The family of the child with cancer: socioeconomic needs

A família da criança com câncer: necessidades sócio-econômicas

La familia del niño con cáncer: necesidades socioeconómicas

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ABSTRACT
Objective: To identify the socioeconomic variables which influence the families of the child with cancer.
Methods: Quantitative, descriptive, correlational research with 128 families of children with cancer. Three instruments were used: "Questionnaire evaluating the impact on the family of children with cancer", "Social Support Satisfaction Scale", and "Graffar Scale".
Results: Families report increased economic spending due to the disease, with the displacements to hospital and medication. The loss of income by one of the parents also exacerbates the economic impact of the disease. Families with greater support needs and lower social support present greater economic impact.
Conclusion: The social support assumes an important role in the decrease of the economic needs incited by the disease. Nurses must identify the economic needs of the families and become part of the support network of them, being a source of support so they can strengthen themselves in caring.
Keywords: Psychosocial effects of the disease. Family. Child. Nursing.

RESUMO
Objetivo: Identificar as variáveis socioeconômicas que influenciam as famílias da criança com câncer.
Métodos: Pesquisa de natureza quantitativa, descritiva e correlacional com 128 famílias de crianças com câncer. Foram utilizados três instrumentos: "Questionário de avaliação do impacto na família de crianças com câncer", "Escala de Satisfação com o Suporte Social" e "Escala de Graffar".
Resultados: As famílias revelam gastos econômicos acrescidos com a doença devido aos deslocamentos para o hospital e à medicação. A perda de rendimento por parte de um dos progenitores também agrava o impacto econômico da doença. As famílias com maiores necessidades de apoio e menor suporte social apresentam maior impacto econômico.
Conclusão: O suporte social assume um papel importante no decréscimo das necessidades econômicas incitadas pela doença. Os enfermeiros devem identificar as necessidades econômicas das famílias e tornar-se parte da rede de apoio das mesmas, sendo fonte de suporte para que as mesmas consigam fortalecer-se no cuidar.
Palavras-chave: Efeitos psicossociais da doença. Família. Criança. Enfermagem.

RESUMEN
Objetivo: Identificar las variables socioeconómicas que influencian a las familias del niño con cáncer.
Métodos: Investigación de naturaleza cuantitativa, descriptiva y correlacional llevada a cabo con 128 familias de niños con cáncer. Fueron utilizados tres instrumentos: "Cuestionario de evaluación del impacto en la familia de niños con cáncer", "Escala de Satisfacción de Soporte Social" y "Escala de Graffar".
Resultados: Las familias revelan un aumento en los gastos económicos con la enfermedad debido a los desplazamientos hacia el hospital y a la medicación. La pérdida de ingresos por parte de uno de los progenitores también empeora el impacto económico de la enfermedad. Las familias con mayores necesidades de apoyo y menor soporte social presentan mayor impacto económico.
Conclusión: El soporte social asume un papel importante en la reducciónde las necesidades económicas incitadas por la enfermedad. Los enfermeros deben identificar las necesidades económicas de las familias y convertirse en parte de la red de apoyo de las mismas, siendo fuente de soporte para que las mismas consigan fortalecerse en el cuidar.
Palabras-clave: Costo de enfermedad. Familia. Niño. Enfermería.

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■ INTRODUCTION

The diagnosis of cancer in the child disturbs the whole functional balance of the family, since it occurs in a family system, producing negative effects on all its elements[1]. In order to maintain the balance of the different family members, caregivers need to adapt to new demands in their daily routine, which implies changes in the behavior and redefinition of roles[2].

The experience of having a child with cancer triggers in the family different feelings and a need to change their daily lives[3-4].The impact leads the family's to develop new skills and tasks, which interfere in their daily lives at various levels: personal, emotional, social, family, and financial[1,4].

Children with cancer require long periods of hospital stays and special care, with consequent needs for hospital transfers, which can lead to additional emotional, physical, spiritual, social and economic costs for these families, contributing to the increase of its fragility[5].All these needs that emerge either from the disease or from the treatments themselves imply a physical, emotional and economic burden on the family[6].

The financial and emotional resources are oriented to the sick child, and when this happens, there is not only a reduction of the normal activities of the family, but also of the economic resources[7].

In many families, the mother assumes the child's primary caregiver, which causes a loss of the monthly income of one of the caregivers. The economic difficulties that emerge with the disease, combined with this loss of income, can further weaken the family relations and generate conflicts among its members, shaking its whole structure[8-9].

The distance from their residences, during long periods of hospitalization, is another factor that exacerbates the economic burden of these families[9].

Regarding these needs, the social support network plays an important role in the lives of these families as it will help them reorganize and direct the resources to care for the child with cancer and the rest of the family. They expect to have the provision of the extended family support[10].

The families of children with cancer are exposed to factors of great vulnerability. Thus, it is extremely important to identify the socio-economic factors that make families more vulnerable to the disease, in order to support nurses' interventions, so that they can help them and enable them in relation to the resources in the adaptation process.

In view of the above, this study aimed to: identify the socioeconomic variables that influence the families of the child with cancer.

■ METHOD

This is a quantitative, descriptive, correlational study carried out in a health institution in the northern region of Portugal, in which 128 families of children with cancer participated. The sample was conventional, families of children with cancer up to the age of 18 years old, who had previous experience of hospitalization and were in treatment (chemotherapy/radiotherapy) were included. Families of children with cancer were excluded: (i) in palliative care; (li) post-transplant, and (iii) under surveillance (which were no longer under treatment). The sample was defined by the total number of families contacted in the period between August of 2011 and January of 2013, taking into account the inclusion and exclusion criteria defined.

The data collection took place between August of 2011 and January of 2013, in a health institution in the northern region of Portugal, through the application of three instruments: The "Social Support Satisfaction Scale (SSSS)", the "Graffar's Scale", and the "Apgar Scale". These instruments were applied by the investigator to the father and mother, with an average duration of about 30 minutes during the child's hospitalization, in a room provided by the service, where it was possible to maintain the privacy of the families. During this period, the children remained in the company of volunteers, in a playful educational room.

One of the instruments used in the data collection was the QAIDOF, built and validated by us, with the objective of evaluating the impact of the child's cancer in the family[11]. Consisting of two parts: in the first, it makes a sociodemographic and economic characterization of the families; in the second, it evaluates the impact of the disease in the family through 47 items, with five response options, on a Likert-type scale (1- Totally disagree; 2 - Disagree; 3 - Neither disagree nor agree; 4 - Agree; 5 - Totally agree). It presents four dimensions: the Impact of Illness on the Healthy Siblings (IIHS) -10 items; The Family Perception of Nurses' Interventions (FPNI) -10 items; The Impact of Illness on Family Structure (IIFS) -15 items; the Economic Impact of Illness in the Family (EIIF) - 12 items. In order to compare and evaluate the internal consistency of QAIDOF, the Cronbach's alpha, obtaining a global alpha of 0.88 has been used.

In this study, the dependent variable was the "economic impact of the illness in the family" that we evaluated through one of the dimensions of QAIDOF, the EIIF. This dimension (EIIF) is composed of 12 items, and presents a Cronbach alpha of 0.73.

We have also used the SSSS to evaluate the perception of families regarding their social support. It is a self-completion scale, composed of 15 phrases that allow families

to indicate their degree of agreement with each one. The sentences are presented on a Likert-type scale with five response positions (1 – Totally agree, 2- Agree, 3 - Neither agree nor disagree, 4 - Disagree, 5 - Totally disagree). This scale has four dimensions, "satisfaction with friends/friendship" (5 items), "intimacy" (4 items), "family satisfaction" (3 items), "social activities" (3 items). The Cronbach's alpha value of the scale is 0.85.

In order to assess the socioeconomic conditions of the families, the Graffar scale has been used to identify the families in the following dimensions: profession, level of education, source of the family income, comfort of accommodation, and aspect of the housing area. At grade 1, it corresponds to score 1; To grade 2, score 2, and so on. The sum of these scores allows the family to be included in one of the following social positions: (i) High class (I) – from 5 to 9; (ii) Upper middle class (II) – from 10 to 13; (iii) Middle Class (III) – from 14 to 17; (iv) Lower middle class (IV) – from 18 to 21; e (v) Low class (V) – from 22 to 25.

The Apgar scale has also been used to assess family functioning and satisfaction. This is of self-completion, composed of five questions, on a Likert-type scale with three response options, (1-Often, 2-Sometimes e 3-Rarely), each of them having a score varying on a scale of 0 to 10, relative to the perception about the degree of family functioning: highly functional (7 to 10 points), moderate dysfunction (4 to 6 points), and with severe dysfunction (0 to 3 points).

All the stages of the study have followed the ethical principles and the determinations of the Resolution 466/12 of the National Health Council on research with human beings. The study was approved by the Board of Directors of the Institution where it was held, as well as by the Ethics Committee of the same institution, under the protocol number CA/292.

All families who agreed to participate in the study were asked to sign the two copied of the Free and Informed Consent Form, ensuring confidentiality, privacy and anonymity. One of the instruments used was the Social Support Satisfaction Scale (SSSS), which was already validated and translated into the Portuguese language and culture, and only the "author" authorization was requested for its use.

For the treatment of the data, the statistical package software for the social sciences (SPSSâ) version 20 was used. The categorical variables were described by absolute (n) and relative (%) frequency. Since the variables had a normal distribution and the sample size was greater than 30, we chose to perform parametric tests.

The association between the categorical variables was performed by the chi-square test or the Fisher's test,

when applicable. In the comparison of averages between the two groups, the Student's t-test was used for independent samples.

■ RESULTS

We have presented the results of the application of the instruments of data collection to the 128 families of children with cancer, initially through a sociodemographic characterization.

Table 1 shows the distribution of families according to the "provenance area", since in Portugal there are only four pediatric oncology centers, two in the north of the country (Porto), one in the center (Coimbra) and one in the south (Lisbon). All children with cancer coming from the north are sent to Porto. In the North of Porto we have included the regions of Minho-Lima, Cavado, Ave and Alto-Trás-os-Montes, which are regions with less aid, poorer and more distant in kilometers; in the South of Porto, we cover: Tâmega, Douro, Entre-Douro and Vouga. We have found that 46.9% of the population comes from the greater Porto, backed by Northern Porto (43%). The families were predominantly nuclear and extended (80.5%), with the average age of the parents being 30-40 years old. The mother was the "primary caregiver" in 79.7% of the cases. According to the Graffar scale, the study sample belonged to a middle social class (42.2%) and upper middle (39.1%), perceived as "highly functional" (75.8%) according to the Apgar's scale, and they were satisfied with their social support (53%).

The children with cancer, members of the families of the study sample, were characterized according to "age group", "gender" and "diagnosis".

The children presented predominant ages between the ages of 6-12 years old (36.7%) and 13-18 years old (33.6%); they are mostly male (56.3%) and have the most frequent diagnosis of leukemia (71.9%).

The families under study were also characterized according to the implications of cancer at the socioeconomic level.

We have verified that the families of children with cancer have an enormous need to go to the hospital so that the children can perform treatments/consultations in the outpatient clinic, with 44.5% referring to having to move on "alternate days". The majority uses their "own transportation means" when traveling to the hospital (56.3%). About 27.3% said they spend "up to 10 euros" on such displacements; the same percentage refers to spend "more than 20 euros", (36.8%) "between 10 and 20 euros" and only 8.6% said "not having transportation expenses". We have found that 76.6% of the families report "absence of any kind of transportation subsidy".

Table 1 – Sociodemographic characterization of families of children with cancer

	n	%
Provenance		
North of Porto	55	43.0
Greater Porto	60	46.9
South of Porto	13	10.1
Type of families		
Nuclear and extended families	103	80.5
Single parent families	25	19.5
Age group		
Mother		
< 30 years old	24	18.8
30 to 40 years old	68	53.1
40 or more	36	28.1
Father		
< 30 years old	11	8.6
30 to 40 years old	62	48.4
40 or more	55	43.0
Primary caregiver mother		
Sometimes	26	20.3
Always	102	79.7
Social class		
High class	10	7.8
Upper middle class	50	39.1
Middle class	54	42.2
Low Middle Class	13	10.2
Low class	1	0.8
Family functionality		
Highly functional family	97	75.8
Family with moderate dysfunction	24	18.8
Family with severe dysfunction	7	5.4

Source: Research data, 2013.

Table 2 - Socio-demographic and clinical characterization of the child with cancer

	n	%
Age group		
[1-2 years old]	14	10.9
[3-5 years old]	24	18.8
[6-12 years old]	49	36.7
[13-18 years old]	43	33.6
Gender		
Female	56	43.8
Male	72	56.3
Diagnosis		
Lymphomas	13	10.2
Leukemia	92	71.9
Sarcomas	8	6.3
Osteosarcomas	9	7.0
Neuroblastomas	3	2.3
Carcinoma of the testicle	1	0.8
Wilms tumour	2	1.6

Source: Research data, 2013.

When asked whether any of the parents "continued working" during the child's illness, we found that in most families (74.2%), one parent continued to work. As for the "increased expenses" caused by the disease in the family, it was evident that 44.5% of the respondents said they had "always" existed, 28.9% "quite often", and 26.6 "few and sometimes". However, the majority (48.4%) reported never having felt the need to resort to the economic support of family/friends, with 32.8% saying they had done it "few/

sometimes". Regarding the "loss of family income", 39.8% of the families in our sample referred to constant deprivation of this income during the period of illness. In what refers to "medication expenses", the majority (58.6%) spend between 10 and 40 euros per month.

It was also intended to know the relationship between the economic impact caused by the child's cancer in the family and some socio-demographic variables.

It is possible to observe in Table 4 that in the sample under analysis the majority of families that do not show "economic impact with the disease" belong to a "nuclear or extended" household (84.8%), they live in the "Porto area" (48.5%) and "never needed support from other relatives/friends" (66.7%). On the other hand, those that show "economic impact" always show "loss of family income" (50.0%) and "increased economic expenses" (62.9%). The results show a statistically significant association between the following variables: "loss of income" (X^2=14,554; gl=4; p=0,006), "economic expenses with the disease" (X^2=18,484; gl=2; p= <0,001), "Need for family/friends support" (X^2=18,391; gl=2; p= <0,001) And economic impact of the child cancer in the family.

It was also carried out the study of the variation of some variables in function of the economic impact of the cancer of the child in the family.

Table 3 - Socio-economic characterization of the families of children with cancer

	n	%
Hospital visits		
1 to 6 times per month	53	41.4
Every other day	57	44.5
Daily	18	14.1
Transportation costs		
Up to 10 euros	35	27.3
10-15 euros	24	18.8
15-20 euros	23	18.0
> 20 euros	35	27.3
No transport costs	11	8.6
Co-participations with transportation		
Some Co-participations	30	23.4
No Co-participations	98	76.6
Some of the parents continued to work		
Yes	98	74.2
No	33	25.8
Increased economic expenses during illness		
Few and sometimes	34	26.6
Quite often	37	28.9
Always	57	44.5
Need of support from family/friends		
Never	62	48.4
Few and sometimes	42	32.8
A lot of times and always	24	18.8
Loss of family income		
Never	28	21.9
Sometimes	26	20.3
Quite often	23	18.0
Always	51	39.8
Monthly expenditure on medication		
Up to 10 euros	28	21.9
10 to 40 euros	75	58.6
More than 50 euros	25	19.5

Source: Research data, 2013.

The results shown in table 5 show that the families that show economic impact with the disease, on average, present: greater number of trips to hospital (Average=2.74), more transport costs (Average=2.90), greater impact on the family structure (Average=57.42) and greater impact of the disease on healthy siblings (Average=26,36). On the other hand, families that do not show an economic impact, on average, receive more contributions in the trips to the hospital (Average=4,48), and greater satisfaction with their social support (Average=54,30).

Looking at the obtained values and the comparative analysis of averages between the economic impact

Table 4 - Association between the economic impact and sociodemographic variables

		Economic impact of the disease on the family				
		Disagree		Agree		
		n	%	n	%	p
Type of family	Nuclear and extended families	56	84.8	47	75.8	0.265
	Single parent families	10	15.2	15	24.2	
Area of residence	North of Porto	27	40.9	28	45.2	
	Porto	32	48.5	28	45.2	0.888
	South of Porto	7	10.6	6	9.7	
Loss of income	Never	16	24.2	4	6.5	
	Few times	5	7.6	3	4.8	
	Sometimes	17	25.8	9	14.5	0.006
	Quite often	8	12.1	15	24.2	
	Always	20	30.3	31	50.0	
Economic expenses in illness	Few and sometimes	26	39.4	8	12.9	
	Quite often	22	33.3	15	24.2	<0.001
	Always	18	27.3	39	62.9	
Need of support from family/friends	Never	44	66.7	18	29.0	
	Few and sometimes	15	22.7	27	43.5	<0.001
	A lot of times and always	7	10.6	17	27.4	

Source: Research data, 2013.

Table 5 - Comparison of the social support, "impact of the disease on the family structure", "impact of the disease on healthy siblings", according to economic impact

	Economic impact of the disease on the family	n	Average	DP	p
Average travels	Disagree	66	2.59	0.803	0.285
	Agree	62	2.74	0.788	
Transport costs	Disagree	66	2.53	1.350	0.119
	Agree	62	2.90	1.339	
Co-participation in travels	Disagree	66	4.48	1.167	0.354
	Agree	62	4.27	1.393	
Social support	Disagree	66	54.30	10.364	0.017
	Agree	62	49.98	9.730	
Impact of the disease on the family structure	Disagree	66	49.09	9.457	<0.001
	Agree	62	57.42	7.498	
Impact of the disease on healthy siblings	Disagree	42	23.21	9.008	0.085
	Agree	41	26.39	7.520	

Source: Research data, 2013.

groups, we concluded that there was a statistically significant difference between the average values of the variables: "impact of the disease on the family structure" (t=2,427; *gl*=126; p =0,017), "social support" (t= -5,498; *gl*=126; p =<0,001) and among groups of the economic impact dimension of the child cancer in the family.

■ DISCUSSION

This study aimed to identify the socioeconomic variables that influence the families of the child with cancer. From the analysis of the results, it is possible to observe that the mother assumes the role of primary caregiver of the child with cancer, which implies in a loss of family income[8]. We verified that, in addition to the loss of the monthly income, families of children with cancer are confronted with other situations that affect them at the economic level, such as: the increase in expenses related to the number of trips to the hospital, medication expenses, increased expenses caused by the illness itself. The economic needs that emerge from the disease itself further contribute to weakening and making families more vulnerable[6-8].

Children with cancer had leukemia as main diagnosis. This type of pathologies, due to their treatments and their side effects, implies long periods of hospital admissions and special care[5], thus contributing to the increase of economic expenses with the disease. In this sense, we verified a relationship between the "economic impact", the mediation expenses and the increased expenses of the families of children with cancer, which may be associated with the needs that emerge during the treatment[5,7,9].

We also found that the greater the social support available to the families of children with cancer, the lower the "economic impact". The social support is a key contribution to families as it helps them to reorganize and direct their emotional and financial resources to care for the child[11].

Cancer, due to its treatment and frequent hospitalizations, causes changes in the socioeconomic context and in the family routines, leading to changes in the family functioning that can be reflected in the care that is provided to the child[1,3-4]. In this context, the family will necessarily need the support of the extended family either to take care of the child or as a financial resource[10]. In this sense, we found that families with a lower "economic impact" presented lower needs for support from relatives/friends, suggesting that this need is highly recognized by the families[11].

Regarding the "impact on the family structure", we found that families with "greater economic impact" have a greater "impact on their family structure". These data reinforce the idea that the diagnosis of cancer in the child causes changes in the family, in the level of its family and economic functioning, producing negative effects in all its elements[1].

■ CONCLUSION

Due to the results obtained, it was possible to identify some of the socioeconomic variables that influence the families of children with cancer. The needs that emerge from this pathology imply increased expenses with the disease itself, medication and travel to the hospital, aggravated by the loss of income of one of the parents, who stops working to care for the child, who in most cases is the mother.

In addition to the disease itself, which causes emotional, physical, psychological, spiritual, and emotional burnout, many families are faced with economic difficulties to respond to the needs of the child with cancer. This economic overburden, imposed on families, may further weaken its relations.

The social support assumes in these families an important role for their relationship in minimizing the economic impact. It is thus essential that health professionals, particularly nurses, identify the support systems available to these families. In this sense, nurses must identify the economic needs of families and become part of their support network so that they can increase their resilience.

Some limitations of this study should be recognized. Firstly, this instrument should be applied in future research, both nationally and internationally. The study was only carried out in the northern region of Portugal, and the results could vary within the same country, hence the need for further studies.

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