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Artículo de Investigación

Overload and quality of life perception in caregivers of people with the autistic spectrum

Sobrecarga y percepción de calidad de vida en cuidadores de personas con el espectro autista

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ABSTRACT

Introduction: it is essential to understand aspects related to quality of life in primary caregivers of people with autism spectrum syndrome.

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Objective: To identify the incidence of overload and some sociodemographic factors on the perception of quality of life in a group of primary caregivers of people with autism spectrum disorder.

Methods: A quantitative, cross-sectional, observational, *ex post facto* and correlational-explanatory study involving 52 primary caregivers of people with autism spectrum disorder. The following instrument were used the Quality-of-life perception questionnaire, which evaluated four dimensions: physical, psychological, social relationships and environment; the Caregiver Overload Scale and a sociodemographic survey.

Results: Overload represents an important risk factor for the quality of life of caregivers, considering that being female, being single or divorced, having more dependents and the age of the dependents, combining care with work, devoting more time to caregiving and receiving insufficient support increase the burden, while decreasing simultaneously the perception of their quality of life.

Conclusions: The perception of quality of life in primary caregivers of people with autism spectrum disorder is associated with the degree of overload and psychosocial factors.

RESUMEN

Introducción: Es de gran relevancia comprender aspectos relacionados con la calidad de vida en los cuidadores primarios de personas con trastorno del espectro autista.

Objetivo: Identificar la incidencia de la sobrecarga y algunos factores sociodemográficos en la percepción sobre la calidad de vida en un grupo de cuidadores primarios de personas con trastorno del espectro autista.

Métodos: Estudio cuantitativo, de corte transversal, método observacional, *ex post facto* y nivel correlacional-explicativo. Participaron 52 cuidadores primarios de personas con trastorno del espectro autista. Se empleó el cuestionario de la percepción sobre la calidad de vida, que valora cuatro dimensiones: física, psicológica, relaciones sociales y ambiente; la escala de sobrecarga del cuidador y una encuesta sociodemográfica.

Resultados: la sobrecarga representa un importante factor de riesgo para la calidad de vida de los cuidadores, considerando que ser mujer, soltera o divorciada, tener más personas a cargo y la edad de estas, combinar cuidado con el trabajo, dedicar mayor tiempo al cuidado y no contar con ayuda suficiente aumentan la sobrecarga, disminuyendo al mismo tiempo la percepción de su calidad de vida.

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Conclusiones: La percepción sobre la calidad de vida en los cuidadores primarios de personas con trastorno del espectro autista está asociada al grado de sobrecarga y factores psicosociales.

INTRODUCTION

The burden on caregivers of people with autism spectrum disorder (ASD) is a highly relevant issue due to the unique challenges these caregivers face.[1] Individuals with ASD have a wide variety of emotional and behavioral problems, including irritability, social withdrawal and stereotyped behaviors, anxiety, depression, somatization, rule-breaking behavior self-harm and aggression, attention problems, hyperactivity, impulsivity and abnormal thinking. These behaviors and difficulties are associated with increased burden on caregivers.[2]

On the other hand, the overload has a negative impact on the perception of quality of life of the caregiver and on the dimensions that integrate it, such as: psychological well-being, related to levels of anxiety, depression, and fear; physical well-being, determined by strength, rest and functional activity; social well-being, which includes relationships, affection, and economic situation; and finally, spiritual well-being, which includes the core meanings of hope, religiosity and transcendence.[3,4] Research shows that caregivers have high levels of stress, anxiety and depression, increased by social prejudice and limitations in access to psychosocial support resources.[5,6] The burden affects leisure time, holidays and personal relationships, impairing general well-being.[7]

The Fadinnaf Foundation reported that approximately 80% of caregivers have high levels of stress linked to the lack of family support and excessive responsibility.[8] A systematic review of 21 studies in 16 countries indicates that caring for a person diagnosed with autism not only exposes primary caregivers to high levels of stress and anxiety but profoundly alters the structure of cohabitation and the psychological well-being of the whole family unit.[9]

However, there are studies that have found no effect on quality of life or high overload, possibly due to variations in samples and therapeutic support.[10,11]

In general, overload can cause physical and mental exhaustion, affecting the ability to provide care, so it is urgent to implement support programs that improve their mental health and quality of life.[12-14]

In order to implement evidence-based psychosocial care and support programs, it is necessary to identify sociodemographic variables associated with caregiver overload and how these can mediate the relationship between overload and perception of quality of life in primary caregivers in different socio-cultural contexts.

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In this context and based on the relevance of the described problem, the objective of this research was to identify the incidence of overload and some sociodemographic factors in the perception of quality of life in a group of primary caregivers of people with autism spectrum disorder in Medellín, Colombia.

METHODS

A quantitative research methodology was used with a correlational study design, cross-sectional and observational approach.

Participants

The study population consisted of 120 caregivers of people with ASD, belonging to a corporation for people with special needs in the city of Medellín. For a 95% confidence level (margin of error 10%), 54 caregivers were randomly selected, of which two were withdrawn in the final phase of the study, leaving 52 participants.

Instruments

The Zarit Caregiver Burden Scale[15] was used, which measures the impact of caring for others in different areas of their lives, such as the quality of their social relationships, their economic capabilities and the perception of their physical and psychological well-being.[16]

The study by Breinbauer et al.[17] reported high levels of validity of the instrument with respect to the two aspects of the instrument (subjective burden indicator and depression), as well as good values of internal consistency, inter-observer reliability and test-retest reliability.

The WHOQOL-BREF[18] was used to assess the perception of quality of life in primary caregivers of people with ASD. It contains 26 items with 5 response options, covering physical, psychological, social relations and environmental dimensions. Validation of the instrument in the Mexican population indicated a Cronbach's α of .70 in the different dimensions, confirming the four factors of the original model.[19] The Cronbach's alpha coefficient of the instrument obtained in the sample of this study was of .76, indicating good psychometric properties of the instrument.

Finally, an *ad hoc* sociodemographic questionnaire was applied in order to collect information about the primary caregiver of people with ASD, which included information about the variables of gender, age, area of residence, occupation, income level, number and age of dependents, time spent in care and availability of help.

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Data analysis

A normality test was performed indicating non-parametric distribution in the study variables. Descriptive statistics included means and standard deviations. The Mann-Whitney (two groups) and Kruskal-Wallis (more than two groups) tests were used to compare variables according to sociodemographic groups. The correlation between quality-of-life perception and overload was analyzed using Spearman's rank correlation coefficient, and binary logistic regression was used to evaluate the impact of overload on quality of life perception, dichotomizing the latter into a qualitative variable with a cut-off point in 46. The analysis was performed with SPSS version 25 (IBM Corp. Armonk, NY, USA).

Ethical considerations

The research was classified as minimal risk and met current administrative, technical and ethical standards. In order to collect data, the Corporation for Persons with Special Needs was contacted and authorization and cooperation were obtained from the institution. After collecting the information, the results were delivered together with recommendations for improving psychosocial support strategies to the participating caregivers.

RESULTS

The participants in this study had an average age of M = 37.5 years (SD 6.0). In relation to gender, 84.6% (N=44) were female and 15.4% (N=8) male; 92.3% live in urban areas and 7.7% in rural areas; 42.3% of the caregivers in the sample work as employees and the average income in the families in the sample is 1 to 2 minimum wages; 94.2% of the sample has one person with ASD in charge, and 5.8% two.

The age range of people with ASD varies from under 5 years old with 5.8% to over 30 years old with 3.8%. As regards hours devoted to care, 59.6% devote more than 8 hours per day and 25% between 4 and 6 hours; 82.7% of the sample is engaged in care work more than 5 days a week and 30.8% receive no help.

The study data show that 57.7% of the sample had a high overload level, 13.5% a low overload level and 28.8% no overload.

Descriptive data for quality of life variables indicate that primary caregivers in the sample of this study are in the range greater than 56% of the reference population in terms of the physical and psychological dimension, greater than 50% of the reference population in terms of the social relations dimension and greater than 63% of the reference population in terms of the environment dimension, indicating a satisfactory perception of quality of life at an overall level.

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Differences in quality of life perception and overload according to sociodemographic variables of caregivers

The comparison of the variables of perception of quality of life according to age indicated the presence of statistically significant differences in the physical dimension (p=.045) with lower scores in the more advanced ages; and in the psychological dimension (p=.025), social relations (p=.047) and environment (p=.039), with lower scores at younger ages. As for overload, there was no statistically significant difference according to caregiver age range.

The comparison of quality-of-life perception variables according to gender showed a statistically significant difference in the physical (p=.035) and psychological (p=.039) variables, indicating lower scores for the female gender. In the overload, the statistically significant difference was also identified (p=.038), with higher scores for the female gender.

The comparison of variables of perception of quality of life and overload according to marital status showed a statistically significant difference in the physical dimension (p=.027) and environment (p=.002), indicating lower scores in the single group; in the psychological dimension (p=.013) and social relations (p=.004), with lower scores in the single and divorced group. Regarding overload, there were also differences in the scores (p=.009), indicating higher levels for the single group, followed by the divorced, and lower scores in the married group.

The comparison of variables of perception of quality of life and overload according to educational level indicated only statistically significant differences in the psychological dimension (p=.043), indicating lower scores in the group with the lowest level of secondary education.

The comparison of variables of perception of quality of life and overload according to occupation indicated a statistically significant difference for the environmental dimension (p=.010), indicating lower scores for the unemployed group. The overload variable showed a significant difference (p=.035), indicating higher score for employees and lower score for the housewife group.

The comparison of quality-of-life perception variables according to the family income level revealed the presence of statistically significant differences in the physical (p=.012), psychological (p=.001) and social relations (p=.001) variables, and environment (p=.001), indicating lower scores in groups with lower incomes. No significant difference was identified between income groups in terms of overload.

The comparison of quality of life and overload perception variables according to area of residence (urban or rural) did not present statistically significant differences.

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Comparison of quality of life perception variables according to the number of people with ASD under care indicated the presence of statistically significant differences in the physical dimension (p=.015), psychological dimension (p=.033), social relations (p=.043) and environment (p=.020), with lower scores in the two-person group.

The overload also presented differences (p=.029) with higher score in the group with two persons in charge.

The comparison of quality-of-life perception variables according to the number of dependents without ASD did not present statistically significant differences.

The overload presented difference (p=.024), indicating increase in load as the number of dependents without ASD increases.

The comparison of variables of perception of quality of life according to the age range of people with ASD under care indicated the presence of statistically significant differences in the physical dimension (p=.041) with better scores for the age group less than 5 and more than 30; and the psychological dimension (p=.027), with lower scores in younger age groups.

The overload presented differences (p=.047) with lower scores in the groups under 5 years and over 30, being higher in the group 18-30 years.

The comparison of quality-of-life perception variables according to the number of hours per day spent in caregiving showed significant differences for the physical dimension (p=.038) and the environmental dimension (p=.049), indicating decrease in scores as the number of hours increases.

The overload also showed differences (p=.043) showing an increase as the hours of daily care increased.

Comparison of quality-of-life perception variables according to the number of days per week spent in caregiving indicated differences in the psychological dimension (p=.039) and environment (p=.035), with a tendency for the score to decrease as the number of days per week in care increases.

The overload also presented statistically significant differences (p=.037), increasing the scores with the increase of days.

As for the comparison of variables of perception of quality of life according to the aid variable, statistically significant differences were observed in the physical dimension (p=.016), psychological dimension (p=.017), social relations (p=.005) and environment (p=.002), indicating higher scores in the assisted care group for people with ASD.

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The overload variable also presented significant differences (p=.023), showing a higher burden in the group that does not receive help with the care of the person with ASD.

Relationship between overload and quality of life perception

The correlation between the overload variable and the perception of quality of life showed a negative, high and statistically significant correlation between the two variables (r=-.550, p<.001) (Table 1).

Table 1. Correlation between overload level and quality of life perception

Sperman's rho	**Total overload**
Total quality of life	Correlation coefficient: -.550**
	Sig. (bilateral): <.001
	N: 52

** p<.01

The binary logistic regression indicated that overload acts as a risk factor for the perception of quality of life, decreasing it by approximately 18%. (Table 2)

Table 2. Logistic regression for overload and of quality of life perception variables

Variables in equation	**B**	**Standard error**	**Sig.**	**Exp(B)**	**95% for EXP(B)**	
					Lower	**Superior**
Total overload	1.115	.042	.006	.892	.821	.968
Constant	9.347	3.036	.002	11467.928	-	-

Dependent variable: perception of quality of life.

DISCUSSION

The present study analyzed the relationship between the overload of primary caregivers of people with autism spectrum disorder (ASD) and their perception of quality of life, evaluating multiple dimensions, identifying associated factors and relevant patterns.

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The results show that 57.7% of the caregivers in the study present an intense overload, reflecting the high demand for care of people with ASD, coinciding with other similar studies.[20] There was a significant negative correlation between overload and perception of quality of life, indicating that the greater the burden, the lower the physical, psychological, social and environmental well-being. Overload reduces the overall perception of quality of life by 18%, confirming it as a relevant risk factor.

The results of this study indicate that overloading affects physical energy, increases tiredness and makes daily activities more difficult, especially for caregivers with longer hours. Psychologically, it generates stress, low self-esteem and negative feelings, mainly in less educated women and caregivers. Socially, it promotes isolation, most notably in single or divorced caregivers with less social support. In the environmental field, lack of financial resources and access to services worsens perception of the environment.

These findings coincide with investigations that attribute the high burden to ASD characteristics, negatively affecting the quality of life of the caregiver.[2,20] Negative effects include fatigue, stress, feelings of helplessness, guilt, chronic exhaustion, burnout syndrome, anxiety, depression, interpersonal difficulties and family disruption.[21-23]

The study identified that overload and perceived quality of life are related to individual and contextual factors. Young caregivers have lower perception of quality of life in psychological, social and environmental dimensions, which may be related to less experience in the care of such patients and less knowledge of appropriate strategies, while older caregivers show lower perception of the physical quality due to natural aging.[24] Women have greater overload and worse perception of quality of life in physical and psychological dimensions, which is probably due to traditional gender roles within families where women assume a greater burden related to multiple responsibilities relating to the household.[22]

Singles and divorcees report more overload and worse perception of quality of life, except in the physical dimension, possibly due to lower social support, while married people show less burden, highlighting the role of family support, coinciding with other studies.[24] The lower level of education is associated with higher levels of stress and negative emotional states such as anxiety and depression, probably due to fewer stress management tools. Economic security influences the perception of quality of life, as low-income caregivers and the unemployed show worse environmental perceptions, although no significant differences were observed in overloading according to income.[9]

There were no significant differences related to geographical location. Caring for more than one person with ASD increases overload and decreases the perception of quality of life in all dimensions. The burden is greater in those who care for people aged 18 to 30, due to the demands of this stage. Perception of quality of

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life is better in caregivers of children under 5 or adults over 30, although other studies have mixed results and highlight the importance of patient characteristics.[25]

The increase in hours and days devoted to care reduces the perception of the physical and environmental quality of life and increases overload, showing the direct impact of time spent.[26] The support received improves the perception of quality of life in all dimensions and reduces overload, underlining the importance of social and family support for the well-being of the caregiver as reflected in other studies.[27]

In summary, overload negatively affects all dimensions of the caregiver's perception of quality of life, and multiple individual and contextual factors influence this relationship. A comprehensive approach combining psychological, social and economic support is required to improve the well-being of the caregiver and care for people with ASD.

The study concludes that the majority of primary caregivers of people with ASD in the study (57.7%) present intense overload, reflecting the high physical, emotional and social demand for care. Only 28.8% report no overload. There is a significant negative correlation between overload and perception of quality of life, with the latter decreasing by about 18% as the load increases. Despite this, caregivers perceive a satisfactory quality of life in various dimensions, although it decreases with increasing burden.

Sociodemographic factors such as age, gender, marital status, level of education, hours devoted to care, number of dependents, income and external assistance directly influence the overload and perception of quality of life.

The study highlights the need for strategies to reduce overload and improve the perception of quality of life, such as psycho-educational programs, support networks, public policies with resources and services, and care for vulnerable groups (women, single/divorced, low income, and lower school level).

Limitations of the study

The small size and numerical imbalance in some sociodemographic groups should be acknowledged, suggesting that future research should include larger and more representative samples. The sample size and type do not allow statistical generalization to the general population. However, the findings offer robust internal validity for the studied context and can be taken into account for similar contexts.

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Conflict of interest

The authors declare no conflicts of interest related to the preparation of this manuscript, or the conduct of the research.

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