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"Quality Of Life Assessment Of Caregivers Of Children Diagnosed With Autism Spectrum Disorder In Autistic Centers Of Peshawar, Khyber Pakhtunkha, Pakistan"

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ABSTRACT:

Autism spectrum disorder are neurodevelopmental diseases that effect social, behavioral and communication skills of the patient, commonly diagnosed at an average age of 3.1 years. Due to young age , these children are fully dependent on their caregivers. The impact of this continuous responsibility and job impacts the life of caregivers personally, psychologically, physically, socially and economically. This research will assess the quality of life of caregivers of autistic children and its impact on different aspects of their lives. A cross-sectional study was carried out, with a sample size of 96, collected through cluster sampling from five different autistic centers based in Peshawar. The result were quantified and analyzed to find that the quality of life of 8.3% the sample size was severely effected, 83.4% was moderately effected and 8.3% was mildly effected by their caring duties. Significant co relations were found between quality of life with different parameters. Most significantly with financial matters (.748), followed by carer choices and stress (.745) > social life (.743) > personal satisfaction (.659) > personal growth (.292). Further ANOVA test was performed with socioeconomic status as the factor and Qol scale as the dependable variable, which came out to the significant value of .013. The negative impact of the added responsibility on the carer's quality of life is also supported by other similar studies done internationally in differentstudies done in China, America, India and Malaysia. Same results were also obtained on the National level of Pakistan.

Key-words: quality of life, autism, autistic children, caregiver burnout, quality of life indicators, Peshawar,

INTRODUCTION:

A collection of neurodevelopmental diseases known as Autism Spectrum Disorder has three basic deficits: inadequate social interaction, communication, and behavioral patterns(1-3). Early indications of autism include no response to name, avoidance of eye contact, repetitive gestures like flapping hands or flicking fingers, repetition of the same sentences, lack of facial expressions, agitation over small changes, delayed language and motor skills, and gastrointestinal problems(4-5). The American standard for diagnosing autism is the Diagnostic and Statistical Manual, Fifth Edition (DSM-5)(6), while the international norm is the International Classification of Disease, 11th Revision (ICD-11)(7). The average age for diagnosing ASD is 3.1 years(8). Individuals acquiring ASD not only effects their lives but their condition also reflects negatively on their families, friends and other relatives(9). A caregiver for an ASD child is usually a family member or paid helper who tends to the daily needs and requirements of the child, while also providing financial, emotional and psychosocial support(10). It has been noticed that caregivers of children with ASD tend to suffer from stress(11), depression and anxiety(12) stemming from behavioral difficulties, insufficient support from family members, discrimination and decreased societal acceptance and stigma with ASD. The WHO introduced WHOQOL-BREF, which assesses Quality of life in 6 domains, including areas of relationships ,physical and psychological health, independency, environment etc.(13). According to a systemic review done in 2012, the median of prevalence worldwide estimates of autism spectrum disorders was 62/10 000(14). However in 2022, another global systemic review approximated 1/100 children to be diagnosed with ASD(15). Although, these statistics show an upward trend in the prevalence of the disease overtime, there are large variations amongst different sociodemographic groups. In Pakistan, there isn't a reputable source for the incidence of autism but the Pakistan Autism Society estimates that in 2020, over 350,000 children were diagnosed with ASD(16), and that number rose to 400,000 in 2021(17). According to a study done in Netherlands 42% of the caregivers of Autistic children reported pain and discomfort, whereas 40% reported anxiety or depression(18). Another similar study done in the US, stated the presence of mental health problems in 58.1% , physical health problems in 55.6%, and financial problems in 52.3% of their sample size of caregivers of ASD patients.(19). This quality of life study, will prove to be helpful in evaluation of social, physical, psychological and financial well-being of ASD children caregivers. Very few studies have been conducted on Autistic patients and their caregivers, both nationally and in KP region. Autism remains a heavily underdiagnosed condition especially due to its societal stigmatization leading to decreased awareness, education and medical intervention available. This affects not only the patients but also their caregivers. This study gives an insight into the day-to-day problems and obstacles faced by the person responsible for providing for the autistic patients in a Pakistani setting. The struggles faced may be physical, mental, psychological, social, financial and so on. The study provides beneficial guidelines that will not only improve the caregivers quality of life but will also eventually improve the life of the autistic patient, as the caregiver will be better equipped to care and provide for them to the best of their ability, without facing critical burnout themselves.

OBJECTIVES:

1. To assess quality of life of caregivers of diagnosed ASD children.
2. To identify major areas of struggle among the caregivers, such as psychological, financial, familial etc.
3. To asses caregivers demographics most associated with decreased quality of life.
4. To quantify degree of satisfaction with their quality of life through Likert Scale.

HYPOTHESIS:

The Quality of life for caregivers of ASD children in Peshawar, is going to be negative impacted. It is an alternative hypothesis.

MATERIALS AND METHODS:

The study was held in different autistic centers of Peshawar, namely; The Autism Jewel, Franklin Autism Center and inclusive school, Ayla Bells, I-We Learning System and Autism And Learning Disabilities Organization (ARCL). It was a cross-sectional study, carried out in three months from 8th August to 13th October 2022. The population under study were the caregivers of children diagnosed with ASD under the age of 18. The sample size was calculated by using the formula $n = z^2 * p * (1 - p) / e^2$, values being Z= 1.96, p= 0.5, q=0.5, e= 0.1, which came out to be 96 to the power of 90 for an unknown population, as currently there is no known National Autism population data available for Pakistan. Cluster sampling technique was followed for data collection. The inclusion criteria was based on confirmation of ASD diagnosis by a psychiatrist; consenting caregivers who are willing to respond to the interview-based questionnaires in English, Urdu or Pashtu; Caregivers that are settled residents of Peshawar. The exclusion criteria was non-consenting caregivers, those who faced the language barrier, caregivers of children not clinically diagnosed with ASD and residents of other cities of Pakistan.

Based on our objectives, questions were chosen from two Standardized Questionnaires namely, Wisconsin Quality of life caregiver Questionnaire(20) and Adult carers quality of life questionnaires (AC-QoL), Nottingham, UK(21). Different autistic centers of Peshawar were reached via calls and visits, and centers who allowed us to conduct our research were chosen. The said questionnaires were then presented to the selected sample through interview based questions.

The collected filled questionnaires were entered and then analyzed in IBM-SPSS version 25. After the completion of data entry, every subcategory of the questionnaire was processed as a scale, and a total score was given. Each scale was then divided into three groups, namely severe, moderate and mild impact on the QOL of ASD children caregivers. Each scale was then further analyzed to find its frequency, mean, range, standard deviation and levels of significance (p-value). Various correlations were found among each scale and biographic data. At the end, the means of the independent groups were analyzed through ANOVA test, followed The Bonferroni Post-Hoc test.

RESULTS:

The questionnaire had 5 categories, each with variable number of questions, as shown in the figure 1. The first category is 8 questions about different choices and its effect in adding physical and emotion stress to the carer’s life.

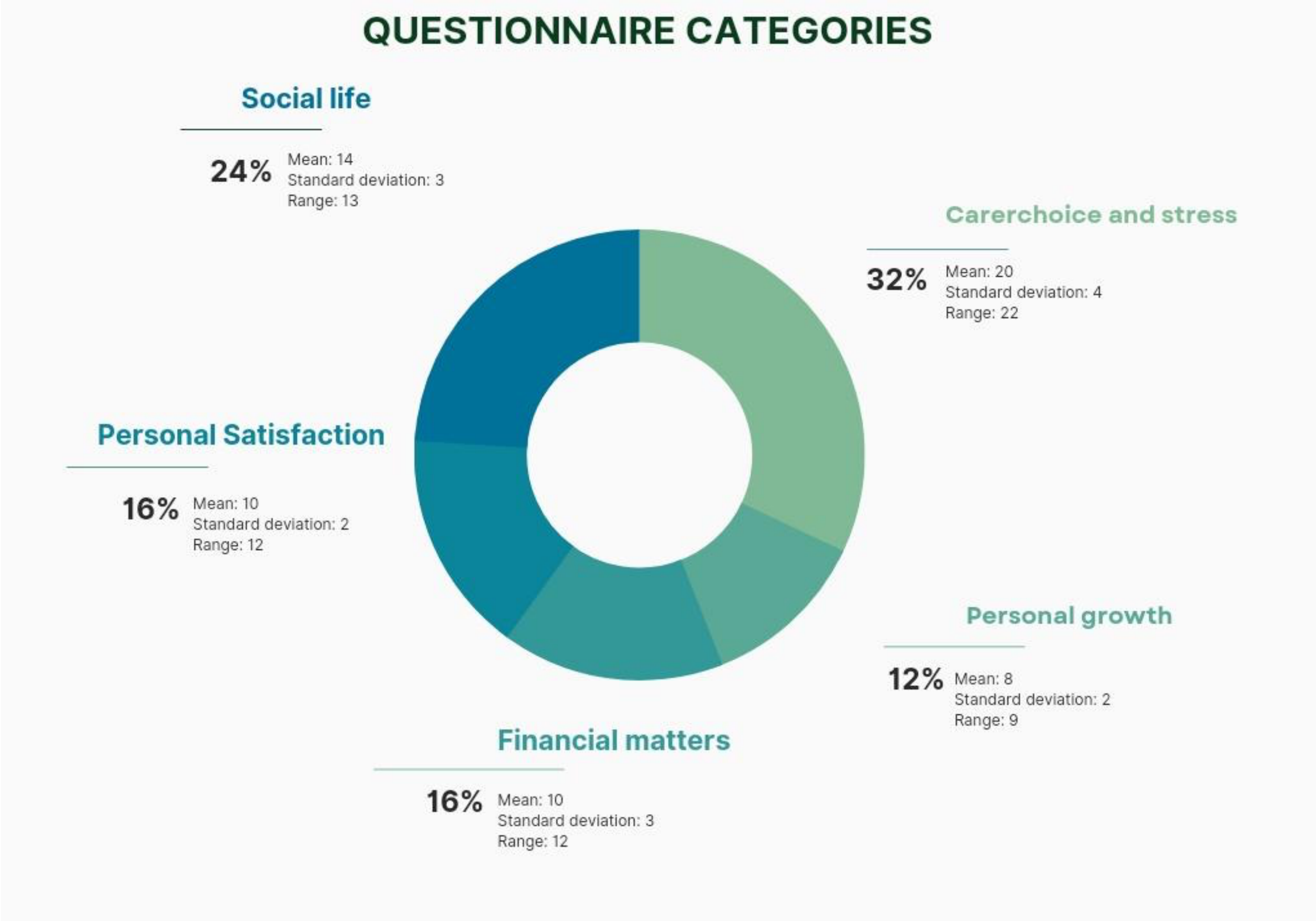


Figure 1: questionnaire subcategories explained

This category accounted for 34% of the total score. The second category contained 3 questions regarding the personal growth the carer did as a direct consequence of their duties, this contributed to 12% to the total score. Third category was of 4 questions inquiring about their financial situation, contributing 16% of the whole score. Next, 4 questions inquiring about the level of satisfaction of the carer with different aspects of their life, this category also contributed 16% to the total score. Last category consisted of 5 questions about the social life of the carer, adding the last 24% to the total QoL score of ASD carers.

Each category was then further analyzed individually and as a whole.

Our first category, out of the 96 sample size, 9.4% scored between 8-16 out of 32, indicating that caring for an ASD child as severely impacted negatively. A major chunk i-e 68.7% of the sample scored between 17-24 out of 32, showing a moderate impact on their life's. The average mean was 20.3, range was 22 and the standard deviation was 4 (Fig 2a).The second category related to personal growth had a mean score of 8.08 out of 12, Range is 9 and standard deviation is 2. 18.8% of the sample population scored between 3-6,showing a negative impact on the QoL. While 61.4 % of the population sample scored between the range of 7-9 indicating a moderate impact, while 19.8% of the population scored high in the range of 10-12, showing a mild impact of personal growth in Qol of theguardians of autistic children (Fig 2b).

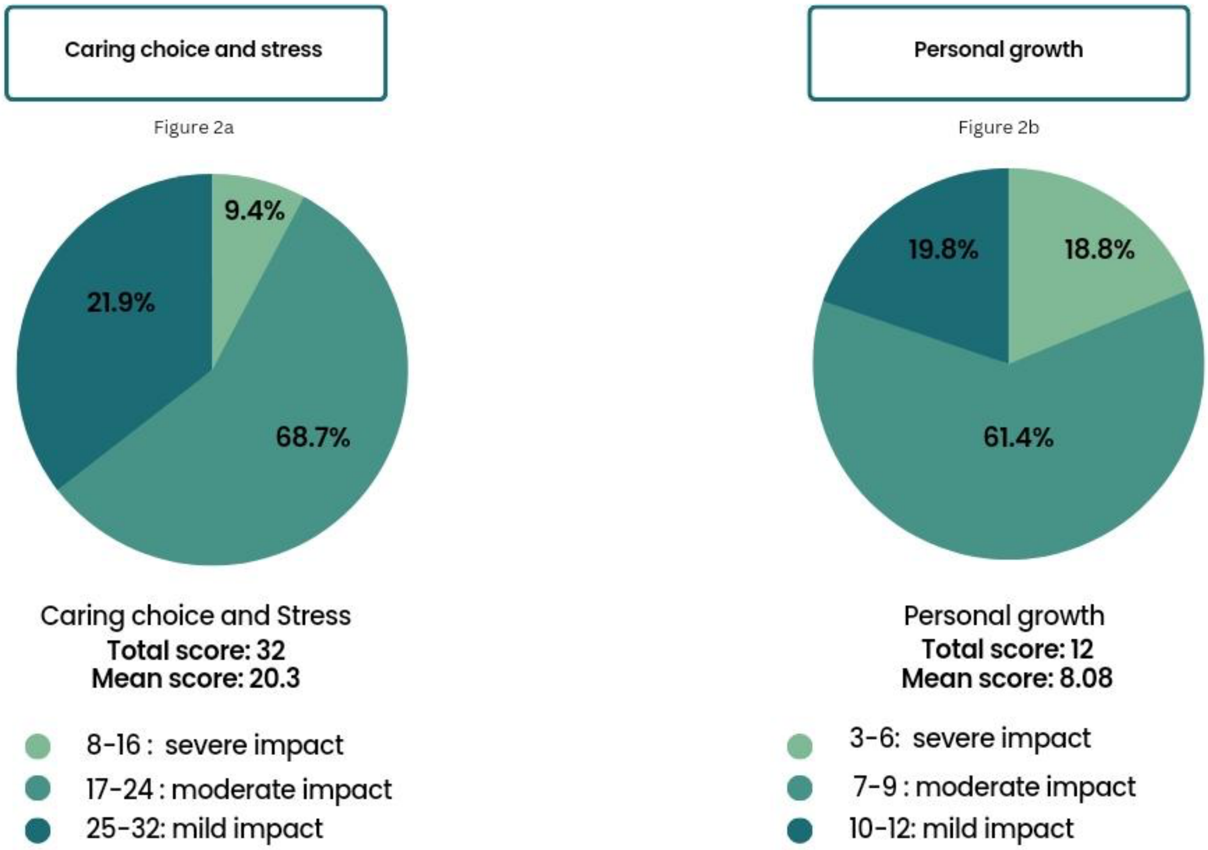


Figure 2a & 2b: impact on caring choice, stress and personal growth

Next we the impact of finances on the Qol. The total score of this category was 16. The means score 10, while the standard deviation was 3 and the range was of 12. 19.8 % of the population scored between the range of 4-8, showing a high impact. 63.5% of the population scored between 9-12 indicating a moderate impact, while 16.5% scored 13-16 indicating a mild impact of finances on the QoL (fig 3a).

The next category is of personal satisfaction of the caregiver, had a total score of 16. The average mean score of which came out to be 10, with a standard deviation of 2, and a range of 12. 18.8% of the sample scored in the range of 4-8, showing a severe impact of their responsibilities on their QoL. On the moderate range of 9-12, the majority of the population failed i.e. 61.4%. The remaining 19.8% of the sample size had a very mild impact, as shown by their score of 13-16, showing that their personal satisfaction was only mildly affected by there added responsibility of caring for an autistic child. (Fig 3b)

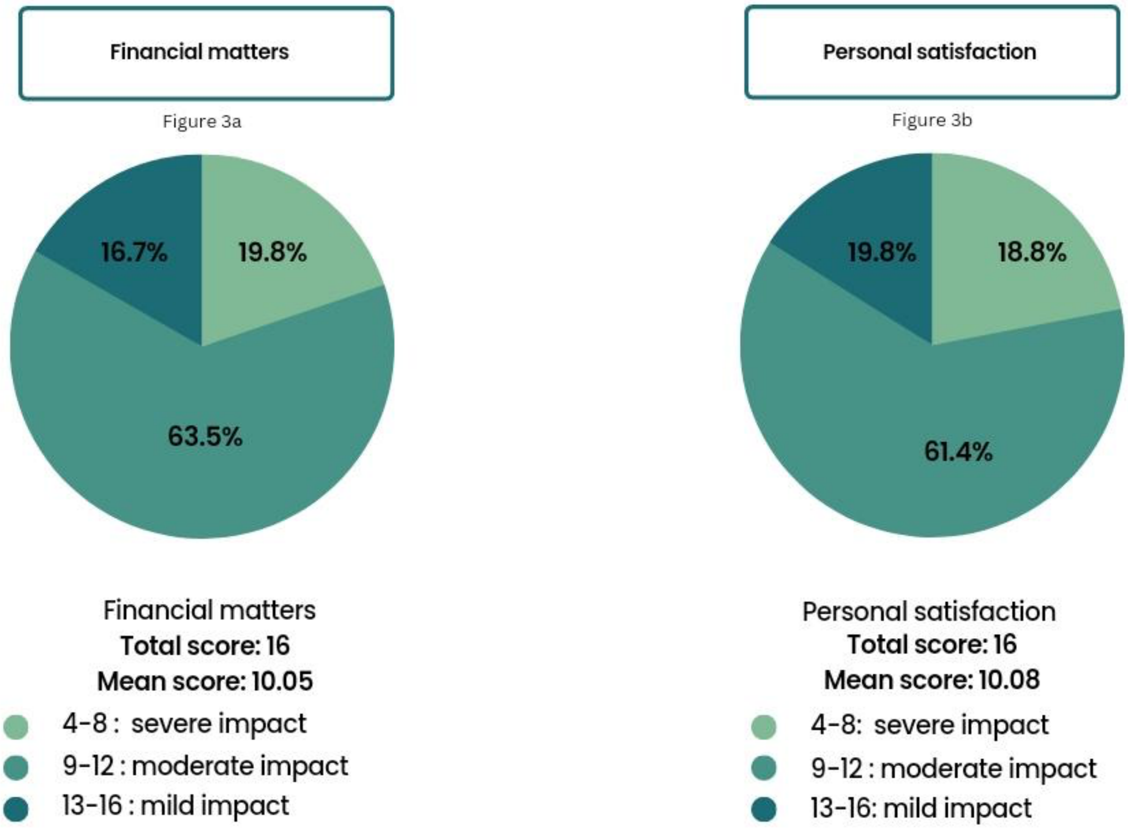
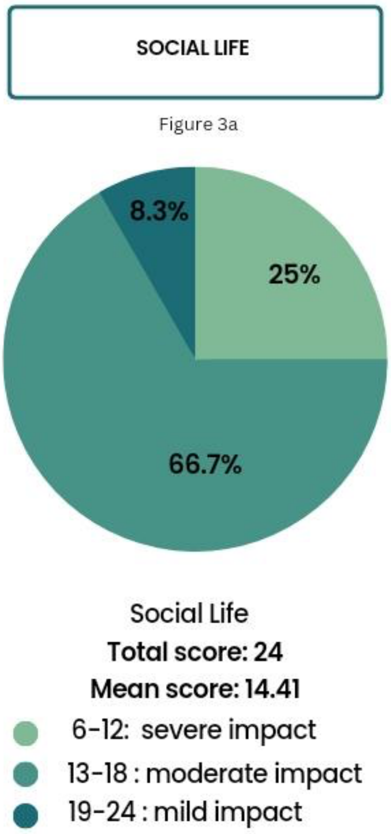


Figure 3a & 3b: impact on finances and satisfaction

Moving on to our last category, the impact on social life. This portion had a total score of 24, with an average score of 14, standard deviation of 3, and a range of 13. 25% of the sample fell into the severely impacted group, scoring between 6-12. While 66.7% of the population scored moderately between 13-18, and only 8.3% scored between 19-24, indicating a mild impact of their caring duties on their social life. (Fig 4a)

Lastly, summing up the previously discussed 5 categories, we have a total quality of life score of 100, in which the mean score was 62.95, respectively. This gives an overview of the previously discussed figures. The results were also further divided into three groups. The first group, in which 8.3% of the sample size lie is the one that scored between 25-50, indicating a high negative impact on their quality of life due to their caring duties. A large portion of the population i-e 83.4% lied in the moderate group, scoring between the range of 51-75. A small portion of 8.3% of the sample size, fell into the range of 76-100 , indicating a mild impact of their caring duties to the ASD child on their quality of life as a whole.



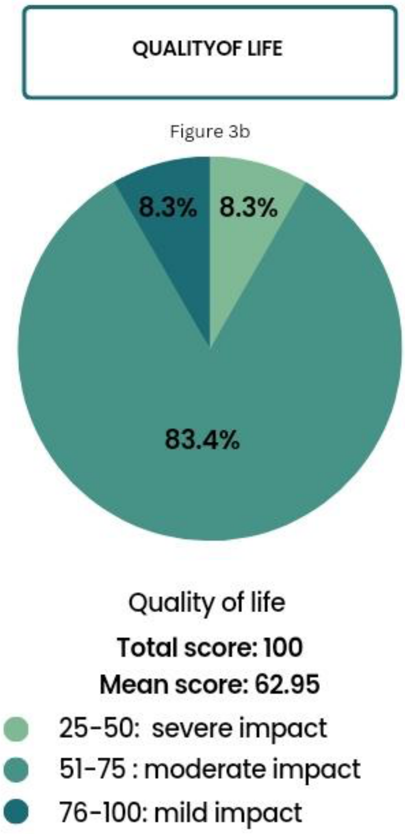


Figure 4a & 4b: impact on social life and total sum of all categories

Moving on, to further data analysis, all the category scales and the total quality of life scale was computed through a bivalent two tailed test to find correlations between them. The significant data has been highlighted in Table 1 below. The personal growth scale was only related to the total quality of life scale by .292 with a significance of 0.004. Financial scale most related to Qol total score the value of .748 significance of 0.000. It was also related to social life scale (.509 with the sig. of 0.000), personal satisfaction scale (.504 with the sig. of 0.000) and carer choices and stress scale (.352 with the sig. of 0.000). Next, the carer choice and stress scale was most significantly related to the Qol of the value of .745 with the sig. of 0.000. It was also related to the financial scale (.352 with sig. of 0.000), social scale (.345 with the sig. of 0.001) and personal satisfaction (.292 with the sig. of 0.001). The next scale is of personal satisfaction , which was correlated the most to the Qol scale by .659 with the sig. of 0.000; it was also related to financial scale (.504 with the sig. of 0.000), social life (.452 with sig. of 0.000) and personal satisfaction (.292 with the sig. of 0.004). The next correlation was of social life scale with Qol total score that came out to be .743 with the sig. of 0.000. It was also related to financial scale (.509 with the sig. of 0.000), personal satisfaction (.452 with the sig. 0.000) and carer choice and stress scale (.345 with sig of 0.001).

		personal growth	financial matters	carer choices and stress	personal satisfaction	Social life	QoL (Total score)
Personal growth	Pearson Correlation	1	0.132	0.044	0.001	0.157	**.292****
	Sig. (2-tailed)		0.198	0.669	0.993	0.126	0.004
Financial matters	Pearson Correlation	0.132	1	**.352****	**.504****	**.509****	**.748****
	Sig. (2-tailed)	0.198		0.000	0.000	0.000	0.000
Carer choice and stress	Pearson Correlation	0.044	**.352****	1	**.292****	**.345****	**.745****
	Sig. (2-tailed)	0.669	0.000		0.004	0.001	0.000
Personal satisfaction	Pearson Correlation	0.001	**.504****	**.292****	1	**.452****	**.659****
	Sig. (2-tailed)	0.993	0.000	0.004		0.000	0.000
social life	Pearson Correlation	0.157	**.509****	**.345****	**.452****	1	**.743****
	Sig. (2-tailed)	0.126	0.000	0.001	0.000		0.000
QoL (Total score)	Pearson Correlation	**.292****	**.748****	**.745****	**.659****	**.743****	1
	Sig. (2-tailed)	0.004	0.000	0.000	0.000	0.000	

**. Correlation is significant at the 0.01 level (2-tailed).

Table:1 Different significant Correlations of education and socioeconomic status with various subcategories scales

Lastly we discuss the correlation of all the categories with the total score. It was found that the highest Correlation of total Qol score is with financial scale (.748 with the sig. 0.000), that implies that the financial burden has the highest impact on the quality of life of care providers of autistic children. After that the carer choices and stress scale is significantly related (.745, sig. 0.000), followed by social life scale (.743, sig. 0.000), personal satisfaction scale (.659, sig. of 0.000) and lastly the personal growth scale. It is least correlated to the personal growth scale (.292 of the sig. of 0.004), which implies that although it's a significant correlation to have an impact on the quality of life, it is still the least impactful in the previously discussed 5 categories.

Continuing our data analysis, following the trend of highest Correlation of financial scale on the quality of life. A descriptive analysis of the socioeconomic status revealed that in a sample size 96, 18 were in lower class, 64 in middle class and 14 in the upper class. Then test of homogeneity of variances was performed between the Qol scale and socioeconomic status, which resulted in rejection of the null hypothesis. Then socioeconomic status of the caregivers was chosen as a factor to run the ANOVA test with the total quality of life scale as the dependable variable which resulted in a significant value of .013. Further analysis was done by applying the Bonferroni Post-Hoc test, Qol scale remaining the dependable variable. it performed multiple comparisons between the three socioeconomic status. The result came out to be that the significant value of .013 from the ANOVA test is due to the correlation between lower and upper socioeconomic class, accounting for a mean difference of 9.484 and -9.484 vice versa. No correlation was found with any comparison of middle to upper and lower socioeconomic classes. The figure 5, plots the means of Qol scales of different socioeconomic classes together, in which we can also observe the significant cross comparison between the upper and lower socioeconomic classes.

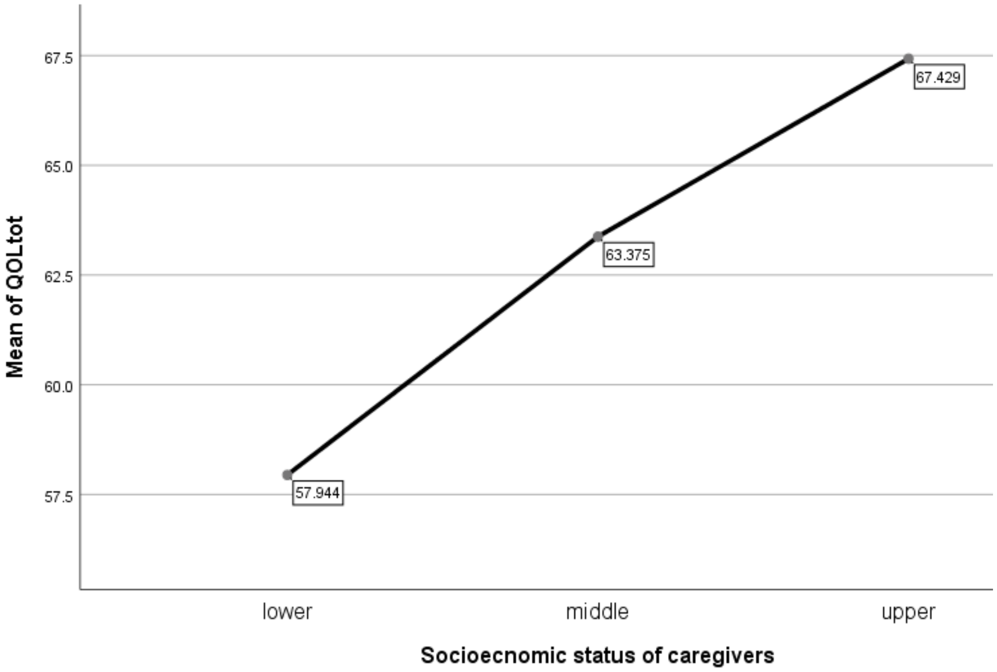


Figure 5: Graphical representation of Bonferroni Post-Hoc test

DISCUSSION:

This research aimed to assess the quality of life of caregivers of children diagnosed with ASD and different aspects of their life. Our data suggested the highest correlation of 0.748 (p value of 0.000) of QoL with socioeconomic status of the caregivers. This is also reflection of many international studies done on the same topic. Like in China, caregivers with higher household income showed significantly lower levels of social burdens such as anxiety and depression(22).. Similarly in an American study, it was noticed that the majority of ASD caregivers had financial difficulties inversely impacting their quality of life(23). Additionally this was reinstated in another northern Indian article(24).

Our research also found a significant correlation with social life of the caregivers 0.743 (p value

=0.000). A study conducted in Saudia Arabia (N=406) proved that social functioning was significantly lower for caregivers of ASD children as opposed to caregivers of non-ASD children (p value: 0.000)(25). Likewise, in another study in Utter Pradesh India, psychological and social life of caregivers was negatively impacted (26) .A study published in Khyber medical University, Pakistan, showed increased burden on life satisfaction and social life (p vale < 0.05)(27) .

Additional analysis on our data also reflected that the Quality of life of caregivers was also correlated to carer choice and stress scale (0.745, p value =0.000), which also included questions about emotional and physical burnout. A Malaysian study stated that 10.2% of the caregivers under their study would often be overwhelmed with their problems stemming from their ASD children(28). Similar studies stated significantly higher levels of depression, anxiety, burnout and mental and physical exhaustion, due to their limited choices, as also proven by our study(29)(30).

CONCLUSION:

The data collected showed the strongest Correlation for socio-economic status, carer choice and stress and social life respected. Lower financial income carers were associated with higher burden levels. Stress, anxiety and other psychological conditions were linked to decreased carer choices, support both physically and financially, as well as, deterioration in their social life.

RECOMMENDATIONS:

The future researches and recommendations on this topic can include:

- A larger sample size of the target demographic .
- More autistic centers from different cities to be included, to do intercity cross comparison.
- Focus therapy groups sessions for the caregivers, to facilitate them overcome the different obstacles and hurdles they face.
- Caregivers who cannot afford professional help for their children should also be included in the samples size.
- Increased awareness of both ASD and caregiver burnout, and how to deal with it.
- A caregiver stipend should be introduced to help with the financial burden of the caregivers
- Professional help should be made accessible and available for the caregivers of Autistic children

STRENGTHS AND LIMITATIONS:

The strengths of this study are;

- Very few studies in Pakistan, especially KP region have been conducted on this topic
- It was a multi-centered study
- A Standardized Questionnaire was used to evaluate the demographic.
- Only children who were diagnosed with ASD by a certified psychiatrist caregivers were included.

The limitations of this study are;

- Limited available sample size
- Duration of the study was short i-e 3 months.

- Only centers based in Peshawar were included in the study.
- Caregivers availing professional services for their children were interviewed only.

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