

# Relationship between wellness and sociodemographic characteristics of caregivers of people with cancer

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## Relationship between wellness and sociodemographic characteristics of caregivers of people with cancer

**Objective.** To investigate the association between wellness and sociodemographic characteristics of caregivers of people with cancer. **Methods.** This was a cross-sectional study conducted in Maringá, Paraná, Brazil, with 96 caregivers. Data were collected between July 2011 and February 2012. A global wellness assessment scale was used to measure wellness and data on sociodemographic characteristics were gathered using a complementary form. **Results.** The characteristics associated with reduced wellness among caregivers of people with cancer were: being separated, being a mother, having a higher education degree, being employed, being the sole caregiver, having a family income of up to one minimum wage and presenting health problems. **Conclusion.** Some demographic characteristics are associated with loss of wellness among these caregivers. Nurses must take this

information into account when formulating strategies to improve the wellness of caregivers, considering their context.

**Key words:** nursing; neoplasia; caregivers; quality of life; social wellness.

## Relación de bienestar y las características de socio-demográficas cuidadores de personas con cáncer

**Objetivo.** Explorar la asociación entre el bienestar y las características sociodemográficas de los cuidadores de las personas con cáncer. **Metodología.** Estudio de tipo transversal realizado en Maringá-PR, con 96 cuidadores. La recolección de datos se llevó a cabo de julio de 2011 a febrero de 2012. El bienestar se midió mediante la escala de Evaluación Global de Bienestar y las características sociodemográficas se obtuvieron mediante un formulario complementario.

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**Resultados.** Las características que se relacionan con la disminución del bienestar en cuidadores de personas con cáncer son: estar separado, ser madre, nivel de educación superior, estar empleado, ser el único solo cuidador, ingreso familiar inferior a un salario mínimo y tener problemas de salud. **Conclusión.** Existen características demográficas asociadas a pérdida de bienestar en estos cuidadores. El enfermero debe tener en cuenta esta información con de realizar estrategias de intervención que mejoren el bienestar del cuidador teniendo en cuenta su contexto.

**Palabras clave:** enfermería; neoplasia; cuidadores; calidad de vida; bienestar social.

### Relação entre o bem-estar e as características sócio-demográficas de cuidadores de pessoas com câncer

**Objetivo.** Investigar a associação entre o bem-estar e as características sócio-demográficas de cuidadores de

## Introduction

Cancer is considered one of the worst diseases. It is greatly feared and always aggregate the idea of imminent risk of death, mutilating and aggressive treatments. This disease causes a number of weaknesses in the life of the sick person, which implies a condition of dependence and need someone who can intervene with this individual.<sup>1</sup> The caregiver is, therefore, who takes the maintenance of assistance necessary for the person with cancer. Commonly, he comes from the is from the nuclear family, because he is a closer member, one who the patient has more confidence and because in this relationship, there is affection, compassion and love.<sup>2</sup>

The literature states that caregivers of cancer patients decompensate over time, as they strive to take care, take on household chores, the family, financial responsibilities and support the damage, as they try to meet their own needs and maintain a normal familiar routine.<sup>3</sup> Despite it, they are seen by health professionals as those who help

peessoas com câncer. **Metodologia.** Estudo transversal realizado em Maringá – PR, com 96 cuidadores. Os dados foram coletados no período de julho de 2011 a fevereiro de 2012. Utilizou-se a escala de Avaliação Global do Bem-estar para medir bem-estar e um formulário complementar para coletar dados sobre características sócio-demográficas. **Resultados.** As características associadas à redução do bem-estar entre cuidadores de pessoas com câncer são: estar separado, ser mãe, ter nível de educação superior, estar empregado, ser o único cuidador, ter uma renda familiar inferior a um salário mínimo e apresentar problemas de saúde. **Conclusão.** Existem características demográficas associadas à perda de bem-estar entre esses cuidadores. O enfermeiro deve levar em conta essa informação ao formular estratégias de intervenção para melhorar o bem-estar de cuidadores, considerando seu contexto.

**Palavras-chave:** enfermagem; neoplasia; cuidadores; qualidade de vida; bem-estar social.

in the care process, without being recognized as someone who is going through a painful process and who need help and support.<sup>4</sup> Given the severity of the cancer situation as a health problem which affects not only the family of the patient, but also his caregiver, it is necessary that the health teams are aware of the difficulties experienced by these individuals in order to promote adaptation to the conditions generated by the disease, and together with them, to find ways of coping it. Thus, it is intending to identify the needs of caregivers of people with cancer and plan strategies that facilitate their day-to-day and, consequently, promote their well-being that is appropriate to identify the socio-demographic characteristics of these subjects.

Faced with the presented problem, this study is guided on the following question: Is there an association between sociodemographic characteristics and the well-being of caregivers of individuals with cancer? To answer the announced question, this study aims to investigate if there is association between sociodemographic

characteristics and the well-being of people with cancer and identify caregivers which of them are related with the reduction of welfare. It is expected that the answer to these questions can contribute to the teams, institutions and health professionals in order to guide their actions in the care of these caregivers.

## Methods

It is a descriptive, cross-sectional study conducted in the city of Maringá-PR, with family members who care for adults with malignancies. Contact with these caregivers was given by Women Against Cancer Network (WACN) - Maringá Regional, which serves cancer patients, users of the Unified Health System (UHS), with few financial conditions, residents in the cities belonging to 15<sup>th</sup> Regional of the State of Paraná Health. The inclusion criteria for the selection of caregivers were: having some family ties (by blood or emotional ties) with the person with cancer; be identified as caregiver by the patient himself or with the help of a family when he was in health conditions that impeded him from providing the information; being older or equal to 18 years old; not receive salary as compensation to care; live daily with the individual with cancer; provide care to familiar with cancer for over two months; caregiver and family with cancer must reside in Maringá (it was decided to exclude cases of people with cancer, registered in WACN who lived in other cities, because of the difficulty of transportation to the interviews). Were excluded, families in which it was not possible to identify the primary caregiver and caregivers of children with cancer.

The period of data collection, the WACN contained the records of 273 patients with malignancies. Of these, 170 lived in the city of Maringá and the others were from other cities belonging to the 15<sup>th</sup> Regional of Health of Paraná. Of the 170 selected contacts, 74 were excluded because of: impossibility of telephone contact - incorrect or disabled number (47); death (9); switching to other cities (5); failure to

identify the primary caregiver (3); caregivers of children with cancer (2); refusal to participate in the study (8). Therefore, the final population of this study consisted of 96 caregivers. To describe the sociodemographic profile of caregivers was prepared a questionnaire with 12 questions. To assess the well-being of familiar caregivers of cancer patients, were used the General Comfort Questionnaire (GCQ), which consists of a self-report instrument, but that can also be applied by the researcher, containing 49 questions that are answered by Likert scale, which have answer ranging from 1 to 6, where 1 strongly disagree and 6 strongly agree. The numbers between the two extremes should be marked according to how strong the feeling/impression about the availability or not of resource/condition. Twenty-six items are worded in a negative way to avoid biases response. The items written in the negative way were inverted during the data processing stage, ie, when presenting the score 6 were converted to 1, and so on.<sup>5</sup>

The questionnaire of GCT evaluation has been tested, firstly, in the United States and recently translated into Brazil.<sup>6</sup> The analysis of the Portuguese version assessed the well-being of 133 caregivers of women with cancer, whose Cronbach's Alpha was 0.83, which indicates the adequacy of the scale and excellent internal consistency among its items. Data collection was carried out between the months of July, 2011 to February, 2012. Initially, contact was conducted by telephone with the patient and/or family in order to identify the primary caregiver. After his identification, was held contact with this caregiver and launched the invitation to participate. In case of claim, it was scheduled a visit in the caregiver's home to the application of the questionnaire. Data collection was carried out individually, where for each respondent, the questions of the instrument were read and the answers recorded by the interviewer.

Data were organized and analyzed from databases in Excel 2012 and Statistical Package for Social Sciences (SPSS, version 18.0). After, a descriptive analysis was carried out through obtainment

of mean, standard deviation, frequency and percentage. To investigate the association between categorical variables (sociodemographic data) and metric variables (scores of General Comfort Questionnaire) was performed inferential analysis of mean comparison using the Student's t- test for comparing two means and Analysis of Variance (ANOVA) for multiple comparisons with established level in  $p < 0.05$ . This study was preceded by routing the research project to the Standing Committee on Ethics in Research Involving Human Subjects (COPEP) of the State University of Maringa, having obtained a favorable opinion with number 423/2010. and record in the National System of Research Ethics Information filed with CAAE No. 0171.0.093.000-10, according to Resolution 196/1996 of the National Health Council.

## Results

From the 96 caregivers who participated in the study, 77 were female, corresponding to just over 80%. Regarding the distribution of ages, it was found that the mean age was 54.9 years (SD=15.8), and the minimum age of 18 years and maximum 85 years. With regard to marital status 77.1% were married. Regarding the family bond with the patient (by blood or emotional ties) 95.8% respondents were family members, 50% spouse. Most caregivers had low education, and 54.2% of them had even finished elementary school, 84.4% lived with the patient and 87.5% had care for over 12 months.

Regarding the occupation, 82.3% reported not having extradomiciliary activities, devoting himself fully to the patient with cancer and domestic chores. From this percentage, 42.7% were retired or pensioners. Regarding the socioeconomic status of the family, 52% of caregivers reported having a family income of one to two minimum wages. It was observed also that 43.8% of respondents mentioned not receive help from others to provide care and 49% reported have a health problem. Among the main health problems mentioned, there is high blood pressure (21.8%),

diabetes mellitus (5.2%) and problems related to the musculoskeletal system (7.3%). The great majority 94 (97.1%) reported having a religion.

From Table 1, it showed that the characteristics that were related to the decrease in welfare were being separated/divorced, mothers, higher educational level, employees, only one caregiver, family income lower than minimum wage and with health problems.

## Discussion

The results obtained in this study corroborate the literature in which adult and/or elderly women are seen as most caregivers.<sup>7</sup> A previous study, pointed out that men are responsible for this task when only there is not a close and available woman to occupy this place.<sup>8</sup> This may be grounded in anthropology reiterating this information from social and cultural perspective, mentioning the man as provider and the woman as the caretaker of the children, the parents, the family.<sup>9</sup> International research bring that women caregivers have higher levels of depression than men who exercise the same role.<sup>10,11</sup> Another study showed that male caregivers of people with cancer had a degree of welfare significantly higher than the female caregivers.<sup>5</sup> However, in this study, the welfare indices showed no statistically significant difference in relation to gender. It was observed that among caregivers over 60 years, 39.6% were men, while in other age groups this percentage drops to 5.45%. It is inferred therefore that the highest percentage of elderly men exercising caregiver job is related to the fact that these individuals are retirees/pensioners and not exercise work outside the home. Thus, it was concluded that the time available for dedication to of the familiar care with cancer is a determining factor when choosing the caregiver.

Regarding the link with the person with cancer, it was found that most caregivers were spouse/partner of patients. This finding may be explained by the progressive aging of the population and the changing social dynamics that have determined

**Table 1.** Sociodemographic characteristics of caregivers of people with cancer by score obtained from the General Comfort Questionnaire

Characteristics	Frequency	Percentage	Mean and standard deviation	Significance
Gender				
Male	19	19.8	214.1 ± 20.6	0.986
Female	77	80.2	214.9 ± 21.1	
Age				
18 to 30 years	10	10.4	213.1 ± 14.3	0.747
31 to 60 years	45	46.9	216.0 ± 21.9	
More than 60 years	41	42.7	213.8 ± 21.2	
Marital status				
Single	11	11.5	208.5 ± 16.2	0.021
Married	74	77.1	217.2 ± 21.3*	
Separate/divorced	9	9.4	203.1 ± 19.8	
Widower	2	2.1	211.0 ± 13.0	
Link with the familiar with câncer				
Spouse/Partner	48	50.0	218.8 ± 21.2 <sup>†</sup>	0.011
Son	28	29.2	213.9 ± 18.6 <sub>†</sub>	
Mother	6	6.3	192.5 ± 19.9	
Others relatives	10	3.1	212.5 ± 16.4 <sup>†</sup>	
Friend/Neighbor	4	4.2	210.5 ± 22.3	
Education				
No study	5	5.2	216.2 ± 14.7	0.027
Primary (complete or incomplete)	52	54.2	216.1 ± 22.4 <sup>‡</sup>	
Secondary (complete or incomplete)	22	22.9	215.9 ± 19.7 <sup>‡</sup>	
Higher (complete or incomplete)	17	17.7	208.8 ± 19.5	
Occupation				
Employed	17	17.7	203.2 ± 21.8	0.022
Not employed	38	39.6	216.9 ± 19.6 <sup>§</sup>	
Retiree or pensioner	41	42.7	217.5 ± 20.3 <sup>§</sup>	
Lives with the patient				
Yes	81	84.4	214.2 ± 21.6	0.887
No	15	15.6	217.6 ± 17.0	
Time that participate in the care				
Less than 1 year	12	12.5	209.4 ± 20.5	0.072
From 1 to 2 years	42	43.8	215.0 ± 20.9	
From 2 to 5 years	36	37.5	216.3 ± 20.7	
More than 5 years	6	6.3	214.1 ± 21.9	
Rotation with others caregivers				
Yes	54	56.3	218.6 ± 17.2*	0.012
No	42	43.8	209.8 ± 24.1	

**Table 1.** Sociodemographic characteristics of caregivers of people with cancer by score obtained from the General Comfort Questionnaire (Cont.)

Characteristics	Frequency	Percentage	Mean and standard deviation	Significance
Family income				
Less than 1 minimum wage	4	4.2	206.5 ± 21.9	
From 1 to 2 minimum wages	50	52.0	216.5 ± 21.4	0.034
From 2 to 5 minimum wages	42	43.8	213.4 ± 20.1	
Has some health problem				
Yes	47	49.0	210.9 ± 24.5 <sup>†</sup>	0.029
No	49	51.0	218.4 ± 16.0	
Has religion				
Yes	94	97.9	214.9 ± 21.2	0.087
No	2	2.1	207.5 ± 4.5	

\* Significant difference from the group separate/divorced (ANOVA). † Significant difference in relation to the mother as caregiver (Anova). ‡ Significant difference compared to group education at the college level (ANOVA). § significant difference with respect to family income. || Significant difference from the employed group (ANOVA). ¶ Student's 't' Test for independent samples.

the increase in care between spouses due to the significant decrease in the number of fathers who live with their children or live in closes places.<sup>12</sup> Continuing with variable link with the family of the patient with cancer, it was noted that when the role of primary caregiver is exercised by the mother, there is a negative association with welfare. This result can be justified because she is the person who is more emotional attachment to the son, which makes their role as caregiver covering an attitude of self-denial and total dedication.

The fear that the sick son die from cancer causes do the mother becomes emotionally dysfunctional, since death is not having him in their friendship, and perhaps, there is no more painful experience for a mother than to have to bury a son. The faithful of the mother, her emotional involvement and the abandonment of other tasks such as being a mother, wife, professional and homemaker, to take care of the sick son may also explain the decrease in their wellbeing. Study showed the psychological commitment of parents, especially mothers of children diagnosed with cancer.<sup>13</sup> This fact justifies the importance and necessity of these mothers receive appropriate psychosocial support in order to alleviate the suffering experienced, so that they feel prepared and strengthened to act in this process.

With regard to marital status, most caregivers were married. It was observed that the separated/divorced group, composed of nine women, the well-being was significantly affected. This variable was one that was statistically significant. One possible explanation for this is that the decline in well-being for these individuals is associated with feelings caused by separation/desquite of the partener. In this regard, a study showed that separated women had a quality of life index below average when compared with married and widows women.<sup>14</sup> The psychological strain of women in the condition referred to in the paragraph above can be enhanced before the impact caused by cancer on a limb family, making manifest their own vulnerability to forward this difficult time. Thus, health professionals and other family members should be aware of possible manifestations of depressive disorders in these subjects. It emphasizes that individuals in this group may not be the most suitable people to take care of a family member with cancer.

With respect to the education, in general, caregivers showed low level. This variable showed statistical correlation, but reversed, indicating that those who have higher levels of education have lower welfare average relative to other caregivers. On this issue, study claims that individuals with higher education

are able to perceive the constraint in maintaining their social life as a result of care, and consequently have a higher impact of the disease on their quality of life.<sup>15</sup> Another variable that showed statistical significance was the occupation. The results show that those who reported being employees had lower average of welfare. It is noteworthy that, in cases where caregivers add the task to look after the work has been the accumulation of responsibilities which confirms the commitment of their welfare, since beyond concern for the sick family member, yet absorb themselves with work obligations. Thus, a possible explanation for this result is that these individuals feel overwhelmed, physically and emotionally, because when they return from the working day, they assume on a new role as caregiver.

By informal conversations with the participants' caregivers of the study showed that the option of staying concurrently with their professional activities and in the care of the patient with cancer, most often, is associated with financial need of the family, since this subject needs to help in the support of the household. It was observed in the present study, most caregivers lived with the family with cancer. In many cases, patient and caregiver moved to the same house after the diagnosis of cancer for easy care. However, evidence that refer to cohabitation as a generator of tension was not significant in the present study. As for the time participating in care, 81.3% of caregivers reported exercise care between one and five years. However, it became clear that, while not obtain statistical significance, the lowest average welfare is among those who exercised the care for less than one year. This finding may be related to the fact that in the first year, the impact of the diagnosis of cancer in a family member, yet it is a recent event, which brings changes in routine of the caregiver, how to live with the fear of being losing a loved one; see her physical and emotional distress; commitment of family income; lack of expertise in the provision of care. Over time, there may be ahead adapt to the new situation experienced, resulting in reduced levels of stress and anxiety and increased welfare.

The existence of rotation among caregivers was associated, in this study, with welfare. Thus, in cases where only one individual takes the direct care of the person with cancer without receiving support from other family members, resulting in commitment to his welfare. Highlight the benefits when there is the presence of other family members, friends and social care and health services providing to the caregiver support in the provision of care. It is noteworthy that in cases where only a family member takes the direct care of the patient, without receiving support from other family members, the burden becomes even bigger.<sup>16</sup> Therefore, the participation of health professionals is important in the sense to promote shared responsibility of all family members to the harmonic division of the care.<sup>17</sup>

Regarding family income, it was observed that receive only minimum wage or less ( $M=206.5$ ), is statistically associated with lower welfare. In research conducted with families of people with cancer, it was found that the lack of financial resources was cited as the biggest faced problem.<sup>18</sup> This, possibly occurs because the familiar with cancer, due to his bad health condition imposed by the disease is compelled to leave their daily work, and the caregiver in most cases, also decreases or stops working, which consequently effects in the family income. Not to mention that the treatment of this disease is hugely expensive and, even with the coverage of the National Health System there is always extra expenses for the family.

It is noticed that in the face of some physical limitations from any health problems, caregivers are more concerned with providing care to sick family member than to themselves, and devote much of their time to this activity. This result highlights the need of health professionals to turn their attention also to the caregiver, since this individual neglects his own care to devote to his family.

Family caregivers, in general, are a group subject to various health problems and, in many cases without assistance and guidance. These problems can be a result of lack of preparation for the

provision of care, which predisposes to overload of muscles and joints, besides the involvement in patient care, which leads them to not pay attention to their own needs and personal limitations.<sup>17</sup> Of all the caregivers only two reported no religion and these in turn had average scores of welfare lower than others. Research states that participation in religious activities is considered as a support for most caregivers, because it provides subsidies to overcome obstacles and keep hopes.<sup>19</sup> Thus, religiosity can help in promoting the welfare of caregivers, and works as important ally in the process of acceptance and coping the cancer, comforting, giving hope and providing subsidies to overcome this difficult time.

The knowledge generated in this study reaffirms the importance of developing a focused assistance not only to the individual with cancer, but also to their caregivers, enhancing their participation in the care process. Highlight, also, the benefits when caregivers have the support of a health care team, providing them with support in the provision of home care. It concludes that identify the main problems and needs of caregivers who experience the cancer in their homes is fundamental for teams, institutions and health professionals can incorporate this information and plan interventions that promote the welfare of these guys, to contribute to quality care.

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