

Perception Of Parents Of Childrens With Autism Spectrum Disorder On Their Social Quality Of Life: A Case Of Langata Constituency, Nairobi- Kenya

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Abstract

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that presents individuals with difficulties in various domains, including social interaction, communication, repetitive behaviors, and restricted interests (Maenner et al., 2023). This study focused on parents' perception of children with autism on their social QoL in Langata constituency, Nairobi. This study further addressed the following objectives: the perception of parents of children with autism on QoL, the influence education level and gender have on QoL of parents of children with autism. The study had a sample size of 100 participants. This study employed a descriptive survey research design. The theoretical framework used was an elaboration likelihood model. The data was analyzed using SPSS version 23 and the summary was presented in tables. Result indicated that 49.4% (n = 48) of the participants were within low social QoL, 41.3% (n = 40) of the participants were in moderate social quality of life, while 9.3% (n = 9) of the participants were high in social quality of life. The study recommends support group, a reliable support system as well as advocacy and awareness made a collective responsibility in the communities to prevent all odds that parents of children with autism may face.

Keywords: Autism, social quality of life, parents of children with ASD.

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I. Introduction

The American Psychiatric Association (2016) has defined autism spectrum disorder (ASD) as a developmental disorder characterized by three major components: deficits in communication, social interaction, and stereotyped patterns of behaviour. The rising prevalence of cases of ASD in recent periods only ascertains that more parents of children with autism well-being has develop significant concern (Kuhlthau et al., 2014). Globally, the prevalence in Asia and Europe has an average of 1% of boys diagnosed with autism, almost five times than among girls (Disease Control and Protection, 2012). According to Abduelmula (2019), there are 18 per 10,000 children with autism cases in Saudi Arabia, with no specific findings to represent Africa continentally. The rising prevalence of cases of ASD in recent periods points to the direction that more parents of children with autism quality of life have been altered socially due to complexity of the behaviour and services needed for their children diagnosed with autism (Kuhlthau et al., 2014). A study in Canada by Daudji (2011) with Indian families living outside India, showed that 22 out of the 24 parents attributed their child's disability a willed by God and felt blessed for being chosen for the task of raising the children. Also, in Spain Molero et al. (2023) did a study in which a sample which comprised of 197 Spanish fathers (31%) and mothers (69%) raising children with ASD, the finding showed that stigma is associated with parents of children with ASD QoL especially on marital satisfaction where it is perceived that social support and self-efficacy play a significant mediational role in this association. A subscale on QoL, parents/carers from Singapore reported highest mean QoL scores (mean=103.9,) parents/carers in Australia (mean=98.3) indicating great perceived QoL. Contrarily, Romanian parents/carers reported the lowest mean QoL scores (mean=90.7) indicating least perceived QoL. Singapore, had noticeably higher score for areas of Rights, Interpersonal relationship, and Emotional wellbeing. Hungary ranked first in Self-Determination, Physical Wellbeing. Hungary ranked first in self-Determination, Physical Wellbeing, and Social Inclusion (Lee et al., 2008). In South Africa, A qualitative descriptive research design was selected to explore the objectives of the study. Ten participants were recruited; all participants were parents of a child with ASD attending Learners with Special Educational Needs School in Gauteng, data were collected through a semi-structured face-to-face interview survey comprising open- and closed-ended questions, and were analysed using thematic content analysis. The results revealed five main themes, namely communicative challenges, family experiences, communicative coping strategies, speech and language therapy services and strategies provided by the SLPs. Communicative challenges were experienced by parents of one child with ASD. The communication

and behaviour of children with ASD were found to affect the daily functioning of the family. The majority of parents reported not learning a new mode of communication, but rather adapting and adjusting to the communication of their child. Communicative coping strategies were required for novel social settings. In Nigeria, a qualitative study done in Lagos-south western state in Nigeria by Oduyemi et al. (2021) among 230 parents of children with ASD Seventy-four (32.2%) agreed and 99(43%) strongly agreed to the statement 'people without a child with ASD could not possibly understand me' while 54 (23.5%) and 23 (10%) agreed and strongly agreed respectively, that 'being around people who do not have a child with ASD makes them feel out of place or inadequate.' A total of 93 (40.5%) agreed/strongly agreed that having a child with ASD exerts a negative impact on them. Most 192(83.5%) respondents self-stigmatize.

Locally, particularly in Kenya, the Kenya Society of Autism (2007) estimates approximately 4% of children diagnosed with autism or one child with autism for 25 children of the Kenya population, which is much higher than 1% or 160 of children with autism globally, citing more significant communal concern on issues surrounding children with autism particularly on the social QoL of their parents. As already noted by Gona et al. (2015), some parents of children with autism in Mombasa and Kilifi are being neglected and isolated from access to some cultural and communal events like naming rites of the children, religious activities such as communal prayers and other public events. Hence, raising a child with autism, one needs to forego a lot to as opposed to parenting children with typical human development, inevitable challenges like the limited access to knowledge on ASD, cultural and religious negative beliefs, balancing lifestyle between raising the child and other responsibilities infringes on social QoL of parents (Acharya & Sharma, 2021). Social quality of life (QoL) here focuses on environmental and societal connections necessary for individual development to provide a sense of belonging, affection, and security. Social quality of life could be seen as an opportunity in which a person obtains self-identity to survive (Okoroafor et al., 2012). Similarly, Social quality of life could be seen as an opportunity in which a person obtains a self-identity to survive, thus, the isolation nature of society has implications that has shaped parental perspective to achieve high social QoL. A number of studies have demonstrated a correlation between the degree of psychological distress experienced by parents and the intensity of their child's ASD symptoms and challenging behaviours (Ambikile et al., 2012; Divan et al., 2012; Ugoji et al., 2018). Additionally, Kanja et al. (2022) did a study in Nairobi County and Qualitative data was collected using a descriptive phenomenological inquiry enveloped in focus group discussions and in depth or one on one interviews. The study used the following instruments: semi structured interview schedules for one-on-one in-depth interviews; semi structured guiding questions for focus group discussions. The study established that majority of the caregivers had not known about ASD prior to their children being diagnosed. Only 2(8.30%) of the caregivers reported to having heard of the word ASD before their children were diagnosed. Therefore, there are clear evidence that parents of children with autism have challenges achieving better social QoL because of many factors which this study intended to address.

II. Methodology

This quantitative research employed descriptive survey research design which is one point in time approach to collecting data with the simple purpose of being able to describe the character of the population of parents of children with autism social QoL who are residents of Langata, Constituency, Nairobi, Kenya. The population was focused on parents between the ages of 26 to 50 and above. This study targeted the parents of children with autism within Langata constituency, Nairobi. Langata constituency is centrally located in Nairobi with more special needs Centres among other counties. This study targeted the parents of children with autism between the ages of 26 to 50 and above. Cluster sampling was preferential because it focused on parents of children with ASD from the special needs centres as cluster A and the Differently Talented Society of Kenya (DTSK) as cluster B. Cluster sampling focuses on mutually homogeneous yet heterogeneous grouping. A total population size of 115 were selected from clusters A (special needs centre) and B (DTSK), with cluster A=50 and cluster B=65. Using Krejcie and Morgan's table (Morgan, 1970), the population size of cluster A 50=44 while cluster B is 65=56, bringing the total sample size to 100 participants. The SPSS IBM Statistics 25 Version was employed in the statistical analysis and all data generated or analysed is available in this published article. A standard questionnaire, the Quality of Life Autism for Parents (QoLA-P), designed by Autism Research and Treatment, and borrowed from WHOQOL-BREF (Eapen & Water, 2014) to collect data. The questionnaire was modified by the researcher to make 28 items that fit the research objective. The QoLAP has been used in many psychological and clinical related autism and parents/caretakers, and in this study its modified for use on social QoL of parents of children with autism. The researcher obtained a permit from Tangaza University Research Ethics Committee (TUREC), and the National Commission for Science, Technology and Innovation (NACOSTI). Informed consent forms were sought from participants respectively at the beginning of data collection. The participants were aware that the study's findings would be held with the utmost confidentiality and anonymity was guaranteed. Moreover, participation was voluntary and freedom to pull out was observed on the part of the

involved students. The researcher ensured safety on the part of the respondents and debriefing was done for members who needed it. The researcher adhered to academic etiquette concerning citations or references.

III. Findings

Results

This study focused on perception of parents of children of autism social quality of life. A case of Langata Constituency, Nairobi, Kenya. The distribution of the demographic variables was analysed before presenting the findings of the study. The analysis was done on the five demographic variables: age, gender, level of education.

Table 1

Social Demographic Characteristics of the Respondents

Age	Frequency	Percent
26-30 years	23	23.7
31-35 years	16	16.5
36-40 years	17	17.5
41-45 years	14	14.4
46-50 years	21	21.6
50 years and above	6	6.2
Total	97	100.0

Levels of Education of participants

Levels	Frequency	Percentage
Primary	8	8.2
Secondary	8	8.2
Certificate	11	11.3
Diploma	29	29.9
Bachelor's degree	23	23.7
Masters's degree	12	12.4
PhD	6	6.2
Total	97	100.0

Gender of participants

	Frequency	Percent
Female	59	60.8
Male	38	39.2
Total	97	100.0

The results in table 1 showed that 23.7% (n = 23) of the participants were in the age bracket 26-30 years, 21.6% (n = 21) were in the ages bracket 46-50 years, 17.5% (n = 17) of the participants were 36-40 years, 16.5% (n = 16) were in the age bracket 31-35, 14.4% (n = 14) were in the ages bracket 41-45 years, and 6.2% (n = 6) of the participants came under the ages bracket 50 years and above. Implying that the study was conclusive to all ages. On the level of education, 29.9% (n = 29) of the respondents had Diploma, 23.7% (n = 23) had Bachelor degree, 12.4% (n = 12) with Masters, 11.3% (n = 11) had Certificate, 8.2 (8) had their primary school and secondary certificates respectively, while 6.2% (n = 6) had PhD. In addition, further analysis revealed that 60.8% (n = 59) of the research participants were females, while 39.2% (n = 38) of the participants were males.

The perception of parents of children with autism social quality of life

The study measured the perception of parents of children with autism QoL and was calculated as in the table 2 below.

	Frequency	Percentage
Low	48	49.4%
Moderate	40	41.3%
High	9	9.3%
Total	97	100

As seen in Table 2 above, result indicated that 49.4% (n = 48) of the participants were within low social QoL, 41.3% (n = 40) of the participants were in moderate social quality of life, while 9.3% (n = 9) of the participants were high in social quality of life.

IV. Discussion

The present study focused on the perception of parents of children with autism spectrum disorder on their social quality of life: A case of Langata Constituency, Nairobi- Kenya. The investigation showed that 49.

4% (n = 48) of the participants recorded low social quality of life. 41.3% (n = 40) of the participants experienced moderate social QoL, while 9.3% (n = 9) have high social QoL. The fact that half of the population recorded low social QoL suggests that mostly they focus on providing the basic needs such as food, medication, accommodation, clothing and education for children with autism, than other elements that support social growth such as birthdays celebrations, outings, games and use of toys are considered luxuries. To arrive at moderate or high quality of life, there is a requirement for individual and collective responsibility from families and society at large as suggested by Marcella (2020), that investments in social policies, material and human resources should also be made to enhance the emotional wellbeing of family members.

The study showed 49% of parents with low social QoL and 41% of parents recorded moderate social QoL because of life style related factors that requires adjustment. This position agrees with a study in Spain, by Molero et al. (2023), in a sample which comprised of 197 Spanish fathers (31%) and mothers (69%) raising children with ASD. The findings showed that affiliate stigma is associated with parents of children with ASD QoL especially on marital satisfaction where it is perceived that social support and self-efficacy play a significant mediational role in this association. A suggestion that, individually, parents must arise from inferiority, low self-esteem and face with courage the many challenges this study highlighted. Highlighted factors like discrimination and isolation from community events, negative religious and cultural myths that are hindrances to achieving high social QoL must be dealt with (Dardennes et al., 2011; Ravindran & Myers, 2012; Shyu, Tsai & Tsai, 2010).

Furthermore, the study revealed that isolation and discrimination have a huge influence on the perception of social QoL. This finding corroborates with a study by Gona et al. (2016) in the Kenya coast in which thirty-seven interviews and eight focus group discussions were conducted with parents of children with autism and professionals in regular contact with these parents from rural and urban counties of the Kenyan coast. The findings pointed that regardless of parents' religious, cultural connections and areas of location, all encountered communal hostility, inabilities adapting with social situations, and social isolation of their children, which had an adverse effect on their socio QoL. It is then probable that parents should adopt various recommended approaches such as support groups, spirituality, and counselling to enhance acceptance and self-compassion, talk therapy, cognitive reformation to reduce the harmful effects of self-stigma and improve their QoL.

The findings also showed that 9% of the participants achieved high social quality of life, and this assured a possibility that high social quality of life is achievable. Equally, the study pointed to some effective interventions like dual supportive parenting, support groups, involving other close family members in child's life and investing in knowledge of the children's ASD (Ravindran, 2010; Christon et al., 2010; Autism Society of Kenya, 2017). Agreeably, a study by Correale et al. (2022) using a semi-structured interview with focus on groups of parents of children with autism affirmed that limited level of integrations of different services as well as non-existence of structured care pathways were the major obstacles to improved QoL reported by parents. Thus, parents of children with autism can invest in interpersonal relationship within social service environment with various experts who are part of their children's growth such as care takers, teachers, physicians, therapists, nutritionists and clinicians so that collective responsibilities can be attained and better QoL.

V. Conclusion

This study found out that were more female parents 60.8% compared to 39.2% male parents of children with autism who participated. The respondents had different education levels with most being diploma holders 23.7% and the least being PhD holders (6.2%). Also, the study achieved a return of 49.4% low QoL, 41.3% and only 9.3% of the respondents recorded to have high in social QoL. These results were an indication that the parents of children with autism have significant challenge achieving a high social QoL, yet with a glimpse of possibility that attaining high QoL is possible like the few (9.3%) that attained QoL. Therefore, empirically, it is evidence that this finding attested to the fact raising children with autism requires huge commitment that limits parents' social engagement hence low QoL.

VI. Recommendation

Based on the conclusion in the foregoing, this study recommended that the parents of children with children with autism to renew their commitment and devise new ways to cope. The study results offer an effective reference to not only parents of children with autism but also the rest of the society for peaceful and harmonious co-existence. The study recommends more Psychosocial support, reliable support system, awareness programs through government agency like National Council for Persons with Disabilities (NCPWD) and non-governmental institutions like Differently Talented Society Kenya (DTSK) to counter societal stereotypes, advocate for law and policies that appeal for collective community responsibility in handling exploiters of parents of children with autism. This will go a long way improving the status of QoL of parents of children with autism.

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