

Social determinants of health and quality of life of caregivers of children with cancer

Determinantes sociais da saúde e qualidade de vida de cuidadores de crianças com câncer

Determinantes sociales de la salud y calidad de vida de los cuidadores de niños con cáncer



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ABSTRACT

Objective: to associate the social determinants of health and quality of life of caregivers of children with cancer.

Methods: a cross-sectional study conducted in a paediatric cancer centre in Fortaleza, Brazil, with 176 participants in November and December 2013. Data were collected using a questionnaire with social determinants of health, and quality of life was assessed using the World Health Organization Quality of Life-Bref. The determinants were correlated with the averages of the quality of life domains using analysis of variance (ANOVA).

Results: there was a statistically significant association between the domains of social relations and education ($p = 0.01792$) and between the psychosocial domain and the gender of the caregiver ($p = 0.01901$). The male caregivers that were highly educated, younger, married, stay-at-home dads from the interior had a better quality of life.

Conclusion: the study sheds light on the influence of social determinants of health in the quality of life of caregivers of children with cancer.

Keywords: Child care. Quality of life. Neoplasms. Caregivers.

RESUMO

Objetivo: Associar os determinantes sociais de saúde e a qualidade de vida de cuidadores de crianças com câncer.

Métodos: Estudo transversal, realizado em centro pediátrico do câncer, em Fortaleza/CE, com 176 participantes, durante novembro e dezembro/2013. Utilizou-se questionário contendo determinantes sociais de saúde e *World Health Quality of Life-Bref* para a avaliação da qualidade de vida. Foram correlacionados os determinantes com as médias dos domínios da qualidade de vida, utilizando a análise de variância (ANOVA).

Resultados: Houve significância estatística na associação entre o domínio das relações sociais e a escolaridade ($p=0,01792$) e entre o domínio psicossocial e o sexo do cuidador ($p=0,01901$). Os cuidadores do sexo masculino, nível educacional alto, mais jovens, casados, do lar e procedentes do interior possuem melhor qualidade de vida.

Conclusão: O estudo permitiu a compreensão da influência dos determinantes sociais de saúde na qualidade de vida de cuidadores de crianças com câncer.

Palavras-chave: Cuidado da criança. Qualidade de vida. Neoplasias. Cuidadores.

RESUMEN

Objetivo: asociar los determinantes sociales de la salud y la calidad de vida de los cuidadores de niños con cáncer.

Métodos: estudio transversal, realizado en el centro de cáncer pediátrico, en Fortaleza/CE, con 176 participantes durante noviembre y diciembre/2013. Se utilizó un cuestionario con los determinantes sociales de la salud y la *World Health Quality of Life-Bref* para la evaluación de la calidad de vida. Se correlacionaron con dominios determinantes el promedio de la calidad de vida utilizando el análisis de varianza (ANOVA).

Resultados: había asociación estadísticamente significativa entre el dominio de las relaciones sociales y la educación ($p = 0,01792$) y entre el dominio psicossocial y el sexo del cuidador ($p = 0,01901$). Los cuidadores de sexo masculino, alto nivel de educación, más joven, casado, casa y desde el interior tienen una mejor calidad de vida.

Conclusión: el estudio permitió la comprensión de la influencia de los determinantes sociales de la salud en la calidad de vida de los cuidadores de niños con cáncer.

Palabras clave: Cuidado del niño. Calidad de vida. Neoplasias. Cuidadores.

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■ INTRODUCTION

Today, paediatric cancer is considered a global public health problem because of its high mortality rate. In 2011, it was classified as a disease that kills, and it was responsible for the deaths of 2812 children and adolescents in Brazil. In Brazil, around 11840 new cases of cancer in children and adolescents were recorded in 2014⁽¹⁾.

The diagnosis and treatment of paediatric cancer cause physical and emotional stress not only for the patients, but also for their families. In addition to the time and effort required of the parents to care for their children, the financial and logistical problems that the treatment can create expose parents to considerable stress, which has implications for their quality of life⁽²⁾.

Quality of life is a subjective and multidimensional construct involving multiple meanings and is, therefore, difficult to measure. It is how people assess the things that are happening in their lives in relation to their objectives, expectations, standards, and concerns. Therefore, when the caregiver's quality of life is compromised, the rehabilitation of sick child is negatively affected⁽³⁾.

A widely adopted method to assess the quality of life of diverse populations the abbreviated instrument developed by the Quality of Life group of the World Health Organization (WHO), the World Health Organization Quality of Life – Bref (WHOQOL-Bref), derived from the WHOQOL-100 version, that aims to support the organization's commitment with the holistic view of health⁽⁴⁾. The instrument groups various aspects of quality of life in the areas of psychological, physical, environmental, and social relations.

Some studies have used this instrument to assess the quality of life of diverse populations, including the caregivers of people with chronic diseases⁽⁵⁻⁶⁾. A study that sought to verify the quality of life of family members who care for patients with dementia with Lewy bodies noted that the domain environment obtained greater averages (26.92 ± 5.88), while the psychological (19.66 ± 4.32) and social relationship domains obtained the lowest averages (9.84 ± 2.18). The averages of the domains were influenced by sex and by the time during which the family member was the caregiver⁽⁵⁾. Another study included caregivers of children with phenylketonuria and identified that the factors that were more closely related to a lower quality of life were occupation, especially in the case of unemployed caregivers, and high levels of anxiety and depression⁽⁶⁾.

Few studies, however, have sought to analyse the caregivers of children with cancer⁽⁷⁻⁸⁾. A study that assessed the quality of life of caregivers of Iranian children with cancer concluded that the physical, psychosocial, and environ-

mental domains were lower than the general population⁽⁷⁾. Another study found significant changes in the lives of caregivers, especially in their social and work lives, and that the psychological domain had the greatest effect on their quality of life⁽⁸⁾.

By observing the domains, it is evident that quality of life can be significantly affected by the social characteristics in which life occurs, defined as Social Determinants of Health (SDOH)⁽⁹⁾.

The definition of SDOH helps us understand that it is possible to reduce the occurrence of diseases by targeting their causes through specific actions on determinants, such as income, occupation, sanitation, family structure, education, availability of services, exposure to diseases, social support networks, social discrimination, and access to preventive healthcare⁽¹⁰⁾.

Thus, at distal level, there are macro-determinants represented by general socioeconomic and cultural conditions; at mid-level, there are the intermediate determinants that consider living and working conditions, education, employment, income, housing, sanitation and health; and at the central level, there are the proximal determinants or micro-determinants related to individual lifestyles, such as hereditary factors, age, and gender⁽¹¹⁾.

Therefore, this study sought to answer the question: what are the social determinants of health that interfere with the quality of life of caregivers of children with cancer? Identifying and analysing the social determinants of health are strategies to formulate healthcare policies for the health-sickness process of a population and to consider how quality of life influences the illness/recovery of persons or their caregivers.

Thus, this paper aims to associate the social determinants of health (SDOH) and the quality of life of caregivers of children with cancer.

■ METHODOLOGY

This is a cross-sectional study with a quantitative approach carried out in a Paediatric Centre that specialises in the treatment and early diagnosis of children with cancer, located in the city of Fortaleza. This centre is the unit of reference in the north and northeast regions of Brazil and it is run by the Unified Health System.

The population was caregivers of children with cancer. The sample of the study consisted of 176 participants. Simple random sampling without replacement considered a sampling error of 5%, confidence level of 95%, and a population of children registered at the Chemotherapy Day of the paediatric centre, which totalled 325 according to

data provided by the research site, resulting in 177 subjects. There was a sample loss of one participant.

The inclusion criteria were family members who directly took care of the sick child, who were over 18 years of age, and who were present at the institution. The exclusion criterion was caregivers with a mental disorder that prevented them from understanding the research questions.

Data were collected by interviews with a structured instrument in November and December 2013, every other day, during the morning and afternoon shifts. The caregivers were approached as they waited for their children to start chemotherapy or immediately after the chemotherapy session. Those who agreed to participate were invited to a private spot in the unit so they could listen to the research development guidelines and sign an informed consent statement. The individual interview lasted, on average, 30 minutes.

Data were collected using two instruments. The first was a questionnaire containing the social determinants of health. The individual determinants were age and sex; the proximal determinants were marital status and number of children (part of the lifestyle of people); and the intermediary determinants were occupation (part of living and working conditions), education (the education component), and origin (the housing component)⁽¹²⁾.

To assess the quality of life of caregivers of children with cancer, we used another instrument developed by the Quality of Life group of the World Health Organization (WHO), called the World Health Organization Quality of Life – Bref (WHOQOL-Bref)⁽⁴⁾.

This instrument consists of 26 questions, of which two (Q1 and Q2) are general and 24 are divided into psychosocial, physical, environmental, and social relations domains graded with a Likert-type table, which is the most widely used scale in opinion polls. Each item is scored on a scale of 1 to 5; the higher scores indicate a better quality of life. The average score of each domain denotes the perception of quality of life of each domain. This value is multiplied by four in order to obtain a range of 4-20 and then turned into a 0-100 scale so that it can be compared with the WHOQOL-100⁽⁴⁾.

The data were organised using Microsoft Office Excel and analysed statistically with the EpiInfo version 7.1.4.0, considering absolute and relative frequency. Associations were made between the social determinants of health and the averages of the quality of life domains using analysis of variance (ANOVA). The adopted significance level was 5% ($p \leq 0.05$).

In accordance with ethical aspects, this study was approved by the ethics committee of the Faculdade Católica

Rainha do Sertão, via Plataforma Brasil, with protocol number 316.667 (date of report: 26/06/2013). This study complies with the standards and guidelines of human research of Resolution 466/12 of the National Health Council.

■ RESULTS

The sample consisted of 176 caregivers of children with cancer. The age of the caregivers ranged from 18 to 67 years, with an average of 33 years (SD: 8.17). Most of the caregivers were mothers (161 – 91.48%), 26 to 35 years old (95 – 53.41%), had not finished elementary school (55 – 31.25%), were married to the child's father/mother (63 – 48.26%), were stay-at-home parents (91 – 51.7%), and lived in the interior of the state (97 – 72.16%).

The quality of life of the caregivers of the children with cancer was evaluated using the WHOQOL-Bref instrument. The domains of the instrument were associated with the social determinants of health, as described in the following table.

The associations between the quality of life domains and the social determinants of health reveal that there was no statistically significant association between social relations and education ($p = 0.01792$). There was statistical significance between the psychosocial domain and the sex of the caregiver ($p = 0.01901$). Thus, the male caregiver (the father) has a better quality of life with regard to the psychosocial domain. No statistically significant association was observed in relation to the other determinants and domains.

■ DISCUSSION

Characteristics of the social context that trigger inequalities and vulnerabilities affect the health of people. These social and economic circumstances determine unequal living and work conditions, influence behaviours and lifestyles, which are risk factors of diseases and affect the well-being and quality of life of people.

The social determinants of health range from individual factors that are inherent to the individual and unchangeable, such as age, genetic factors and sex, to a macro level that includes cultural, environmental, and economic factors that dominate the population as a whole. The Dahlgren and Whitehead model stresses the relevance of non-clinical factors on the health situation of individuals and populations and categorises these social determinants of health into these different levels. It should be noted, however, that although each of these levels carries its own importance, they are interconnected and cannot be per-

Table 1 – Association of the quality of life domains and the social determinants of health of mothers of children with cancer. Fortaleza – CE, Brazil, Nov/Dec 2014.

Social Determinants of Health	Domains							
	Environment		Physical		Social Relations		Psychosocial	
	Average	p	Average	p	Average	p	Average	P
INDIVIDUAL								
Sex		0.30889		0.27432		0.34751		0.01901
Men	59.07		71.20		71.33		69.73	
Women	56.06		67.11		68.25		62.90	
Age		0.13508		0.07720		0.14440		0.71278
18 – 25	58.00		71.04		69.74		65.00	
26 – 35	57.24		68.31		69.72		63.38	
Over 35	53.91		64.27		65.85		62.92	
PROXIMAL								
Marital status		0.20011		0.20097		0.58502		0.18896
Married to the father/ mother of the child	56.89		67.48		67.50		63.86	
Divorced	58.06		68.97		71.03		65.06	
Married to other spouses	61.40		78.60		68.60		70.20	
Single	53.94		65.55		68.68		61.37	
Number of children		0.10587		0.84769		0.46211		0.64734
1 to 3	56.64		67.29		68.92		63.52	
4 to 6	55.37		69.10		65.89		64.00	
More than 6	40.50		65.50		62.50		56.50	
INTERMEDIARY								
Education		0.27575		0.94452		0.01017		0.98794
Illiterate	54.33		70.67		62.67		64.67	
Did not finish elementary school	53.56		67.58		64.18		63.21	
Finished elementary school	56.95		65.67		73.52		62.09	
Did not finish secondary school	58.51		69.27		71.64		64.42	
Finished secondary school	57.67		66.52		69.17		63.68	
Did not finish university	51.40		71.20		62.40		61.40	
Finished university	59.18		66.45		72.81		64.45	
Occupation		0.16290		0.58904		0.94014		0.56474
Homemaker	57.43		68.01		68.45		63.03	
Works out of the home	55.13		66.89		68.59		63.98	
Origin		0.69434		0.40990		0.44908		0.96367
Capital	55.79		66.08		69.63		63.43	
Interior	56.52		68.00		68.09		63.51	

ceived as isolated actions. Thus, the combined influence of these factors is considered a determinant of the health status of populations⁽¹⁰⁾.

The Dahlgren and Whitehead model was used as a conceptual framework to analyse the influence of social determinants of health on the quality of life of caregivers of children with cancer.

In this study, as mentioned previously, the caregivers were mostly young mothers, aged 26 to 35, with little formal education, married to the father of their child, and did not work out of the house. A similar profile of caregivers of children and adolescents with cancer has been frequently reported⁽¹³⁻¹⁴⁾.

The quality of life of the participants was reasonably good for each of the domains, except for the domain environment, which obtained the lowest score. This corroborates the findings of another study that assessed the informal caregivers of elderly people and where this was the only domain that scored less than 60 (58.38 points) and revealed a statistical significance between the groups of adults caregivers and the elderly caregivers ($p=0.017$)⁽⁷⁾. This domain expresses the following aspects: physical safety and protection, home setting, financial resources, health and social care (availability and quality), opportunity to obtain information and skills, participation and availability of recreation/leisure, physical environment (pollution, noise, traffic, weather), and transport⁽⁴⁾. Thus, it is perceived that of all the quality of life domains, this is probably the domain that is most influenced by the social determinants of health, especially the intermediary determinants and macro-determinants.

According to the model of social health determination, the individual determinants – age, sex, genetic inheritance – have an influence on their potential and health conditions⁽¹²⁾. It was found that the younger caregivers have a better quality of life, although there was no statistical significance. A study involving the caregivers of patients with metastatic cancer in palliative care showed that the younger family members feel physically better in relation to their health⁽¹⁵⁾. Similar to the obtained results, another study revealed that a younger age negatively influences the quality of life of the caregiver and family members of hospitalised patients with cancer⁽¹⁶⁾.

The male caregivers (fathers) had a better quality of life regarding the domains social relations, denoting a statistical significance. This result corroborates the findings of a recent study in Iran, in which quality of life scores of male caregivers were higher⁽⁷⁾. Another study found an essentially female sample (95.7%) in the care of children with cancer (82.6%), formed by mothers who mostly expressed they

were overburdened⁽¹⁷⁾. In most cases, the mother takes on the role of single or primary caregiver, which is an arduous and difficult task that can cause social losses and decrease their quality of life⁽¹⁸⁾.

Since they are modifiable by people, behaviour and lifestyle are considered proximal determinants⁽¹²⁾. This study considered marital status and found that caregivers married to other spouses who were not the parent of the child with cancer presented better quality of life scores, with the exception of the domain social relationships. Unlike this study, a study that compared the care influx of children with cancer with caregivers alone or with companions concluded that there was no difference in the demand of care regarding physical or psychosocial aspects⁽⁶⁾.

With respect to the number of children, it was observed that a lower number of children resulted in higher quality of life scores. Corroborating this data, researchers claim that a higher number of children has a statistically significant effect on the domains of care overburden in the quality of life assessment⁽¹⁴⁾.

Regarding the intermediary social determinants of health for living and working conditions – represented by access to public services, education, housing, sanitation, health, food production, employment, and income⁽¹⁹⁾ – this study considered education, origin, and the occupation of the caregivers of children with cancer.

It was observed that the quality of life gets higher as the mother's education increases, and there is a statistically significant association with the domain social relationships. A study found the same correlation between quality of life and schooling of the caregiver, however with statistical significance only in the domain environment⁽²⁰⁾.

Despite the lack of a considerable association, the fact that the caregiver does not work outside the home and lives in the interior subtly contributed to a better quality of life. A study showed that the occupation of the caregiver and the domains psychosocial, social relations and environment are associated⁽²⁰⁾. Contrary to the result, researchers found a correlation between living in an urban area and a better quality of life⁽¹³⁾.

■ FINAL CONSIDERATIONS

In this study, it was found that the social determinants of health that influence quality of life among the caregivers of children with cancer are sex (male), education (high schooling level), age (younger), marital status (married), occupation (stay-at-home), and origin (outside the capital), with a statistical significance in the first two correlations.

The domain environment was the most affected in the quality of life of the caregivers of children with cancer, showing that the studied population still suffers with the precarious environmental and financial conditions, and with the lack of leisure opportunities and safety. Of all the quality of life domains, this was possibly the domain that is most influenced by the social determinants of health, especially intermediary and macro-determinants.

The cross-sectional design of this study is an important limitation because it does not allow an association of quality of life factors over time. Since the participants were recruited at a hospital before and after treatment, the answers may have been influenced by positive or negative experiences at the particular moment rather than by their general view. The lack of studies that address a similar population and that use the same instrument hindered any comparison of the findings and discussion of the results.

Based on the results, it appears that the Dahlgren and Whitehead model can be used to shed light on the influence of social determinants of health in the quality of life of caregivers of children with cancer, and encourage the perception of access points for the selection of political and welfare interventions to reduce the inequities of health-care, and consequently improve the quality of life of these caregivers. New studies that can cover a larger numbers of social determinants of health should be conducted to obtain even more consistent data.

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