



Original Article

Quality of Life in Parents of Children with Autistic Spectrum Disorders (ASD) in Oman

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Rearing a child with Autism Spectrum Disorder (ASD) is a unique challenge for both parents. Evidences indicate that parental Quality of Life (QOL) is influenced by having a child with ASD. This study aimed to assess the level of QOL, social support, and demographic variables. For parents of children with ASD. A descriptive cross-sectional design was used to collect data from 81 parents from two psychiatric outpatient clinics in Oman. The results showed that parents reported acceptable QOL level in the psychological and social health domains, followed by the environmental domain, and is comparatively poor for the physical health domain. The findings would help the stakeholders to develop appropriate psycho-social intervention programs for the parents of children with ASD.

Keywords: Quality Of Life; Parents; Autistic Spectrum Disorder; Social Support

1. INTRODUCTION

Autistic Spectrum Disorder (ASD) is considered as one of the most complex childhood disabilities (APA, 2000). Children with ASD facing a wide range of symptoms that markedly presented as impairment in communication, imagination, social interaction, and restricted in activity, interest and behavior (APA, 2013).

Indeed, rearing children having ASD is a challenge for both parents; ASD not only affects the diagnosed children through their life but also their parents' life (Spore, 2012; Karst &

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Van Hecke, 2012). By the end, it will disturb parents Quality of Life (QOL) (Dardas and Ahmad 2014a). Further understanding on how caregiver quality of life will be affected will help to improve the quality of care in term of services and resources (Halterman J, Yoos H, Conn K, et al. 2004). Moreover, Operationalizing parental QOL allows care providers to quantify the degree of burden that parents experience (Halterman et al., 2004). So that more effective disorder related programs can be developed.

Quality of life (QOL) can be highly influenced negatively by the disease situation, however there are many factors that affect the way how they perceive. In this sense, it is important to assess the quality of life of those parents and to identify the factors that influence them perception which ultimately affects the care provided to these children with ASD. Because of the important role that parents play in their children's psychosocial condition, especially during an illness, we chose to focus the current study on the parents' quality of life (QOL).

There are only a few studies carried out on the quality of life among parents of children with Autistic Spectrum Disorder in Arab world. To my Knowledge, this study is the first study in Oman to gain a better understanding of the QOL of parents with children having ASD in Oman.

Oman is one of the Arab peninsula countries with a high middle-income level group with a population approximately 3.5 million, with 42.7% of its inhabitants being under the age of 15 (Central of Intelligence Agency (CIA)). The prevalence of ASD in Oman is 1.4 case over 10000 (Al-Sharbaty, Al-Farsi, Al-Sharbaty, Ouhtit, Waly, Al-Khaduri, et al. (2014). However, the prevalence of autism among Gulf countries' in general has been ranged between 1.4 and 29 cases per 10,000 people (Salhia, Al-Nasser, Taher, Al-Khathaami, & El-Metwally 2014). Factors such as lack of reliable "biological marker" and lack of health services for ASD children might contribute to that low rate appearance (Ouhtit, Al-Farsi, Al-Sharbaty, Waly, Gupta, Al-Farsi, Al-Khaduri, Al-Shafae, & Al-Adawi, 2015). While the country has a traditional system with the norm that the family is the primary social support system and the primary care provider, limited information has been seen about consumer and family associations (WHO, 2008). Earliest pieces of evidence point out that children and their parents have interrelated social and health needs (Tischler, Karim, Rustall Gregory, & Vostanis, 2004). Therefore, it is important to consider the mental health of the parents in the interventions proposed for children with neuro developmental Disorders.

Purpose of the Study

The major purpose of this study was to assess the Quality of Life among parents of Children with Autistic Spectrum Disorder. The results aims to identify the predictive factors that influence Quality of Life of parents.

The objectives of the present study were:

- To assess the QOL in parents of children suffering from ASD
- To identify the predictive factors that affect QOL among parents of children with ASD
- To explore the relationship between socio-demographic, perceived social support and clinical variables on QOL among parents of children with ASD .

Literature Review

Autistic Spectrum Disorders is considered one of the most serious complex childhood disabilities (APA, 2000), ASD has become recently one of the major childhood health problems and concern across worldwide (Simonoff, Pickles, Charman, Chandler, Loucas, & Baird, 2008). Unlikely, studies of mental disorders among children show that there is pervasive comorbidity between purportedly different diagnostic entities. As described by Achenbach (2005), few children who had mental disorders, had only one single disorder; Munir(2016) have found that around 40% of the children and teens who had ASD had at least one co morbid mental disorder.

The plight of children and families coping with ASD is significant. In fact, ASD is complex conditions, which involves impairments in social interaction; communication; and behavioral functioning (APA, 2013). BakerEriczen, Brookman-Fraze, and Stahmer (2005) found that parents of children with ASD experience higher level of parenting stress and psychological distress than other neurodevelopmental disorders.

Parents can play an important role in child's psychological, social, and academic development. Children with Autistic Spectrum Disorders (ASD) create special challenges for parents; parents have to deal with challenging behavior; judgements from others; and lack of support (Ludlow, Skelly, & Rohleder, 2012). Furthermore, owing to being in need with more intensive educational, behavioral and health services, which can be challenging for parents to contact and when handy can require parental time and resources to assist (Rapin, 2001).

As caregiving is a regular parental responsibility, providing highest level of care that required by a child who has long-term functional impairment can become difficult and oppressive; which can have an influence on parents' physical and mental health vehemently (Benjak, Vuletic, Mavrinac, & S'imetin, 2009). Indeed, it has been found that parenting a child with ASD can disturb the whole family's life, furthermore having several economic, social, physical and psychological problems (Parish, Seltzer, Greenberg, & Floyd, 2004). These problems can results in more parental distress, male adjustment, and finally, it can affect the QOL of those parents (Dardas, 2014).

Quality of life (QOL) is a a multidimensional phenomenon encompassing physical, mental, and social functioning and well-being (Hays, Anderson, & Revicki, 1993). According to World Health Organization Quality of life is defined as "an individual's perception of his/her position in life, in the

context of the culture and value systems in which s/he lives, and in relation to goals, expectations, standards and concerns” (Fitzgerald, et al., 2001).

In spite of the increasing awareness of the need to “shaping, directing, delivering, and evaluating support services”, limited data are available on the impact of raising children with ASD on parents’ QoL when it is compared to other chronic disorders (Dardas & Ahmad, 2014).

Our role as health care professionals working with children having ASD and their parents is to ensure that care plans are set to target the family system. Parents and children may need special help to ensure higher and healthier interaction. Examining parents’ QoL can help us to measure and to overcome the impact of ASD on parents.

2. METHODOLOGY

Design

A quantitative correlational cross-sectional study carried out between March 2016 until April 2017. Participants were recruited from two major child psychiatric outpatient clinics located in Muscat; Sultan Qaboos University Hospital (SQUH) and Al-Massarrah Hospital. SQUH is one of the leading hospitals in Oman, it offers free psychiatric and mental health services, inpatient and outpatient services are provided for all Omani patients. And Al-Massarrah Hospital, is a specialized Psychiatric and Mental Illness Hospital offer wide range of care for patients with mental illnesses and received patients from overall Oman.

Sampling and Data Collection Procedure

Target population of the current study was all Omani parents who have at least one child diagnosed with ASD and have a regular checkup in either AlMassara Hospital or SQUH between March 2016 until April 2017. The inclusion criteria for the parents were: Omani parents age between 18 and 65 years, and able to read and write in Arabic to understand the questionnaire questions. Only parents who have some mental disorder were excluded from the study.

Data were collected from parents by the researchers in a private area in the clinic where privacy is maintained using a structured interview method. The researchers interviewed each participant to complete the questionnaire. The average interview time to complete the questionnaire was around 20 min for each participant.

Around 95 questionnaires were obtained. From them, fourteen questionnaires were excluded from the analysis because they have too much of missing data. The final sample consisted of 81 questionnaires.

Ethical consideration

Before starting data collection, the ethical approval was obtained from the Research and Ethics Committee at College of nursing, SQUH research ethical approval committee, and the ministry of health research and ethics committee for Almassara Hospital. Data were collected by the research team or staff nurses in child follow up psychiatric clinic (SQUH, and AL Massarra). All eligible parents were invited

to participate in the study. Parents who expressed the interest to participate in the study were approached by researchers who explained the study purpose and provided them with all needed details. Then the parents who volunteered and agreed to participate signed the informed consent. Researchers assured participants that their responses will be treated confidentially. Parents were told not to include their names or any identifying information on the questionnaire.

Instruments

Data were collected through a self-administered questionnaire consisted of the World Health Organization Quality of Life Assessment-BREF self-administered instrument (WHOQOL-BREF) was used to assess Quality of Life and consisting of the following domains; physical capacity, psychological well-being, social relationships, and environmental health. And The Multi-dimensional Scale of Perceived Social Support (MSPSS) was used to assess the perceived social support from friends, family members, and significant others.

1. Arabic version of World Health Organization Quality of Life Assessment-BREF self-administered instrument (WHOQOL-BREF)

WHOQOL-BREF is a multidimensional, conceptualized, generic, 26-item self-administered dependent questionnaire (Skevington, Lotfy & O’Connell 2004). Its Emphasizing in persons subjective experiences rather than objective life conditions (Olusina & Ohaeri, 2003). WHOQOL-BREF consisting of four independent Health related domains: physical capacity (7 items), psychological well-being (6 items), social relationships (3 items), and environmental health (8 items) (WHO, 1996). Score for each item within domains uses a from 1 (very dissatisfied/very poor) to 5 (very satisfied / very good). Higher score indicates a higher QOL. Each domain scores will be calculated by multiplying the mean of all facet scores by a factor of 4. Then, potential scores for each domain will be vary from 4 to 20 (WHO, 1994). WHOQOL-BREF is a valid and reliable instrument, Cronbach’s alpha for the total QoL score was .91 in Arabic version (Dardas, & Ahmad, 2014). WHOQOL-BREF is sensitive to the Health Related Quality Of Life (Herrman, Hawthorne, & Thomas, 2002).

2. Multi-dimensional Scale of Perceived Social Support (MSPSS)

In 1988, Zimet, Dahlem, Zimet, and Farley had developed MSPSS, It is a 12-item scale, indicating perceived social support from friends, family members, and significant others. MSPSS is a 7-point Likert-type scale (the range from, 1= very strongly disagree to 7= very strongly agree). The total sum score for the three subscales range from 12 to 84, then each subscale ranges from 4-28. Higher score shows higher perceived social support. The Cronbach’s alpha coefficient for the three subscales of friends, family, and significant others were 0.89, 0.91, and 0.91, respectively and was 0.93 for the total scale (Canty-Mitchell & Zimet, 2000).

For the purpose of this study, Arabic valid version of MSPSS (Merhi&Kazarian, 2012) will be used.

3. Potential Covariates

Potential covariates in this study included the following details; gender of the caregiver, gender of child, father or mother age, child age, marital status of parents, having chronic illnesses, employment, age of diagnosis, duration of disease, income, and educational level of children and caregivers, and feeling about caring for a child with neurodevelopmental disorder.

Data Quality and Management

Data collection forms were coded, missing data were checked before each subject submits their surveys. Two of the team member performed the data entry into SPSS database then audited for accuracy. Data were screened for missing values, logical inconsistencies and extreme values. Continuous variables were tested for normality, and non-normal values were categorized or transformed.

Statistical analysis

The Statistical Package for Social Sciences (SPSS, Chicago, IL, USA) was used to analyze data. Descriptive statistics were used for calculating frequencies, mean scores, and standard deviations (SDs). The strength and direction of relationships between variables were determined by using Pearson correlation coefficients. Significance level was set at $P = 0.05$. Stepwise multiple regression analyses were conducted to determine the independent variables that best predict QOL domains among Omani patients. For each of the four domains of QOL, a separate multiple regression analysis was conducted entering: MSPSS and sociodemographic independent variables.

Data Analysis

Statistical analysis will be performed using SPSS 21.0 (SPSS, Chicago, IL, USA). Descriptive statistics (including means, standard deviations, and frequencies) will be used to organize, summarize, and present the study demographic variables (age, number of children, marital status of parents, level of education, number of children who have mental disorders, working status, and financial status) as well as to determine the level of Quality of Life and Social Support. The relationship between socio demographic, social support, and clinical features and parents' QOL domains will be measured by means of Pearson correlation analysis when the data followed a normal distribution; otherwise Spearman rank correlation will be used. Multiple regression using the stepwise method will be used to identify whether Social Support affecting each of the QOL domains.

3. RESULTS

Socio-demographic and clinical characteristics

In this study, a total of 81 parents agreed to participate and completed the questionnaire. Around 33 (40.7%) were mothers and 48 (59.3%) were fathers, those were parents of 22 (27.16) girls and 59 (72.84) boys. The age of the participants ranged between 25 and 49 years (mean = 35.3,

SD = 5.53). As for children characteristics, the age were ranged between 2 and 14 years old (mean = 5.39, SD = 2.56). Most of the participants were educated, (75%) had diploma or higher. Around 57 (73.4 %) had a moderate income. Only 14 (17%) were mothers and not employed.

Level of quality of life

With regard to the first question in the QoL scale (how would you rate your quality of life?), the results revealed that 74% (n=60) of fathers and mothers described their QoL as either good or very good. Regarding the second question in the QoL scale (how satisfied are you with your health?), almost more than 90% (n=75) of the parents were satisfied with their health.

Regarding QoL subscale, the mean score (SD) was 257.98 (45.72), 56.44 (11.69), 66.87 (11.71), 71.71 (16.91), and 62.96 (14.36) for total, physical, psychological, social and environmental subdomains, respectively. Using 60 as a cut of point to determine whether the parents had acceptable, borderline, or poor quality of life; the statistics showed that parents have acceptable QOL level in both social and psychological domain, borderline in environmental domain, and poor level of QOL in the physical domain.

• Social support

The mean score (SD) for MSPSS (total), MSPSS (family), MSPSS (friends) and MSPSS (significant others) was 64.03 (13.79), 21.97 (5.01), 19.29 (5.23) and 22.76 (5.59), respectively. The majority of the respondents (70.4%, N = 57) had high perceived social support, followed by a lower proportion (24.7%, N = 20) with moderate scores and only four person had perceived a low score (4.9%, N = 4) as presented.

• Quality of life (total)

There was significant positive correlation between the different types of social support (total, family, friends and significant others) and QOL. The higher the social support levels in all types of social support perceived by respondents, the higher the quality of life they experienced. The strongest correlation was for total MSPSS ($r = 0.681, p < 0.001$), followed by family ($r = 0.662, p < 0.001$), significant others ($r = 0.616, p < 0.001$) and friends ($r = 0.504, p < 0.001$) in decreasing order as shown in (Table 4).

• Quality of life (physical, psychological, social and environmental domains)

Social support total, significant others, family, and friends showed significant positive correlation with all four domains of QOL; $r = 0.603 (p < 0.01)$, $r = 0.557 (p < 0.01)$, $r = 0.595 (p < 0.01)$, and $r = 0.426$ respectively for Physical Domain; $r = 0.590 (p < 0.01)$, $r = 0.504 (p < 0.01)$, $r = 0.567 (p < 0.01)$ and $r = 0.474 (p < 0.01)$ respectively for Psychological Domain; $r = 0.434 (p < 0.01)$, $r = 0.433 (p < 0.01)$, $r = 0.592 (p < 0.01)$ and $r = 0.245 (p < 0.027)$ respectively for Social Domain and; $r = 0.685 (p < 0.01)$, $r = 0.486 (p < 0.01)$, $r = 0.624 (p < 0.01)$ and $r = 0.582 (p <$

0.01) for Environmental Domain. Higher social support was associated with higher quality of life.

About the demographic variables, there is a statistically significant association between parents gender and Quality of life domains; that is, physical, social and environmental (As shown in table 6). However, there no significant association between parents gender and psychological domain in WHOQOL.

Both fathers and mothers demonstrated almost similar results in QoL domains. However, mothers expressed lower QoL in environmental domain ($p < 0.004$). Furthermore, the employment status was shown to be significantly associated with the Environmental Domain ($p < 0.006$) of QOL.

Multiple regression analyses were performed to determine whether the perceived social support using MSPSS was predicted QoL among parents of children with ASD. The analyses revealed that social support ($F = 68.408, p < .001$; $R^2 = .457$) was able to predict high proportion of variance in QoL. By analyses the prediction of QoL domains, it was found that the total score of MSPSS was predicting most of the WHOQL domains. Indeed, Family subscale ($F = 20.678, p < .001$; $R^2 = .197$) was able to predict the proportion of variance in the social domain QoL. Furthermore, caregiver age as well as the total MSPSS ($F = 44.919, p < .001$; $R^2 = .523$) was able to predict the proportion of variance in the environmental domain of QoL. A Pearson correlation analyses indicated that the level of perceived social support is significantly associated with all quality of life domains.

4. DISCUSSION

The aim of the present study was to assess the Quality of Life among Omani parents of Children with Autistic Spectrum Disorders (ASD), and to explore the correlation between socio-demographic, perceived social support and other clinical variables and QOL.

First of all, QOL domains among Omani parents of children with ASD were relatively similar to previous researches, for example, in the current study, QOL domains' score were 56.44, 66.87, 71.71, and 62.96 for physical, psychological, social, and environmental, respectively. Vasilopoulou and Nisbet (2016) stated that mothers and fathers of children with ASD experience poorer QoL at least in one domain when compared to mothers and fathers of typically developing children. According to Skevington, Lotfy, & O'Connell (2004), the WHOQOL mean scores for the general population on the four domains ranged between 51 and 75 (SD: 11.2-17.6). By using the score 60 out of 100 as the midpoint where QoL is judged by WHOQOL (Skevington et al. 2004), the results of our study showed that QoL is acceptable for the psychological and social health domains, on the borderline for environmental health domain, and is comparatively poor for the physical health domain. Furthermore, many studies found a negative association

between having child with ASD and parental QoL (Eapen V, Guan 2016)

Secondly, it is proved that social support is one of the most important factors that influence Quality of life (Mendoza and Dickson 2010). Furthermore, the perceived social support is significantly associated with better quality of life (Pozo, Sarriá & Brioso 2014). The findings of our study revealed that the vast majority of parents perceived a high level of social support. This finding is consistent with previous research done in Kuwait and Turkey (Bilgin and Kucuk 2010, Al-Kandari, Alsalem, Abohaimed, et al. 2017). Our study finding support the notion that having a child with Autism was not associated with lower social support for parenting. (Montes and Halterman 2007)

Socioeconomic status acts as a moderator for parents QoL (Hatton & Emerson, 2009). In this study socioeconomic status was assessed by using two variables; level of education and income. The result of this study didn't reveal a significant correlation between parents' income and the parents' of education and their QoL. Although the result of our study agreed partially with one study conducted in Jordan by Dardas and Ahmad (2014) in term of parents education, further investigation were required regarding how parents were perceived their child disabilities.

In term of income, there is no doubt that parents' income can play a significant role in helping parents providing care to their children. Healthcare, family support, and service referral needs are more likely less among families of children with ASD than without ASD (Kogan, Strickland, Blumberg, Singh, Perrin, & vanDyck 2008). In our study, around 52% of the participants had low to moderate income. We can justify the result that care and support for Omani children and adults with Autistic Disorder are typically based on the Omani government and all caregivers from low SES are likely to have continuity of care with psychiatric services (Al-Farsi, Waly, Al-Sharbaty, Al-Shafae, Al-Farsi et al. 2013)

Greenhaus Allen and Spector (2006) reported that work domain can intensely affect parents QoL. It appears that having a child with ASD prevent or inhibit career planning and development (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006). Depict the negative impact of these parents caring responsibilities on their work life, some of them view their outside work as a chance to get out their home-related stressors (George, Vickers, Wilkes, & Barton, 2008). In our study all fathers were employed while around 11% of mothers were unemployed, working fathers tend to have significant higher levels of QoL compared to working and nonworking mothers. The result of our study is consistent with logic and revealed that employment status was correlated with QoL level. This may be explained by mothers who were working might have been able to improve their socioeconomic status or they can perceive more support from the community. On another hand, among national and international mothers in Kuwait, the majority of mothers

reported that they spend around 6–10 hours with the ASD child daily, as a result, they reported decrease the ability to perform their social duties and taking care of themselves then decreased the ability to enjoy their life (Al-Kandari, Alsalem, Abohaimed, et al. 2017).

Limitations

It is a descriptive study and the primary purpose was to assess the QOL in parents of ASD children. The results will be based solely on self-report data. Although our study was focused on parent's subjective experience, researchers suggest including supplementary measures that assess equivalent constructs. Moreover, this study used WHOQOL-BREF scale, therefore, BREF may not be sensitive enough to detect changes.

5. CONCLUSION

Clarifying the quality of life concept among caregivers, social support and socio-demographic variables that affect and represents an important step in elucidating factors affecting QOL for caregivers of children with ASD and for guiding future treatment development efforts. It is clear that the impact of ASD condition on parents of affected children with ASDs is varied and substantial. Parents QoL looks to be affected due to their kids disorder. This has important implications for (1) Providing education and psychosocial intervention may improve the quality of life of the parents which indeed results in a better care for their children. (2) Health care provider role is not only to help better coordination to child health, but also to maintain parents wellness.

Recommendation

Further research should include specific disease based data and large samples as well as a control group.

6. ACKNOWLEDGEMENT

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