

Evaluation of the well-being of family caregivers of adults with malignant neoplasm in the home environment

Avaliação do bem-estar de cuidadores familiares de adultos com neoplasia maligna no âmbito domiciliar

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ABSTRACT

The aim of this study was to analyze the well-being of family caregivers of adults with malignant neoplasms in the home environment by means of the Avaliação de Bem-Estar Global (a validated version of the General Comfort Questionnaire for Brazilian Portuguese). A cross-sectional study was developed in Maringá, in the state of Paraná, comprising 96 caregivers. Data were collected between July 2011 and February 2012. Results were analyzed using descriptive statistics. The presence of spirituality and the benefits of a network offering support for care provision are factors that contributed to promoting well-being. Family concerns and physical and emotional discomfort of the patient were the items that had the lowest scores. When comparing the results with a study developed in a hospital environment, we concluded that the scenario has little effect on well-being. However, some items suggest care provided at home has a greater impact on the well-being of caregivers.

Descriptors: Nursing; Neoplasms; Family; Caregivers; Quality of Life.

RESUMO

O objetivo deste estudo foi analisar o bem-estar de cuidadores familiares de adultos com neoplasias malignas no âmbito domiciliar pelo Questionário de Avaliação do Bem-Estar Global. Trata-se de um estudo transversal, desenvolvido no município de Maringá-PR, com 96 cuidadores. A coleta de dados foi realizada entre julho de 2011 e fevereiro de 2012. Os resultados foram analisados por meio de estatística descritiva. A presença da espiritualidade e os benefícios quando se tem a presença da rede de apoio oferecendo suporte na prestação dos cuidados, são fatores que mais corroboraram para promoção do bem-estar. As preocupações com a família e o desconforto físico e emocional do doente, foram os itens que tiveram os menores escores. Ao comparar os resultados com estudo realizado em âmbito hospitalar, concluiu-se que o cenário interfere pouco em relação ao bem-estar. No entanto, alguns itens sugerem que cuidar no domicílio tem impacto maior no bem-estar dos cuidadores.

Descritores: Enfermagem; Neoplasias; Família; Cuidadores; Qualidade de Vida.

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INTRODUCTION

The repercussions caused by cancer to patients and their families are well known, and currently there is a tendency to assign to the family the responsibility for the patient care⁽¹⁾. Through the natural process, a person with cancer gradually becomes more dependent on care. This need culminated in the emergence of a caregiver, who is the person responsible for providing care to the patient⁽²⁾.

The technical literature has addressed the caregivers' burden and their exhaustive and stressful care activity. In this field of study, there is a significant number of studies regarding the deterioration of their health and consequent illness, both physical and psychic⁽³⁻⁴⁾. Considering the severity of the situation, the caregivers require interventions that promote their well-being, providing adaptation to the conditions resulting from the disease⁽⁵⁾.

An alternative way to study and identify the main problems or needs of caregivers is the use of instruments already tested. There are many standardized instruments available in the technical literature on this line, but most are not complete with respect to all dimensions of care (physical, psychological, social, economic and spiritual)⁽⁶⁾.

A critical review study analyzed some of the major standardized instruments made available in the technical literature and used to evaluate the quality of life of caregivers of patients with cancer. It identified the General Comfort Questionnaire (GCQ), created from the comfort theory developed by American nurse Katherine Kolcaba⁽⁷⁾ as a useful tool for clinical practice because it allows a multidimensional (physical, environmental, social, psychological and spiritual) evaluation and identifies the several factors that reduce or increase the well-being of caregivers⁽⁶⁾.

This questionnaire was used in Brazil for the first time, along with 133 caregivers of patients admitted to the oncology ward of a public hospital⁽⁸⁾ and its version to the Portuguese language was entitled *Avaliação de Bem-Estar Global* - BEG. Other studies have also used this

instrument, but it has not been applied to caregivers of cancer patients in the home environment⁽⁹⁻¹⁰⁾.

Thus, this is the reason for developing this study, which aimed at evaluating the global well-being of family caregivers of adults with malignant neoplasm in the home environment, providing opportunities to introduce preventive measures and prompt adjustments in order to minimize the suffering arising from the task of being a caregiver. It is noteworthy that the analysis and discussion of this study were performed especially through comparison with the results found in a study developed with caregivers in hospital environments⁽⁸⁾.

MATERIAL AND METHODS

A descriptive, cross-sectional study was developed in the city of Maringá, state of Paraná, along with family caregivers of adults with malignant neoplasms. These caregivers were approached through the Women's Network Against Cancer (RFCC - Rede Feminina de Combate ao Câncer), which assists cancer patients who are users of the Brazilian Unified Health System (SUS - Sistema Único de Saúde) and live in the cities covered by the 15th Regional Health Department of the state of Paraná.

The inclusion criteria for the selection of caregivers were: having any family tie (consanguineous ties or emotional bonds) to the person with cancer; being identified as the primary caregiver by the patient himself/herself or with the help of a family member when the patient was in poor health condition, preventing him/her from providing the information; being aged 18 years or older; not being paid for providing care; living daily with the person with cancer; providing care to the familiar member with cancer for over two months; living in Maringá, both the caregiver and the family member (we decided to exclude cases of people with cancer registered in the RFCC who lived in other cities, due to the difficulty of transportation to attend the interviews). Caregivers of children with cancer were excluded.

Within the period of data collection, the RFCC comprised the records of 273 patients with malignant neoplasms. Among these patients, 170 were living in the city of Maringá, and the remaining were living in other cities in the 15th regional health department of the state of Paraná. Among the 170 possible contacts, 74 were excluded due to: impossibility of contact by telephone incorrect or disabled telephone number (47); death (nine); patients moving to other cities (five); primary caregiver not identified (three); caregivers of children with cancer (two); refusal to participate in the research (eight). Therefore, the final population of this study comprised 96 caregivers.

For the characterization of research participants, a questionnaire containing 12 objective questions relating to personal characteristics of the family caregivers was created.

To assess the well-being of caregivers, we used the questionnaire Avaliação de Bem-Estar Global - BEG, which consists of a self-administered instrument that can also be applied by the researcher. It contains 49 questions that are answered through a Likert scale, within a numerical range from one to six, in which one refers to "I strongly disagree" and six refers to "I strongly agree". The numbers between the two extremes should be marked according to how strong the feeling/sensation is about the availability or lack of resource/condition. Twenty-six items are written as negative statements to avoid automatic responses by the participant. The items written negatively were reversed during the data processing stage, that is, when they presented a score with number six they were reversed to number one, and so forth⁽⁶⁾. The final score of the BEG is built as a scale starting with 49 points, referring to poor well-being, and finishing with 294 points, indicating excellent well-being.

This instrument was first tested in the United States, and recently translated for use in Brazil⁽⁸⁾. The analysis of the Portuguese version reached a Cronbach's alpha of 0.83, indicating adequacy of the scale and excellent internal consistency among its items.

Data were collected between July 2011 and February 2012. Initially, the patient or the family member was approached by telephone in order to identify the primary caregiver. After this identification, contact was made with this caregiver, who was invited to participate in the research. Upon acceptance, a visit was scheduled to the caregiver's home to apply the questionnaire. The interviews were held individually, and the interviewer read the questions of the instrument for each respondent and recorded the answers in order to circumvent problems related to illiteracy and low education level.

The data obtained through the questionnaires were entered into a database in the Statistical Package for the Social Sciences 18.0 and analyzed descriptively, following the calculation of results in minimum, mean and maximum values and standard deviation. Results were submitted in this manner in order to facilitate comparison with previous studies that used the BEG.

This study was developed once the research proposal was approved by the Permanent Human Research Ethics Committee of Maringá State University, under protocol no. 423/2010 and upon registration in the Brazilian System of Information on Ethics in Research with CAAE (Brazilian Certificate of Presentation for Ethical Consideration) no. 0171.0.093.000-10, according to Resolution 196/1996 of the Brazilian Health Council.

RESULTS

Characterization of caregivers

Among the 96 caregivers who participated in the study, 77 were women, which accounted for just over 80%. Regarding the distribution of ages, it was noted that the mean age was 54.9 years (SD = 15.80), the minimum age was 18 years and the maximum was 85 years.

Evaluation of global well-being

The total scores of well-being ranged between 168 and 255, indicating individual variability (the lowest score

is 65% smaller than the largest one) in global well-being levels.

Figure 1 shows the dispersion of the participants' scores in ascending order within the possible range of scoring on the scale (49 to 294). Most caregivers (71 participants) had their global well-being level included in

the range between 196 and 245, that is, in the fourth quintile of the distribution. It is worth noting that no participant showed score in the first and second quintile and only four participants had scores in the fifth quintile of the distribution.

Somatória dos pontos do BEG

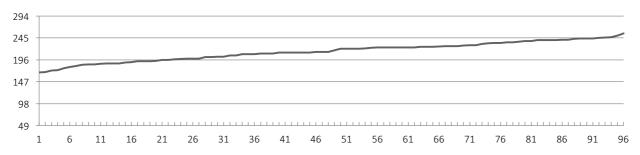


Figura 1: Dispersão dos escores do BEG. Maringá, PR, Brasil, 2012.

Data obtained from the application of the BEG questionnaire were organized to highlight the highest and lowest mean values of the scale questions, suggesting which factors are more or less related to the well-being of caregivers.

The mean value of the questions ranged from 1.00 to 5.96. Table 1 shows, in decreasing order, the highest mean values of BEG questions (between 6.0 and 5.0), and the standard deviation (SD) and individual variations of each answer, from the minimum and maximum values assigned to each question.

The factors that contributed most to reduce the well-being of caregivers can be observed in Table 2, which shows, in ascending order, the lowest mean values (between 1.0 and 2.0) and their standard deviations, and minimum and maximum values.

When the results found in this research are compared with those from the study with caregivers in hospital environment⁽⁸⁾, we notice 13 common items among those that obtained the highest means (between 6.0 and 5.0) and three items among the lowest mean values (between 1.0 and 2.0), as shown in Table 3.

Chart 1 shows the BEG items that were present among the highest and lowest scores in only one of the studies and their final means (μ).

Table 1: Distribution of the highest mean scores obtained with the BEG questionnaire. Maringá, Paraná, Brazil, 2012

No.	Questions	Mean (M)	Σ(SD)	Lowest	Highest
5.	My beliefs give me peace of mind	5.96	0.287	4	6
49.	God is helping me	5.95	0.510	1	6
38.	We are all right with our relationship	5.93	0.417	3	6
8.	I know I am beloved	5.89	0.456	4	6
47.	He/she is clean and dry both at home and in the hospital	5.79	0.724	1	6
18.	I am able to communicate with whom I love	5.77	0.672	2	6
21.	I have special people that make me feel supported	5.73	0.774	3	6
2.	We do not have enough privacy*	5.71	0.972	1	6
23.	I prefer his/her room be quiet both at home and in the hospital	5.71	0.845	1	6
44.	Friends contact us by messages and phone calls	5.67	0.902	1	6
35.	I feel spiritually confident	5.63	1.098	1	6
15.	I feel guilty*	5.48	1.289	1	6
31.	When I look back, I see we have a good life	5.47	1.289	1	6
1.	My body is relaxed at this moment	5.41	1.302	1	6
14.	I am afraid of sleeping*	5.34	1.493	1	6
19.	This room scares me*	5.33	1.499	1	6
33.	I feel strong enough to do some things for him/her	5.23	1.318	1	6
42.	I feel depressed*	5.23	1.546	1	6
3.	I have people to rely on when I am in need	5.20	1.374	1	6
41.	I feel able to say what I need	5.09	1.473	1	6
7.	My life is not worth at this moment*	5.06	1.634	1	6
27.	I can grow with this situation	5.01	1.657	1	6

^{*}Items drafted in the negative form, and which had their scores reversed for analysis

Table 2: Distribution of the lowest mean scores obtained with the BEG questionnaire

No.	Questions	Mean (M)	Σ(SD)	Lowest	Highest
4.	I worry about my family*	1.00	0.00	1	1
45.	His/her emotional state makes me sad*	1.10	0.624	1	6
34.	I constantly think of his/her discomfort*	1.55	1.213	1	6
48.	I have concerns about the financial aspect*	1.64	1.400	1	6
46.	I think a lot in the future*	1.66	1.413	1	6

^{*}Items drafted in the negative form, and which had their scores reversed for analysis

Table 3: Items of the BEG questionnaire that had highest and lowest mean scores in this research and in the study by Rezende et al. ⁽⁶⁾

Questions	Means (M)		
Questions	This study	Rezende et al.	
Highest scores			
We are all right with our relationship	5.9	5.8	
I know I am beloved	5.8	5.8	
He/she is clean and dry both at home and in the hospital	5.7	5.7	
I am able to communicate with whom I love	5.7	5.5	
I have special people that make me feel supported	5.7	5.5	
I prefer his/her room be quiet both at home and in the hospital	5.7	5.8	
Friends contact us by messages and phone calls	5.6	5.0	
I feel spiritually confident	5.6	5.5	
I feel guilty*	5,4	5,2	
When I look back, I see we have a good life	5,4	5.6	
I feel strong enough to do some things for him/her	5,2	5.6	
I have people to rely on when I am in need	5,2	5.0	
My life is not worth at this moment*	5.0	5.1	
Lowest scores			
I worry about my family*	1.0	1.1	
His/her emotional state makes me sad*	1.1	1.6	
I constantly think of his/her discomfort*	1,5	1,5	

^{*}Items drafted in the negative form, and which had their scores reversed for analysis

Chart 1: Items of the BEG questionnaire that had the highest and lowest mean scores in only one study. Maringá, Paraná, 2012

	This study (Mean)	Rezende et al. (Mean)		
	We do not have enough privacy* (μ=5.71)	Nurses bring me hope (μ=5.0)		
Highest	My body is relaxed at this moment (μ=5.41)	The temperature at this room is nice (μ=5.0)		
scores	I am afraid of sleeping* (μ=5.34)			
scores	This room scares me* (μ=5.33)	This situation inspires me (μ=5.2)		
	I feel depressed* (μ=5.23)			
	I have concerns about the financial aspect* $(\mu{=}1.64)$ I think a lot in the future* $(\mu{=}1.66)$	I would like to have more contact with the doctor*		
Lowest		(μ=2.0)		
scores		I need more information about his/her condition*		
		(μ=2.0)		

^{*}Items drafted in the negative form, and which had their scores reversed for analysis

DISCUSSION

Although global well-being total scores have shown a wide variability, values near the minimum level of the scale were not found. This indicates that, according to the instrument, levels of poor well-being were not present among these caregivers. However, the BEG has not an end stratification that allows the classification of well-being levels, it only indicates the items that support the promotion of well-being of caregivers as well as its decline; neither there is a clear separation of the assessed

multifactorial dimensions, which hinders data understanding and analysis and may raise doubts about the suitability to estimate scores for specific factors.

Items that cause higher impact on the well-being

The highest scores found are related to items that correspond to spiritual beliefs and religious conceptions. Therefore, these are the factors that contribute most to enhanced well-being of caregivers. These questions also showed high scores in a study developed with caregivers

during hospitalization of their relatives⁽⁸⁾, which confirms the role of spirituality as an event that helps promoting well-being.

An integrative review research found that many studies identify spirituality and religiosity as a potential influence on the well-being of caregivers of people with cancer, since it releases from pressure, eliminates fears and provides psychological resources to face and overcome such a situation⁽¹¹⁾. Another study indicated many patients, regardless of their religion, seek a cure for cancer in faith, believing in God and hoping for a miracle⁽¹²⁾.

These findings may be related to the fact that spirituality and religion provide caregivers with the possibility of meaning and answer as for the instabilities caused by cancer. Thus, these resources work as an important ally in the process of accepting and facing the disease, since they bring comfort and hope and meet the emotional needs by providing expectations for the future.

Another item that contributed to raising the well-being refers to the relationship between caregiver and patient. A study developed with caregivers of patients with cancer found that a complicity and intimacy relationship was established resulting from the care provided due to illness and treatment⁽¹³⁾. However, another study set forth that the coexistence between the caregiver and the patient with cancer is full of mixed feelings, sometimes of love, understanding and solidarity, other times of anger, grief and frustration, since the caregiver begins to live mainly on the patient's behalf⁽¹⁴⁾. Such demand reinforces the need for a support network that helps caregivers in this difficult mission.

This support can come from other family members, as well as from the friendly relations in the community and from social care and health services. Some of the items found among the highest BEG scores indicated the presence of people coexisting with the caregiver, supporting care provision.

Establishing a network for caregivers support can minimize suffering experienced and facilitate the care of

patients with cancer. However, when this network is poorly established caregivers experience an intensification of their personal exhaustion⁽¹¹⁾. Therefore, professionals working in the Family Health Strategy Project, in particular, should be alert to the needs faced by caregivers, empowering them to care for the person with cancer at home and guiding them according to their reality.

Feeling safe in care increases well-being. In general, in most cases, caregivers have no formal training allowing them to ensure the quality of care and are not emotionally prepared to take the burden of this role. Thus, the presence of nurses at home is essential. They are able to listen, observe and interpret complaints and signals that may arise and take relevant decisions. Without this valuable tool, which is the home visit, the nurse cannot provide full assistance to the patient with cancer and his/her family.

Taking care of personal hygiene of the family member with cancer suggests that keeping the patient clean is an important factor for the well-being of the caregiver as well as keeping the patient's room quiet. This finding suggests the importance of environmental effects for the well-being of caregivers and reinforces the importance of investments in space and architecture (15). Simple, concrete, and fast measures often make the environment more peaceful and embracing: respecting silence, indirect lighting, a suitable choice of colors, good ventilation, cleaning, among others (8).

The statement "I feel guilty"* was one of the negative statements, and which had an inversed final mean. Thus, the feeling of not feeling guilty is associated with the well-being of the caregiver. Corroborating this line of thought, a study established that the fact of feeling responsible for the illness condition of the relative negatively affects caregivers and may be a stress element, resulting in higher rates of stress⁽¹⁵⁾.

Another item that was identified as favorable to the well-being refers to positive remembrances from the past. This indicates that analyzing the past and

remembering the good health condition of the ill relative, the previous family routine and the happy times they spent together provides caregivers with a feeling of well-being. Memories from the past bring satisfaction and may be elicited by the health team during the home visit, since the dialog with the caregiver should not be based only on the illness of the family member with cancer, but on matters that bring joy to him/her.

An increased well-being was also related to the perception of being able to help the family member that is experiencing a poor health condition. Hence, it is important to value the participation of caregivers in the process of care, including them to the care tasks made at home.

Items that cause lower impact on the well-being

Concern for the family was the factor that had the highest negative impact on the global well-being of the caregivers. This result raises the hypothesis that caregivers are worried about other issues related to their families, which results in emotional burden⁽¹⁶⁾.

Witnessing the physical and emotional discomfort and constantly thinking about the person with cancer were aspects that also contributed to the decline in the well-being. When witnessing the agony of the person with cancer, the caregiver starts to experience his/her physical pain⁽¹⁷⁾. This experience brings pain, especially when it comes to someone close to the caregiver. This situation makes the family member sensitive before the suffering of someone so dear, resulting in his/her own constant suffering.

Items that were present among the highest and lowest scores in only one of the studies

Five items were only present in the current study, among the highest scores. They suggest that home care provides family caregivers with higher calm and privacy, decreasing stress symptoms (anxiety, fear, depression and sleeping difficulty). This corroborates a study made with caregivers of patients with cancer, which indicated

that even before all the difficulties faced at home, most of them preferred to take care of the sick family member there than in a hospital $^{(18)}$.

Three items were present only among the highest scores in the study by Rao et al. (8). It implies that the fact that caregivers recognize nurses as a source of hope may be related to the constant presence of this professional in the hospital, or even the absence of a primary care nurse providing care to the patient with cancer and his/her family members.

A significant gap is observed when it comes to monitoring health services provided to the person with cancer at home. Therefore, there is a need for expansion of home care services in their various forms since this support has been inadequate and does not represent an effective assistance to caregivers. Thus, the need to implement public policies in order to help taking care of the person with cancer at home arises.

Items that were only present in the current research among the lowest scores indicate uncertainty about the financial aspect. A study shows that cancer is responsible for the financial decline of many families, since the costs of treatment are high, patients often stop working and caregivers also stop or decrease their workload in order to assist the sick family member^(3,18).

Finally, two items were present among the lowest scores, only in the study made by Rao et al. (8). This result can be explained by the fact that, despite the constant presence of health professionals in the hospital, these are not always willing to answer questions raised by caregivers. It is often observed that this information is insufficiently provided and is not understood by caregivers, resulting in decreased well-being of caregivers.

CONCLUSION

This study is an opportunity to think of the importance of including the caregiver as a participant in the care process. Health professionals must understand and encourage the family religious and spiritual practices,

since the spiritual evaluation and intervention should be part of the holistic care. They should seek ways to build a network to support caregivers, so that these people can match activities related to care to other activities, and also help caregivers effectively during the planning of care tasks at home, providing suggestions to facilitate their daily life, as well as during the organization of the care environment.

Despite being held at a different site and using different sociodemographic sample, the study by Rao et al. showed similarities with the results obtained in this study, which indicates that the setting has little effect on the well-being of the caregiver, that is, their well-being is equally affected regardless of the place. However, some items in the current study may suggest that home care has a higher impact on the well-being of caregivers, compared to hospital care.

The questionnaire used serves as a tool to support planning nursing interventions. However, it is necessary to create other tools that provide a rapid and effective assessment of the needs of caregivers of patients with cancer at home.

Limitations of this study include the difficulties in carrying out the data collection, due to the impossibility of contact by telephone due to incorrect or disabled telephone numbers; few published materials related to the well-being of caregivers; and the possibility of selection bias - despite the care to avoid having a biased sample, it is not a representative group, since they are included in an organization designed to provide care to patients with cancer in poor financial conditions.

Future studies related to the global well-being of caregivers of adults with malignant neoplasms at home are still needed, seeking greater understanding of relevant issues and improvement of services provided to these people. Therefore, we suggest studies applying correlational and multivariate statistics analyses to examine the relationship between global well-being and the personal characteristics of caregivers and people with malignant neoplasms.

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