.97 \pm 28.31 (n=69)	1.173	0.315
	Able to read / write	117.18 \pm 18.66 (n=4)		
	Primary school graduate	131.25 \pm 21.65 (n=3)		
Psychological scale	Unable to read /write	87.40 \pm 21.58 (n=69)	0.357	0.701
	Able to read / write	89.06 \pm 12.88 (n=4)		
	Primary school graduate	97.91 \pm 20.09 (n=3)		
Social scale	Unable to read /write	37.77 \pm 17.65 (n=69)	0.177	0.838
	Able to read / write	37.50 \pm 5.10 (n=4)		
	Primary school graduate	43.75 \pm 6.25 (n=3)		
Environment scale	Unable to read /write	99.45 \pm 30.50 (n=69)	0.657	0.522
	Able to read / write	117.18 \pm 17.95 (n=4)		
	Primary school graduate	104.16 \pm 45.21 (n=3)		

*P<0.005

Table 3.9 One way Anova shows no significant differences between the mean ranks of the education levels of autistic child with QOL subscales.

Table 0.10. Difference between Birth Order of the Child with QOL domains

QoL domains and Items	Child Birth Order	Mean \pm Std. Deviation	F	P
Over scale	First	12.82 \pm 8.95 (n=19)	2.862	0.011*
	Second	14.84 \pm 7.32 (n=24)		
	Third	16.66 \pm 8.40 (n=15)		
	Fourth	13.28 \pm 12.24 (n=8)		
	Fifth	16.25 \pm 9.47 (n=5)		
	Sixth	0.00 \pm 0.00 (n=2)		
	Seventh	-3.12 \pm 13.25 (n=2)		
	Ninth	-6.25 \pm (n=1)		
Physical scale	First	10.53 \pm 22.08 (n=19)	3.601	0.002*
	Second	11.62 \pm 25.47 (n=24)		
	Third	11.41 \pm 25.97 (n=15)		
	Fourth	10.81 \pm 28.49 (n=8)		
	Fifth	11.75 \pm 21.37 (n=5)		
	Sixth	50.00 \pm 17.67 (n=2)		
	Seventh	78.12 \pm 39.77 (n=2)		
	Ninth	37.50 \pm (n=1)		
Psychological scale	First	83.88 \pm 15.63 (n=19)	3.192	0.006*
	Second	92.70 \pm 18.12 (n=24)		
	Third	89.16 \pm 20.92 (n=15)		
	Fourth	89.84 \pm 24.98 (n=8)		
	Fifth	10.25 \pm 14.65 (n=5)		
	Sixth	46.87 \pm 13.25 (n=2)		
	Seventh	59.37 \pm 39.77 (n=2)		
	Ninth	62.50 \pm (n=1)		
Social scale	First	43.75 \pm 27.24 (n=19)	0.809	0.583
	Second	38.28 \pm 8.70 (n=24)		
	Third	35.00 \pm 13.32 (n=15)		
	Fourth	35.15 \pm 13.74 (n=8)		
	Fifth	35.00 \pm 7.12 (n=5)		
	Sixth	25.00 \pm 0.00 (n=2)		
	Seventh	43.75 \pm 26.51 (n=2)		
	Ninth	18.75 \pm (n=1)		
Environment scale	First	94.07 \pm 27.67 (n=19)	2.389	0.030*
	Second	103.64 \pm 22.64 (n=24)		
	Third	106.66 \pm 33.69 (n=15)		
	Fourth	103.90 \pm 38.66 (n=8)		
	Fifth	126.25 \pm 17.34 (n=5)		
	Sixth	43.75 \pm 17.67 (n=2)		
	Seventh	71.87 \pm 48.61 (n=2)		
	Ninth	75.00 \pm (n=1)		

*P<0.005

Table 3.10 One way Anova shows the birth order of the autistic child with respect to each QOL subscale. It can be seen that a significant difference of P=0.01 between birth order of the autistic child with over scale has been found, with a mean score of 12.82 \pm 8.95 (n=19) for the first birth order child, 14.84 \pm 7.32 (n=24) for the second birth order child, 16.66 \pm 8.40

(n=15) for the third birth order child, 13.28 ± 12.24 (n=8) for the fourth birth order child, 16.25 ± 9.47 (n=5) for the fifth birth order child, 0.00 ± 0.00 (n=2) for the sixth birth order child, -3.12 ± 13.25 (n=2) for the seventh birth order child and $-6.25 \pm$ (n=1) for the ninth birth order child.

Significant differences of $P=0.002$ between birth order of the autistic child has been reported with respect to their physical scale. The mean score are 10.53 ± 22.08 (n=19), 11.62 ± 25.47 (n=24), 11.41 ± 25.97 (n=15), 10.81 ± 28.49 (n=8), 11.75 ± 21.37 (n=5), 50.00 ± 17.67 (n=2), -78.12 ± 39.77 (n=2), 37.50 ± 0 (n=1) for the first birth order child, second birth order child, third birth order child, fourth birth order child, fifth birth order child, sixth birth order child, seventh birth order child and ninth birth order child, respectively.

Significant difference of $P=0.002$ between birth order of the autistic child with psychological scale has been noticed, with a mean score of 83.88 ± 15.63 (n=19) for first birth order child, 92.70 ± 18.12 (n=24) for the second birth order child, 89.16 ± 20.92 (n=15) for third birth order child, 89.84 ± 24.98 (n=8) for fourth birth order child, 10.25 ± 14.65 (n=5) for the fifth birth order child, 46.87 ± 13.25 (n=2) for the sixth birth order child, -59.37 ± 39.77 (n=2) for the seventh birth order child and $62.50 \pm$ (n=1) for ninth birth order child.

The table also shows significant difference of $P=0.002$ between birth order of the autistic child with respect to environment scale. A mean score of 94.07 ± 27.67 (n=19) has been recorder for the first birth order child, 103.64 ± 22.64 (n=24) for the second birth order child, 106.66 ± 33.69 (n=15) for the third birth order child, 103.90 ± 38.66 (n=8) for the fourth birth order child, 126.25 ± 17.34 (n=5) for the fifth birth order child, 43.75 ± 17.67 (n=2) for the sixth birth order child, 71.87 ± 48.61 (n=2) for seventh birth order child, and $75.00 \pm$ (n=1) for the ninth birth order child.

Table 0.11. Difference between Residential Area with QOL domains

QoL domains and Items	Residential Area	Mean \pm Std. Deviation	P
Over scale	Urban	13.86 \pm 8.97 (n=73)	0.080
	Rural	4.16 \pm 19.09 (n=3)	
Physical scale	Urban	11.21 \pm 26.18 (n=73)	0.000*
	Rural	64.58 \pm 26.18 (n=3)	
Psychological scale	Urban	89.46 \pm 19.48 (n=73)	0.000*
	Rural	50.00 \pm 27.24 (n=3)	
Social scale	Urban	38.35 \pm 17.12 (n=73)	0.360
	Rural	29.16 \pm 7.21 (n=3)	
Environment scale	Urban	10.39 \pm 28.99 (n=73)	0.000*
	Rural	56.25 \pm 38.01 (n=3)	

*P<0.05

The above Table 3.11 shows that T-test indicates the effectiveness of the residential area of the families with autistic children with QOL subscales. As expected, there is significant difference of P=0.00 between residential area and physical scale with a mean score of 11.21 \pm 26.18 (n=73) for parents who live in urban area and 64.58 \pm 26.18 (n=3) for those who live in rural area.

Another significant difference have been recorded with P=0.00 between residential area and psychological scale with a mean score of 89.46 \pm 19.48 (n=73) for those live in urban area and 50.00 \pm 27.24 (n=3) for those live in rural area.

In terms of environment scale, a significant difference of P=0.00 have been found for both cases with a mean score of 10.39 \pm 28.99 (n=73) for those who live in urban area and 56.25 \pm 38.01 (n=3) for those live in rural area.

Table 0.12. Difference between any other Autistic Child in the Family with QOL domains

QoL domains and Items	Other Autistic Child in the family	Mean \pm Std. Deviation	P
Over scale	Yes	20.3125 \pm 5.98392 (n=4)	0.14
	No	13.1076 \pm 9.56582 (n=72)	
Physical scale	Yes	123.4375 \pm 27.18331 (n=4)	0.30
	No	108.5938 \pm 27.90036 (n=72)	
Psychological scale	Yes	95.3125 \pm 13.85847 (n=4)	0.47
	No	87.5000 \pm 21.39501 (n=72)	
Social scale	Yes	45.3125 \pm 9.37500 (n=4)	0.37
	No	37.5868 \pm 17.18828 (n=72)	
Environment scale	Yes	120.3125 \pm 30.77768 (n=4)	0.18
	No	99.4792 \pm 30.27075 (n=72)	

*P<0.005

In the table 3.12 T-test shows the cases whether the families having other autistic child or not and with respect to all QOL subscales. It can be seen that no significant difference has been found in any cases.

Table 0.13. Difference between Any other Autistic Child in the Family with QOL domains

QoL domains and Items	Other Disabled Child in the family	Mean ± Std. Deviation	P
Over scale	Yes	10.7143± 9.35017 (n=7)	0.42
	No	13.7681± 9.56185 (n=69)	
Physical scale	Yes	94.6429± 37.22618 (n=7)	0.14
	No	110.8696± 26.66023 (n=69)	
Psychological scale	Yes	74.1071± 24.58737 (n=7)	0.06*
	No	89.3116± 20.36832 (n=69)	
Social scale	Yes	33.9286± 10.11467 (n=7)	0.50
	No	38.4058± 17.45778 (n=69)	
Environment scale	Yes	94.6429± 41.36798 (n=7)	0.59
	No	101.1775± 29.45732 (n=69)	

*P<0.005

Table 3.13: After the data entered to the T-test analysis the results shows the effectiveness of the Any Other Disabled Child in the Family with autistic children with QOL subscales. As expected, there is significant difference of P=0.06 between Any Other Disabled Child in the Family and Psychological scale with a mean score of 38.40± 17.45 (n=69) for parents who females haven't disabled child and 33.92± 10.11 (n=7) for those who have disabled child.

Discussion

Most autism related researches, so far, have been directly dealt with the children with a little concern about their parent's quality of life. Unlike these previous researches, the study conducted here explores the quality of life of family care-givers of children with autism. More specifically, it focuses on the quality of life of parents in terms of physical scale, psychological scale, social scale and environment scale.

In this chapter, the effects of having autistic child/children in the family are studied and analyzed under various conditions. The detailed discussion on the results, obtained from chapter 3, are given in sections 4.1 to 4.13.

Referring to the results that obtained from this research, it shows that mothers are the primary care-giver in most cases compared to fathers. That is mainly because of having deep emotional feelings and social responsibilities towards their children in one hand and the culture and the nature of the Kurdish society on other hand.

The result from this study also shows that the parents who falls in the group age of (35-39) are more likely to have autistic children than other group ages. This result is similar to that conducted by Yamada et al (2012) in Japan who stated that most of mothers with autistic children were in middle age, with the mean age of 38.3 years. This result also agrees with the study done by Wang et al (2012) that showed that the mean age of participants was 32.10 years. A similar study by Johnson (2009) found the mean age of the mothers was 39.2 years.

Another result from this research shows that most parents are living together with their autistic children. This result, which was expected due to the culture and nature life of families in Kurdistan, is similar to that conducted by Muhammad Mustafa Muhammad Shahin (2002, p 18.19) in Cairo who confirmed that most of the families with children autism spectrum disorder are living together.

In related to the parents' level of education, the present research found that most participants graduated from secondary school. This result is similar to that obtained by Wang et al (2012, P. 3) done on 145 mothers having autistic children in China and showed that majority of mothers graduated from secondary school.

Regarding their occupation and according to the present research, most of the parents were professional employee working for government. Similar result has been found by Kheir et al (2012,p.3 5) in Qatar on 56 fathers having autistic child which showed that most of them (41%) were professional workers.

The present research insists that most of parents with autistic children live in urban areas which agrees with the study done by Lai et al (2011,P.914) in Taiwan under the title of gender and geographic differences in the prevalence of autism spectrum disorders in children. Many other studies strongly agree with this result including the one that was done by Wang et al (2012) and showed the highest percentage of the sample (72.1%) were from an urban area.

This present research also studied the socio-economic status of the parents and found that most of them were within a medium socio economical level. This result is similar to the work done by Rezan Hussein Aziz (2010,P57-58.), published in Shabang Research Methodology in Iraqi Kurdistan, who also stated that most of parents are from medium economical level. However, families with autistic children may soon find themselves in a difficult economic situation due to the cost of care and unstable economic situation in Iraq.

The result also shows that most of children with autism spectrum disorder are male. Similar result was obtained in the research done by Wang et al (2012) on 290 autistics children in China which showed that the majority of samples were boys (85.5%).

According to the studied sample, children with ages various from 4 to 8 years were more likely to get autism disorder than others. This result is similar to the work done by Firat et al (2002) who stated that most of children were within the age group of 3 to 6 years.

In Kurdistan and according to this research study, most families found to have only one autistic child. However, majority of the children were unable to read/write and that is because of the limited number of autism canters and lack of professional skills in Kurdistan to train autistic children. In medicine, early diagnoses is considered better than late diagnosed. Based on that and according to the result obtained by the present research, late diagnoses of autistic children in Kurdistan had severe negative consequences on quality of life of parents and the health of the autistic children. Similar result has been found by Rezan Aziz (2010) who stated that late autism diagnoses are common in Kurdistan.

The result from the present study insists that there is a strong relationship between the parents' age and their physical domain, which is similar to that conducted by Johnson (2009) who also found significant between the fathers age and physical domain. Furthermore, other

studies like the one done by Benjak (2010) and Johnson (2009) showed that there are statistical significant associations between age of fathers and physical domain.

In contrary, this study has found no significant different between marital status and the quality of life domains. Similar result had been found by Muhammad Mustafa Muhammad Shahin (2002) in Cairo who stated that there is no relations between parent's marital status and their quality of life as majority of the parents are living together.

Unlike the study done by Shuo (2008) who found a caregiver's educational level negatively predicted the social relationship domains of quality of life, the present study found a strong effect of the parents' level of education on the quality of life domains. This is due to various reasons, including the difference in socio-cultural background, difference in the mental health services and programs, poor financial resources, health and social care, low education, lack of home and physical environment.

Furthermore, no significant difference has been found in this research between parents' occupation and their quality of life. The same result was obtained by Muslih Salim (2013) who found no effects of parents' occupation on the quality of life. It has been found that most fathers were strained by work outside and mothers were busy with home deities.

Further results have been conducted by the present study comparing by exploring the effects of the economic status of the parents on the quality of life domains. A strong significant difference has been found between parents' economic status and four domains, namely, over scale, physical scale, psychological scale and environment scale of the quality of life. These findings are similar, in most cases, to the study conducted by Shuo (2008) in Taiwan who also found that the family monthly income was most predictive of three domains (psychological health, social relationships and environment) of caregiver's quality of life. However, there is a difference between the study conducted by Shuo, (2008) in Taiwan and the present study in social relationship domain. This is due to many reasons, including a stronger socio-cultural relationships, community support and religion in Kurdish society compared to the society of Taiwan.

The present study also analyzed the effect of the age and the level of education of the child on the quality of life domains and found no significant difference in any case. These results are supported by those which obtained by Muslih kareem (2013).

In regards to the effectiveness of the residential area of the families with autistic children with QOL domains, the present research shows the significant difference between the

residential area of the parents and three domains, namely, physical scale, psychological scale and environment scale of the quality of life. Reza Hussein Rashwani (2003) also found a strong significant difference between the residential area and psychological scale and environment scale of the quality of life.

The research also studied the birth order of the autistic child with respect to each QOL domain and found a significant difference between second birth orders of the autistic child with over domain. No similar results have been found within previous studies to support the current findings. That may be due to lack of such resources.

Finally, the effect of having a disabled child on psychological domain of the care-giver's quality of life is noticeable from the result of this study. According to the study that conducted by Muhammad Mustafa Muhammad Shahin (2002), families with disabled children suffer from anxiety and feel guilty towards their children.

Conclusion

5.2 Conclusion

This thesis addressed the quality of life of families with child autism spectrum disorder under various conditions, in particular the quality of life of parents in terms of psychological, physical, social and environment domains. To conduct this research, various information have been collected directly from 76 participants (information about the parents and their children) and analyzed using Anova statistic tools, then compared with each domain of the quality of life.

The overall results showed positive correlations between at least one domain of the QOL and age group of the parents, level of education of the parents, economic status, residential area and the birth order of the child. However, the research found no correlations between any domain of the QOL and marital status of the parents, parent's occupation, and age and education level of the child.

These results obtained from the present research study were similar to the previous studies conducted by other researchers in the field. The only difference between this research and others are the place where the sample has been collected from. That had some impacts on the results in some cases, as noticed, especially those related to the religion, social activities, culture, and nature life of people.

5.3 Future Research and Recommendations

This study is an important first step in examining the quality of life of families with child autism spectrum disorder. However, there are some valuable issues arise from the current study that can be concluded in the followings.

All studies up to date, including the present study, only focused on the life conditions of the parents without referring to the quality of life of their children. In other words, only reactions and behaviours from the parents have been studied under various conditions without

examining the consequences of these reactions on the children themselves. Obviously, it is a two-sided effect which requires further research in future.

Another important issue is the lack of datasets and statistic information about the families with child autism spectrum disorder in Kurdistan. That can add another level of difficulty on the researchers of the field.

Furthermore, late diagnosis is another problem that may have severe consequences on the quality of life of families with autistic children. This problem requires more attentions in further studies, in which can help parents to deal with their autistic children in a proper way.

Finally, further studies should include larger samples with more females to examine any possible sex difference in autism spectrum disorder.

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Appendix

A. Socio-demographic information about parents

This form contains necessary information about one of the parent (either father or mother) of the autistic child. Two copies of this form have been provided below, one in English and the other is in Kurdish.

Part One: Information about Parents:	
→	Care-giver of the child: <input type="checkbox"/> Father <input type="checkbox"/> Mother
→	Age: <input type="checkbox"/> 24-29 <input type="checkbox"/> 30-34 <input type="checkbox"/> 35-39 <input type="checkbox"/> 40-44 <input type="checkbox"/> Older than 44
→	Marital Status: <input type="checkbox"/> Married <input type="checkbox"/> Divorced
→	Education Level: <input type="checkbox"/> Unable to read/write <input type="checkbox"/> Able to read/write <input type="checkbox"/> Primary school graduate <input type="checkbox"/> Secondary school graduate <input type="checkbox"/> Bachelor's degree <input type="checkbox"/> Higher degree
→	Occupation: <input type="checkbox"/> Unemployed <input type="checkbox"/> Government <input type="checkbox"/> Private sector <input type="checkbox"/> Self-employed
→	Residential Area: <input type="checkbox"/> Urban <input type="checkbox"/> Rural
→	Economic Status: <input type="checkbox"/> Very Bad <input type="checkbox"/> Bad <input type="checkbox"/> Medium <input type="checkbox"/> Good <input type="checkbox"/> Very Good
→	Number of Family Members: <input type="text"/>

بەشی یەكەم: زانیاری لەسەر سەرپرشتیار	
كەسی سەرپرشتیار: <input type="checkbox"/> باوك <input type="checkbox"/> دایك	←
ئەمەن: <input type="checkbox"/> ٢٩-٢٤ <input type="checkbox"/> ٣٤-٣٠ <input type="checkbox"/> ٣٩-٣٥ <input type="checkbox"/> ٤٤-٤٠ <input type="checkbox"/> زیاتر لە ٤٤	←
ھالەتی ھێزانی: <input type="checkbox"/> ھێزێندەر <input type="checkbox"/> جیابۆتەو	←
ناستی ھۆتەن: <input type="checkbox"/> نەھۆتەنەر <input type="checkbox"/> تەتھا ھۆتەنەر <input type="checkbox"/> ھۆتەنی سەرەتایی <input type="checkbox"/> ھۆتەنی دووھەندە <input type="checkbox"/> بەکالاریۆس <input type="checkbox"/> ھۆتەنی بەلا	←
پێشە: <input type="checkbox"/> بێکار <input type="checkbox"/> ھەرماتبەری ھکومی <input type="checkbox"/> ھەرماتبەری کەرتی تایبەت <input type="checkbox"/> کاسبکار	←
شوێنی نیشەتەجێبوون: <input type="checkbox"/> شار <input type="checkbox"/> لادێ	←
ناستی نابووری: <input type="checkbox"/> زۆر خراپ <input type="checkbox"/> خراپ <input type="checkbox"/> مامناوھەندی <input type="checkbox"/> باش <input type="checkbox"/> زۆر باش	←
ژمارە ھێ ھێزان: <input type="text"/>	←

B. Socio-demographic information about Autistic Children

This form contains information about the child diagnosed with Autism. A version of English and Kurdish of this form have been shown below.

Part Two: Information about the Child	
→	Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female
→	Age: <input type="text"/> Years <input type="text"/> Months
→	Education Level: <input type="checkbox"/> Unable to read/write <input type="checkbox"/> Able to read/write <input type="checkbox"/> Primary school graduate
→	Year Diagnosed: <input type="text"/>
→	Birth Order of the Child: <input type="checkbox"/> First <input type="checkbox"/> Second <input type="checkbox"/> Third <input type="checkbox"/> Fourth <input type="checkbox"/> Fifth <input type="checkbox"/> Sixth <input type="checkbox"/> Seventh <input type="checkbox"/> Eighth <input type="checkbox"/> Ninth <input type="checkbox"/> Tenth
→	Any other Autistic Child in the Family: <input type="checkbox"/> Yes <input type="checkbox"/> No
→	Any other Disabled Child in the Family: <input type="checkbox"/> Yes <input type="checkbox"/> No

بەشی دووهم: زانیاری لەسەر منداڵەکە

ڕەگەز: ☐ نێر ☐ مێ

تەمەن: ساڵ و مانگ

ئاستی خوێندن: ☐ نەخوێندەوار ☐ تەنھا خوێندەوار ☐ قوناغی سەردەتایی

ساقی دەستتیشان کردن:

ڕیزبەندی منداڵەکە لە خێزان: ☐ یەکەم ☐ دووهم ☐ سێیەم ☐ چوارەم ☐ پێنجەم

☐ شەشەم ☐ حەوتەم ☐ هەشتەم ☐ نۆیەم ☐ دەیەم

منداڵی تری نۆتیزم هەیە: ☐ بەڵێ ☐ نەخیر

منداڵی تری پەککەوتە هەیە: ☐ بەڵێ ☐ نەخیر

C. Quality of life domains and items (WHOQOL-BREF) Questionnaire (in English and Kurdish)

Part Three: Quality of Life Domains and Items (WHOQOL-BREF) Questionnaire

	Items1(overall QoL)	Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?					

	Items2 (general health)	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?					

		Not at all	A little	A moderate amount	Very much	Extremely
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?					
4.	How much do you need any medical treatment to function					

	in your daily life?					
5.	How much do you enjoy life?					
6.	To what extent do you feel your life to be meaningful?					
7.	How well are you able to concentrate?					
8.	How safe do you feel in your daily life?					
9.	How healthy is your physical environment?					
10.	Do you have enough energy for everyday life?					
11.	Are you able to accept your bodily appearance?					
12.	Have you enough money to meet your needs?					
13.	How available to you is the information that you need in your day-to-day life?					
14.	To what extent do you have the opportunity for leisure activities?					
15.	How well are you able to get around?					

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?					
17.	How satisfied are you with your ability to perform your daily living activities?					
18.	How satisfied are you with your capacity for work?					
19.	How satisfied are you with yourself?					
20.	How satisfied are you with your personal relationships?					
21.	How satisfied are you with your sex life?					
22.	How satisfied are you with the support you get from your friends?					
23.	How satisfied are you with the conditions of your living place?					
24.	How satisfied are you with your access to health services?					

25.	How satisfied are you with your transport?					
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	Items2 (general health)	Never	seldom	Quite often	Very often	always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?					

بەشى سىيەم: جۆرى ژيانى داىك و باوك

زۆر باش	باش	مام ناوهندى	خراب	زۆر خراب		
					چۈن ژيانىت ھەلدەسەنگىنىت؟	۱

زۆر رازىم	رازىم	مام ناوهندى	نارازىم	زۆر نارازىم		
					تا چەند لە تەندروستىت رازىت؟	۲

زۆر باش	باش	مام ناوهندى	كەم	ھىچ		
					تا چ راددەيەك ھەست دەكەيت نازارى لەشت بەريەستە لە نەنجامدانى كارەكانت؟	۳
					تا چەند دەرمان و چارەسەرى پزىشكىت پتويستە بۆ نەنجامدانى كارى رۆژانەى ژيانىت؟	۴
					تا چەند ھەست بە خوشى دەكەيت لە ژيانىت؟	۵
					تا چ راددەيەك ھەست دەكەيت ژيانىت مانادارە؟	۶

۷	تا چ راددهیهک توانای سهرنج دانت ههیه؟ (بیرکردنهوه، لهبیرچوون، فیربوون)				
۸	تا چ راددهیهک ههست به نارامی و سهلامهتی دهکەیت له ژیانێ رۆژانهت؟ (سهلامهتی بهدهنی، دلنئیایی، نازادی)				
۹	تا چەند ژینگه‌ی ده‌ورو به‌رت ته‌ندروسته؟ (پیس، ناوو هه‌وا، ترافیک)				
۱۰	نایا ووزە‌ی ته‌واوت هه‌یه بۆ به‌رده‌وام بوون له ژیانێ رۆژانهت؟ (هه‌یز، شه‌که‌تی)				
۱۱	نایا تۆ رازیت له‌ روخسار و شێوه‌ی له‌شی خۆت؟				
۱۲	نایا پاره‌ی ته‌واوت هه‌یه بۆ جێبه‌جێکردنی پێویسته‌کانت؟				
۱۳	تا چ راددهیهک زانیاری پێویست فەراهەم کراوه بۆ ژیانێ رۆژانهت؟ (بۆ به‌دهست هه‌ینانی زانیاری نوێ و شارەزایی)				
۱۴	تا چ راددهیهک ده‌رفه‌تی چالاکێ خۆشی و رابواردنت هه‌یه؟				
۱۵	تا چ راددهیهک به‌ ناساتی ده‌توانیت بجوێنیت؟ (سوران و گه‌ران)				

زۆر نارازیم	نارازیم	مام ناوه‌ندی	رازیم	زۆر رازیم	
					۱۶ تا چ راددهیهک له‌ نووستنت رازیت؟ (نووستن و پشوودان)
					۱۷ تا چەند رازیت له‌ تواناکانت بۆ نه‌ه‌جامدانی چالاکیه‌کانی ژیانێ رۆژانهت؟
					۱۸ تا چەند له‌ تواناکانت رازیت له‌ کاتی کارکردن؟
					۱۹ تا چەند ب‌روات به‌ خۆت هه‌یه؟
					۲۰ تا چەند رازیت له‌ په‌یوه‌ندیه‌کانت له‌گه‌ڵ که‌سانی تر؟
					۲۱ تا چەند له‌ ژیانێ سێکسیت رازیت؟ (چالاکێ سێکسی)
					۲۲ تا چەند له‌و پالێشتیانه‌ رازیت که‌ له‌ لایه‌ن هاوڕێکانت به‌دهستی ده‌هینیت؟ (پالێشتی کۆماریه‌تی)
					۲۳ تا چەند له‌و شوێنه‌ رازیت که‌ لێی ده‌ژیت؟ (ژینگه‌ی ماله‌وتان)
					۲۴ تا چەند له‌و خزمه‌تگوزاریه‌ ته‌ندرووستیانه‌ رازیت که‌ بۆت دابین کراوه؟

					تا چەند لە هۆکارەکانی هاتووچۆت ڕازیت؟	٢٥
--	--	--	--	--	---------------------------------------	----

هەمیشە	زۆر زۆر	زۆر کات	کەم	هیچ کات		
					نایا تا چەند تووشی هەستکردنی خراپ بوویت وەکو غەم و نانومیدی و دڵەراوکی و خەمۆکی؟	٢٦

D. Permission for using the Kurdish Version of WHOQOL-BREF form

● Re: permission

People



● **Mosleh Saber**

Dec 8, 2014 ★

To: Goran Kamaran

dear Goran hi
i will permit you to used my questionnaire.
so i willing beneficial for you
my best regards

On Mon, 8/12/14, Goran Kamaran <gorankamaran@yahoo.com> wrote:

Subject: request for permission

To: "Mosleh Saber" <mosleh.saber@yahoo.com>

Date: Monday, 8 December, 2014, 0:12

Dear Mosleh Saber I would like to let you know that I am a master student at Near East university (psychological department) . My Research is about (quality of life mother or father with children autistic). and I realized that your questionnaire and the translation version will be in line with my study , so that I wander weather i can use your questionnaire or not .
your
help with this matter will be high appreciated

Best regard Goran Kamaran