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RESEARCH ARTICLE

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QUALITY OF LIFE OF FAMILIES WITH CHILDREN AFFECTED BY CYSTIC FIBROSIS IN A STATE OF THE BRAZILIAN AMAZON

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ABSTRACT

In This study aimed to evaluate the quality of life of families of children with cystic fibrosis in a state in the Brazilian Amazon. This is a descriptive, cross-sectional study with a quantitative approach, with data collected from the application of the Whoqol-bref quality of life questionnaire. Families with children diagnosed with cystic fibrosis participated in the study. Inferential analysis was used to assess the most representative dimensions of the Whoqol-bref. It was identified that all families had an overall quality of life score classified as regular. The domain of social and environmental relationships reached lower relative frequencies of quality of life. It is concluded that cystic fibrosis contributed to the low quality of life of caregivers, imposing challenges and coping needs on families.

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INTRODUCTION

Cystic fibrosis, also known as Mucoviscidosis and "Salty kiss disease" is an inherited condition. A child with cystic fibrosis has two altered genes for the disease, having inherited one from the father and one from the mother. For each couple's pregnancy, there is a 25% probability of having a child with cystic fibrosis (Oliveira *et al.*, 2017). As it is a multisystemic, complex disease with multiple

peculiarities, the standard treatment of patients with cystic fibrosis involves antibiotic therapy, nutritional support, airway hygiene, physical exercise, oxygen therapy, as well as mucolytic agents, bronchodilators and anti-inflammatory drugs. Due to the complexity of the treatment and to improve adherence to applied therapies, it is recommended that families are included and that they receive regular assistance in a specialized center (Feiten, 2018). It is essential that improving quality of life goes hand in hand with increasing longevity.

For this reason, specific instruments to assess the quality of life of individuals with cystic fibrosis have been developed and improved on. Quality of life assessment questionnaires provide, in a standardized, valid and reliable way, the perspective of patients and families regarding the benefits and limitations of an intervention, information that cannot be obtained in the analysis of other clinical outcomes (Silva *et al.*, 2018). In this context, the present study aimed to assess the quality of life of families with children diagnosed with cystic fibrosis in a state in the Brazilian Amazon.

MATERIALS AND METHODS

A descriptive, cross-sectional study with a quantitative approach was carried out, with data collected from the application of the general quality of life questionnaire Whoqol-bref. The instrument is composed of 26 questions (facets). There are two general questions and another 24 questions that are grouped into four domains: physical, psychological, social relationships and environment. The questions are presented by a Likert-type response scale, using the following parameters: intensity (nothing - extremely), capacity (nothing - completely), frequency (never - always) and satisfaction (very dissatisfied - very satisfied). The values corresponding to these parameters range from 1 to 5. The higher the score, the better the quality of life (Fleck, 2000). In compliance with Resolution 466/2012 of the National Health Council, the study was approved by the Ethics Committee for Research with Humans, under Opinion N. 4.020.487, CAAE 27848519.10000.0003 (Brasil, 2012). Family members who have children diagnosed with cystic fibrosis participated in the study. The entire universe of children aged between 1 year and six months to twelve years, diagnosed with cystic fibrosis in the state of Amapá until May 2021, was used. To meet the study participants, there was collaboration with the Association of Patients with Cystic Fibrosis of Amapá and the "snowball" technique was used. This is developed in such a way that the first interviewees, who the researcher is already aware of, designate others, and so on. This technique is a useful network sampling method for studying populations that are difficult to access or for which there is no precision regarding their number, especially those that contain few members and are spread over a large area (Vinuto, 2014). The study considered families that had a child with a confirmed diagnosis of Cystic Fibrosis; being a native of the State of Amapá; legal guardian being of legal age and signing the Informed Consent Form; family member involved in the care, routine and treatment of the child with cystic fibrosis from the start, and being in physical and psychological condition to provide an interview. For tabulation and organization of the data, Microsoft Excel 2016 and the Statistical Package for Social Sciences-SPSS Version 26 were used. The most representative dimensions of the Whoqol-bref were evaluated by inferential analysis.

RESULTS AND DISCUSSION

Until the month of May 2021, the period in which the data for this research was collected, there were eight children with cystic fibrosis in the state of Amapá. This study had the participation of seven families, represented by nine respondents, seven mothers, one father and one aunt, who are the main caregivers for declaring involvement in the care and treatment of the child, since the diagnosis of cystic fibrosis. Regarding the number of children, Cardoso *et al.*, (2021), looking for factors associated with the quality of life of caregivers of children and adolescents with chronic conditions, identified that this variable had an odds ratio of 3.2, which means that caregivers having two or more children affected by a chronic condition meant an increase by three times the chance of having a low quality of life. Such finding was observed in the present study when verifying a family with two children with cystic fibrosis.

Characterization of Whoqol-bref by Domains: The characterization of the score of the quality of life questionnaire (WHOQOL-Bref) answered by family members responsible for the care of children with cystic fibrosis is described in table 1. Overall quality of life score classified as regular was identified in all families

(100%). Regarding the domain scores, social relationships reached the lowest relative frequency (55.6%) of quality of life, indicating difficulties in personal relationships and social support, followed by the environmental domain (66.7%), as they presented difficulties related to financial resources, opportunities to acquire new information and skills, and a physical environment aspect. The physical (77.8%) and psychological (77.8%) domains had identical percentages, demonstrating homogeneity between these aspects in the lives of the individuals analyzed.

Table 1. Characterization of the domains of the quality of life questionnaire (WHOQOL-Bref) of family members of children with cystic fibrosis in the state of Amapá-2021. (N=9)

	N(%)	Média±Dp
Domain I - physical domain		3,70±0,46
Bad	0(0,0)	
Regular	7(77,8)	
Good	1(11,1)	
Very good	1(11,1)	
Domain II - psychological domain		3,70±0,26
Bad	0(0,0)	
Regular	7(77,8)	
Good	2(22,2)	
Very good	0(0,0)	
Domain III - social relations		3,52±0,69
Bad	1(11,1)	
Regular	5(55,6)	
Good	3(33,3)	
Very good	0(0,0)	
Domain IV - environment		3,56±0,48
Bad	1(11,1)	
Regular	6(66,7)	
Good	2(22,2)	
Very good	0(0,0)	
WHOQOL-Bref		3,66±0,29
Bad	0(0,0)	
Regular	9(100,0)	
Good	0(0,0)	
Very good	0(0,0)	

SOURCE: Survey data

Cardoso *et al.*, (2021), using the Whoqol-bref to assess the quality of life of patients with cystic fibrosis, the research found that 51.7% of the participants had low quality of life, that is, the largest portion of the study group was below the median and, therefore, with compromised quality of life in the face of the chronic condition. Monte *et al.*, (2020), evaluating the quality of life of family caregivers, identified that the physical and psychological domains had the highest score, while the social relationships and environment domains had the lowest score. Such findings are similar to those found in this research. Silva *et al.*, (2020), confirmed that in general there is a decrease in the quality of life of family caregivers and especially in the domain related to the environment, as it was presented as poor, in which the facets related to this interfered in the caregiver's life, as was also observed in this research. Santana *et al.*, (2018), aiming to assess the quality of life of patients with cystic fibrosis using the Cystic Fibrosis Quality of Life Questionnaire, had the participation of caregivers, who revealed better scores in descending order in the social, emotional and physical domains, diverging with the results of this study.

CONCLUSION

The study showed Cystic Fibrosis within the context of a rare disease as a pathology with a long diagnostic and therapeutic trajectory, marked by adversities that contribute to a low quality of life in addition to imposing challenges and coping needs on families. It was identified that all families had an overall quality of life score classified as regular. The domain of social and environmental relationships reached lower relative frequencies of quality of life. It is concluded that cystic fibrosis contributed to the low quality of life of caregivers, imposing challenges and coping needs on families.

Conflict of interests: The authors declare that the research was carried out in the absence of any commercial or financial relationships that could be interpreted as a potential conflict of interest.

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