BURDEN OF CARE AND QUALITY OF LIFE IN MOTHERS OF AUTISTIC CHILDREN

SANTOS, Aline Fernanda Pacheco¹. ALVES, Verônica de Medeiros².

¹Universidade Federal de Alagoas – Campus Arapiraca ²Docente do curso de Enfermagem da Universidade Federal de Alagoas, Mestre em Ciências da Saúde, Doutora em Saúde Mental pelo Instituto de Psiquiatria da UFRJ.

ABSTRACT

Introduction: Autism is a developmental disorder that encompasses changes in the area of socialization, communication and cognition, being sometimes associated to some degree of mental retardation. An autistic child in the family tends to alter the whole routine and the mother, who is the most involved figure in the care of the child, tends to live in function of it, experiencing a continuous psychological overload and compromising its quality of life. Objective: To identify the socio-demographic profile, and to investigate the burden and quality of life in mothers of autistic children attended by Espaço Treat, in Arapiraca-Alagoas. Methodology: This is a descriptive, cross-sectional study with a quantitative approach. Data collection instruments were used: socio-demographic profile questionnaire, Burden scale and WHOQOL-bref. The study was approved by the Research Ethics Committee (REC) of the Universidade Federal de Alagoas. Mothers with a history of psychiatric diseases and those with sensory, motor or cognitive impairments that could impair the application of the instruments used were excluded; Mothers who resided outside Arapiraca/AL; And mothers under the age of 18 years old. Results: The subjects were 35 mothers of autistic children attended by Espaço treat in the period from March to June of 2016. Most mothers had a mean age above 35 years and were predominantly white, married, with more than 10 years of schooling and had a profession. Most of them did not have health insurance and also did not receive financial benefit from the state. Most caregivers of children with autism presented moderate burden of care and the quality of life that was considered mostly as neither good nor bad, showing a lower average in the environment domain (54.73) and higher in the Social relations domain (63.80). There was no statistically significant correlation between quality of life and burden on care of these mothers (P = 0.181). Conclusion: It emphasizes the importance of this study in the search for updated knowledge related to the theme, which will serve to broaden the understanding about autism, the burden of care and quality of life, becoming a subsidy for the Nursing professionals and other health areas plan interventions aimed at improving the mental health of caregivers.

Keywords: Autistic disorder, Mothers, Quality of life.