

Quality of Life in Caregivers of Children and Adolescents with Mental Disorders

ORIGINAL

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Abstract

Introduction: Psychiatric disorders in childhood and adolescence are extremely prevalent, affecting approximately 1 in 10 Brazilian children. Child mental health affects all areas of development and impacts the physical and mental health of the family and in school performance, with its obvious consequences in adulthood.

Objective: The objective was to evaluate the perception of quality of life of children and adolescents with mental disorders caregiver's.

Methodology: There were participating 64 caregivers of children and adolescents with mental disorders who attend one capside at a city of Paraíba backlands. Data from samples were obtained through a socio demographic questionnaire and the quality of life questionnaire WHOQOL Bref. Data were analyzed using the statistical program Statistical Package for Social Sciences (SPSS).

Results: The results showed that sixty (93.8%) caregivers were women, 27 (42.2%) completed high school, 40 (62.5%) were housewives, 31 (48.4%) were married, 46 (71.9%) were Catholic, 55 (85.9%) were mothers of children and adolescents and the overall score for quality of life WHOQOLBref ranged from 12.5 to 62.5 (mean = 43.9; SD = 12.0) and that the lowest average was found in the psychological domain (m = 40.1).

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Conclusion: At the end of it, the results of this study may influence on the availability of social support networks, on the creation of socio-sanitary laws, on the structure and adequacy of mental health services, since the health of children and adolescents depends on the caregiver health.

Keywords

Adolescent; Caregiver; Child;
Quality of life;
Mental disorder.

Introduction

Psychiatric disorders in childhood and adolescence are extremely prevalent, affecting approximately 1 in 10 Brazilian children [1-2]. In addition, it is also the leading cause of health disability related in this age group with lasting effects throughout life.

Child mental health affects all areas of development and impacts the physical and mental health of the family and in school performance, with its obvious consequences in adulthood. The impacts of family distress are difficult to measure, conflict and inadequate social performance in childhood, but retrospective studies indicate these events as early markers of mental disorders in adults [3-4].

Meet the basic needs of psychiatric patients has become part of the family routine that includes coordinate their daily activities, manage their medication, accompany them to health services, deal with their problem behavior and episodes of crisis, provide them with social support, bear costs and overcome difficulties these tasks. Becoming a caregiver of a psychiatric patient can generate overload, because it is a drop in expected life cycle, which assumes that adults are independent [5].

Studies have shown that the intensity of the burden on families has been related with some variables, such as: patient characteristics (diagnosis, severity of symptoms, degree of dependence, age, gender, disease duration and number of hospitalizations), kinship and contact frequency between caregiver and patient, and caregiver characteristics (gender, age, education and socioeconomic status [6-7].

The World Health Organization (WHO) defines the concept of quality of life basing it on three assumptions: subjectivity, multidimensionality and the presence of both positive and negative dimensions. Thus, it defines quality of life as "*the individual's perception of its position in life, in the context of culture and value systems in which he lives and in relation to his goals, expectations, standards and concerns [8]*".

In Brazil the theme quality of life now has meaning and importance in health care research over the last decade, from 1992, when the average number of publications has increased seven times compared to the previous ten years [9].

Understand how people live, their physical and emotional needs as well as what aspects of their life affect their wellbeing, it is essential for the improvement of rehabilitation programs and treatment modalities in the design of these authors [10].

International studies have investigated the experience of family members who care for psychiatric patients since the 1950s and has intensified from the 1970s. When reviewing research in this area, they found that family caregivers of psychiatric patients feel overwhelmed [11-12]. Other international studies have also pointed to the presence of overhead in family caregivers despite the satisfaction that also presented for taking care of these people [13].

Brazilian studies on this topic are still scarce. Identified only 21 national studies that have addressed, directly or indirectly, issues related to families of psychiatric patients [14]. These studies are generally

qualitative and investigated the families' perception of their coexistence with patients, not specifically addressing the evaluation of the burden on caregivers. As regards the caregivers of children and adolescents with mental disorders, it assessed the quality of life in caregivers of children and adolescents with Autism, confirming it has a negative impact on quality of life of caregivers [15].

Knowing then the prevalence of mental disorders in the group of children and adolescents and the lack of Brazilian studies and especially in northeastern Brazil, came the next problem: the perception of quality of life of caregivers of children and adolescents with mental disorders? Thus, this study aimed to: assess the quality of life of caregivers of children and adolescents with mental disorders attended at a Psychosocial Care Center in Paraíba.

Methodology

A cross-sectional study was conducted. Data collection was performed at a Psychosocial Care Center for Children and Adolescents (CAPSi in the town of Patos, Paraíba, in the first semester of 2015 after approval by the Ethics Committee in research of Patos Integrated College and Approval of the Ethics Committee of Medical Sciences in College of São Paulo Holy House).

It was included in the study all caregivers of children and adolescents with mental disorders treated at CAPSi with availability for scheduling an interview for data collection during the period from 01/05 to 06/30/2015 and it was directly responsible (dispense over 50% of their time) for the care of the child or adolescent with mental disorders who present clinical diagnosis issued by a doctor and that are followed at CAPSi.

For data collection were used: sociodemographic questionnaire and the questionnaire of quality of life WHOQOL-Bref. The demographic questionnaire aimed to obtain information on the demographic and socioeconomic profile of caregivers, and involved

issues such as: age, education, occupation, marital status, religion, kinship with the child / adolescent, moreover, it was collected data about the child/adolescent: sex, age, diagnosis.

The WHOQOL-Bref is a specific instrument for the measurement of quality of life, created by the WHO Quality of Life Group from WHOQOL 100. It is a shortened version of WHOQOL 100. The WHOQOL-Bref contains 26 questions, two general questions and the other 24 represent each of the 24 facets that make up the original instrument [8].

It was calculated the WHOQOLBref scores using the statistical program Statistical Package for Social Sciences (SPSS 22.0), according to the proposal of WHO [8].

The description of quantitative variables was performed by calculating measures of central tendency (mean) and dispersion (standard deviation); for qualitative variables were calculated absolute frequencies (n) and relative (%). For the quantitative variables the verification was carried out of the normality of the data by the Kolmogorov-Smirnov which allowed the choice of non-parametric tests (Mann-Whitney test).

It was recognized statistical significance level of 5%.

In assessing sociodemographic characteristics with the scores of WHOQOL Bref, seeking greater uniformity was required reagrup the ages of 24-39 years and 40-65 years; schooling in 2 groups: illiterate with elementary school (incomplete or complete) and high school to higher education; marital situation: caregivers who have partners and those without partners, occupations: in housewives and those who work outside the home, retirees were excluded because there were only 4 caregivers and it could not be grouped into any other category; and the per capita monthly income of up to ½ minimum wage per capita and above ½ minimum wage.

This research followed the norms of Resolution 466/12 of the National Health Council and was referred to the Ethics Committee for Research Involving

Human Subjects of Patos Integrated College, and was approved by the opinion number 829.843 of 09/10/2014.

Results

Characterization of caregivers

It were included in the study 64 caregivers of children and adolescents with mental disorders who had consecutively willingness to participate in the study during the period of data collection. There were no refusals. The age of the caregivers varied from 24 to 65 years (mean = 38.9 years, SD = 8.6 years). Sixty (93.8%) caregivers were women, 27 (42.2%) completed high school, 40 (62.5%) were housewives, 31 (48.4%) were married, 46 (71.9 %) were Catholic, 55 (85.9%) were mothers of the children and adolescents.

Characterization of children/adolescents

Forty-five (70.3%) CAPSi users were male. The age of the children and adolescents ranged from three to 17 years (mean = 10.6 years, SD = 3.7 years). Twenty-eight (43.8%) children were aged between six and 10 years. The most frequent diagnosis was mental retardation (n = 41, 64.1%) (Table 2).

The overall score for quality of life WHOQOLBref ranged from 12.5 to 62.5 (mean = 43.9, SD = 12.0). The WHOQOLBref domain with the lowest average score was the psychological (Table 1).

In assessing the socioeconomic profile with the perception of quality of life of these caregivers, were related the variables age group, education, marital status, occupation and per capita monthly income to the fields of WHOQOLBref. According to the tables 2, 3, 4, 5.

The table 3, described above, shows that the level of education statistically interfere in the physical and environmental domains, as in the general index of quality of life.

When correlated with marital status and domain

Table 1. Quality of life, assessed by WHOQOL-Bref, of caregivers of children and adolescents with mental disorders, seen at CAPSi, in the city of Patos-PB, 2015 (n = 64).

DOMAINS	Average	Standard deviation	Minimum	Maximum
IGQV* (0-100)	43.9	12	12.5	62.5
Physical (0-100)	54.3	8.3	32.1	75
Psychological (0-100)	40.1	8.8	16.7	54.2
Personal relationships (0-100)	49.2	11.4	25	75
Environment (0-100)	51.4	8.6	34.4	84.4

* Quality of Life General Index.

Table 2. Descriptive statistics of WHOQOL Bref domains of caregivers of children and adolescents with mental disorders, seen at CAPSi, the city of Patos-PB, according to age group, in 2015.

DOMAINS	Age group		
	Between 24 and 39 years	Between 40 to 65	p**
IGQV	35.07	29.4	0.2
Physical	35.19	29.26	0.2
Psychological	35.77	28.55	0.11
Personal relationships	36.06	28.21	0.07
Environment	35.2	29.24	0.19

** Mann-Whitney test.

Table 3. Descriptive statistics of WHOQOL Bref domains of caregivers of children and adolescents with mental disorders, seen at CAPSi, the city of Patos-PB, in education, in 2015.

DOMAINS	Education		
	Illiterate and primary school	High school and higher education	p**
IGQV	25.27	37.45	0.00*
Physical	24.42	38.03	0.00*
Psychological	29.21	34.75	0.23
Personal relationships	31.75	33.01	0.77
Environment	26.25	36.78	0.02*

** Mann-Whitney test.

scores of the WHOQOL Bref, it can be seen that no domain has a statistically significant difference by the presence of companion.

In the current study, the differences in occupation and per capita monthly income, did not cause significant changes in the perception of quality of life, as the tables below: (tables 4, 5).

Table 4. Descriptive statistics of WHOQOL Bref of caregivers of children and adolescents with mental disorders seen at CAPSi, the city of Patos-PB, according to the occupation, in 2015.

DOMAINS	Education		
	Housewife	Work outside the home	P**
IGQV	29.84	31.83	0.66
Physical	28.56	24.38	0.21
Psychological	29	33.5	0.34
Personal relationships	29.16	33.18	0.37
Environment	28.83	33.85	0.28

** Mann-Whitney test.
*** The retired group has not been evaluated in comparison because there were only four individuals and not give to include them in another category.

Table 5. Descriptive statistics of WHOQOL Bref domains of caregivers of children and adolescents with mental disorders, seen at CAPSi, the city of Patos-PB, according to the monthly income per capita in the year 2015.

DOMAINS	Monthly Income per capita		
	Until 1/2 MS*	Over 1/2 MS*	P**
IGQV	29.77	36.76	0.12
Physical	30.22	36.06	0.21
Psychological	30.9	35	0.38
Personal relationships	32.44	32.6	0.97
Environment	29.4	37.34	0.09

* Minimum wage. ** Mann-Whitney test

Discussions

In the present study it can be observed the frequency of female caregivers (93.8%), agreeing to various studies, including the Souza Filho and colleagues [17], confirming that in the mental health services is constant the presence of female caregivers because the care relationships were historically built over time, being observed gender roles in them.

As regards the age of the caregivers, it was observed that the median age was of 38.92 years. Studies show that the higher the age of the caregiver, the worse the quality of life. This is due to the fact that older caregivers already have some limitations (physical and cognitive) that hinder the care of the mentally ill, because to be able to perform some acts inherent to the care it is needed to perform tasks involving physical exertion and cognitive ability [18].

There was great variety in terms of schooling, since most have completed high school. Oliveira and colleagues [19] claim that some dreams are interrupted, delayed or modified, both in professional and personal life, as a result of any fatality, in this case the birth of a child with special needs, which requires a lot of dedication. This fact can not justify the no continuity to study of the great majority of carers with a child's illness.

There is a higher incidence of marriage, but there is a high number of single and divorced. In a study of Quadros and colleagues [21] performed with CAPS caregivers of users, in which 936 people were evaluated, it was found that 59.7% of respondents live with a partner.

It can be seen that all caregivers have religion and the mothers, for the most part, become the child's caregivers. Study with family members of CAPS patients showed that all respondents had religion, and resorted to it, asking for divine help to address the difficulties encountered in patient care [22].

Vieira and colleagues [23] reported in their research that the mother is usually the primary caregiver of children with special needs, since in most

cases the family is not psychologically and physically prepared for the situation and leaves the child with the mother: in this new life phase are generated affective conflicts between the couple because of the great responsibility they will have with the disabled child, in relation to financial costs, breakdown of society and family members, or even the father.

The average age of children and adolescents that caregivers care have is 10.6 years, with a minimum age of 3 and maximum of 17 years, $SD = 3.73$. Nineteen (29.7%) were girls and 45 (70.3%) are boys. In the study the average age of CAPSi users was 11.1 years [24]. Girls are less susceptible to psychosocial stresses of childhood [25].

As regards the diagnostic profile of children, the present study shows that mental retardation is the most commonly condition found in 64.1% of cases. Yeargin-Allsopp et al [27] reported that mental retardation (MR) is the most common neuropsychiatric disorders in children and adolescents. The prevalence rate traditionally cited is 1% of the youth population, though some authors mention rates of 2 to 3%, and there are estimates of up to 10%.

The result of WHOQOL Bref assessment scores shows that the lowest score is found in the psychological domain with 40.1, followed by social relationships domain with 49.2, 51.4 in environment and physical domain score of 54.3. In studies showed that caregivers of people with mental disorders have a perception of low social support, especially in the field of "satisfaction with social activities" and "satisfaction with the family [28]."

Comparison of means with other studies, carried out from the application of the WHOQOL-BREF, demonstrates that the quality of life of caregivers is worthy of attention. In a study of 20 mothers of children with pervasive developmental disorders showed the following results: Physical domain: 69.4; Psychological: 66.85; Social relations: 67.5; and Environment: 60.8 [29]. It can be seen that these results are superior to those obtained in our study.

Study with parents of children and adolescents with pervasive developmental disorder (PDD), mental retardation (MR) and cerebral palsy (CP) used the WHOQOL Bref for evaluation of quality of life. For comparison purposes, there were also evaluated 57 caregivers without disorder, which was called control group (CG). Optionally, here we will be only presented the results of the mothers in the WHOQOL-BREF domains: mothers of patients with PDD the results showed 53.94 in the field Physical, Psychological at 57.59, 58.97 in Social Relationships and 48.96 in Environment; in patients with MRI, mothers showed in the field Physical: 64.65 in Psychological: 68.79, in Social Relations: 69.73 and Environment: 57.14; mothers of children/adolescents with CP domain resulted in 60.87 in the physical domain, 67.20 in the Psychological, Social Relations in 66.97 and 54.64 on the Environment; and the mothers in the control group showed in the field Physical: 68.45 in Psychological: 64.38, in Social Relations: 72.22 and Environment: 54.24 [30].

Looking at the correlation of age with perceived quality of life, our study did not observe significant differences according to age group. But old age is associated with worse quality of life levels associated with health [31]. The role of the informal caregiver himself is tiresome and when summed some of the problems inherent to the normal aging process as depression, physiological stress, and degenerative diseases will produce a decrease in the caregiver's quality of life [32].

The differences in the variables: marital status and monthly per capita income did not affect the perception of quality of life in any domain ($p > 0.1$). The presence of a companion in the house and paid work are important factors that could alleviate the suffering of individuals, to the extent that these can share the emotional burden, financial costs and tasks involving the day-to-day carer [21].

In relation to income an important aspect to be noted is that when the subject quality of life is studied, the household income question it is important

to be analyzed, because higher family income can determine better living conditions. In the present study can not be observed significant changes in quality of life due to income, it may be because the studied population falls, the vast major, in the average salary range of low income.

Education levels affected the overall index of quality of life and the physical domains and environments, noting that the highest scores are found in caregivers who have high school and college level. Individuals with higher education are able to perceive the restricting in keep their social life as a result of care provided to the patient and, consequently, present more subjective impact of the disease on their QoL [33].

Regarding the occupation, we did not find a statistically significant correlation in the differences of caregivers been homemakers or work outside, but the lowest scores are found in housewives. This can be explained that the abandonment of paid work can generate a higher rate of stress for caregivers, for having to face the double challenge of caring and providing for their families because been a caregiver of a child and / or adolescent with special needs require much dedication, and it takes comfort and appropriate resources, and for that it's necessary a stable financial income [34]. The fact that caregivers with an active professional life have more time for social activities and spend less time with the mentally ill, has a positive effect on their quality of life [35].

Final considerations

The present study aimed to evaluate Quality of Life of caregivers of children and adolescents with mental disorders and determinants variables of it, because children and adolescents are under development and their health depends on the caregiver's health, showing that being a caregiver of children or adolescents with mental disorders decreases the perception of quality of life.

Given what we have seen, I believe that the results of this study may influence in the availability of social support networks, in the creation of socio-sanitary laws, in the structure and adequacy of mental health services. That said, I consider that this is not the end of a job, but rather the beginning of a long journey in searching of improvements in quality of life of caregivers.

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