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Cancer patients caregivers comfort

CONFORTO DE CUIDADORES DE PACIENTES COM CÂNCER

LA COMODIDAD DE LOS CUIDADORES DE PACIENTES CON CÁNCER

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ABSTRACT

Cross-sectional study, carried out at the outpatient clinic of an oncology hospital. Data were collected from 88 caregivers of cancer patients using the Caregiver General Comfort Questionnaire (GCQ) to assess the caregivers' comfort. The caregivers' GCQ score mean was 203.9; better comfort scores was associated with age, care time and current occupation; positive aspects of comfort were related to the fact that caregivers felt loved, to patients' physical and environmental comfort and to caregivers' spirituality. 203.9; better comfort scores were associated with age of the caregiver and current occupation; positive aspects of comfort were related to the fact that caregivers felt loved, to patients' physical and environmental comfort and to caregivers' spirituality. Caregivers, who didn't have a paid job or leisure's activities showed a worse GCQ. The GCQ scale can help to identify factors that interfere in caregivers' comfort, as well as needs that can be modified through health professionals' interventions.

DESCRIPTORS

Neoplasms
Caregivers
Personal satisfaction
Quality of life
Oncologic nursing

RESUMO

Estudo transversal cujo objetivo foi avaliar o conforto de cuidadores de pacientes com câncer. Envolveu 88 cuidadores de pacientes em atendimento ambulatorial de um hospital especializado em oncologia. Utilizou-se o General Comfort Questionnaire (GCQ) validado para o português. Verificou-se que o escore médio do GCQ dos cuidadores foi de 203,9. Os melhores escores de conforto estiveram relacionados à idade e ocupação do cuidador; os aspectos positivos do conforto envolveram sentir-se amado, o conforto ambiental e físico do paciente e a espiritualidade do cuidador. Cuidadores que não exerciam atividade remunerada ou lazer apresentaram piores escores de GCQ. Concluiu-se que escala de GCQ pode ajudar a identificar fatores que interferem no conforto dos cuidadores de pacientes com câncer, assim como necessidades que permitam a intervenção dos profissionais de saúde.

DESCRITORES

Neoplasias; Cuidadores
Satisfação pessoal
Qualidade de vida
Enfermagem oncológica

RESUMEN

Estudio transversal que tuvo como objetivo evaluar la comodidad de los cuidadores de pacientes con cáncer. Participaron 88 cuidadores de pacientes en atención ambulatoria de un hospital oncológico. Para la recolección de los datos, se utilizó el *General Comfort Questionnaire* (GCQ) validado para el portugués. La puntuación media del GCQ de los cuidadores fue de 203,9. Las mejores puntuaciones de comodidad estaban relacionadas con la edad y la ocupación del cuidador; los aspectos positivos fueron sentirse amado, comodidad física del paciente y de su ambiente y la espiritualidad del cuidador. Las peores puntuaciones fueron observadas en los cuidadores que no tienen trabajo remunerado o descanso. Se concluye que la escala GCQ puede ayudar a identificar factores que interfieren en la comodidad de los cuidadores de pacientes con cáncer, así como identificar las necesidades que permitan la intervención de los profesionales de la salud.

DESCRIPTORES

Neoplasias
Cuidadores
Satisfacción personal
Calidad de vida
Enfermería oncológica

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INTRODUCTION

The evolution of cancer and its consequences for patients are well known, but there is a lack of research assessing the impact of the disease on the primary caregivers' well-being. These caregivers tend to be family members, assume care tasks and spend most time with patients.

Disease progression weakens patients and increases their dependence, turning caregivers' activities increasingly necessary and often stressful(1). Prolonged involvement in care activities may have a negative effect on caregivers' physical and emotional health and can be intensified with the disease progression, the impossibility of cure and the approximation of death. The accumulation of tasks or socioeconomic difficulties could decrease the caregivers' global well-being.

Taking care of a relative with advanced cancer generates physical and emotional tiredness, stress and other health problems(2). The principal caregivers describe the lack of freedom to do things beyond patient care, feelings of solitude and tiredness as negative aspects of care delivery(3).

Caregivers acknowledge positive aspects of care. Elderly cancer patients' caregivers had described care as an act of self-giving and protecting the other, with faith as a motivation for care that grants their personal and family growth(4) and an opportunity to express their love through care delivery to a family member.

Measuring well-being and identifying variables that can influence primary caregivers' quality of life can guide the construction of adequate interventions to help them in this phase. One of the ways to assess well-being is through perceived comfort.

Comfort is a subjective and individual concept, comprising physical, environmental, social and psycho-spiritual aspects. Comfort is holistic and can occur to a greater or lesser extent depending on different factors, involving individuals and their personal perceptions. Hence, physical symptoms, organization of the environment, interpersonal relations, individual beliefs and values are related with patients and caregivers' experiences(5-6).

The comfort concept has been explored in literature according to patients' personal perceptions and has also been used as a synonym of well-being(7-8).

Kolcaba's comfort theory departs from the premise that the comfort experience involves a sense of ease (a state of tranquility, satisfaction or contentment), relief (the experience of having a specific need relieved) and transcendence (a state in which someone overpasses problems or pain); it can be experienced in four contexts: physical, psycho-spiritual, environmental and social(5). Based on this taxonomy, Kolcaba built the General Comfort Questionnaire (GCQ), an instrument to measure comfort and identify positive and negative aspects involved in care delivery to a patient with advanced cancer. The questionnaire has two versions: one for use with patients and the other with caregivers.

The GCQ was translated and validated for use in Brazilian terminal cancer patients(8). The questionnaire was first tested in a group of 133 informal caregivers of women with terminal gynecological or breast cancer.

The multidimensional aspects involved in the general comfort of care patients' primary caregivers through the use of scales have received little attention in literature. The goal of this study is to assess the comfort of cancer patients' primary caregivers and verify the association between comfort and variables related to patients, the disease and the principal caregivers.

METHOD

This cross-sectional study was carried out at the oncology outpatient clinic of a governmental oncology teaching hospital between October 2008 and July 2009, in São Paulo city (Brazil). The sample was composed of the principal caregivers of cancer patients under outpatient follow-up. A Cohen's d of 0.3 was found significant with 80% power and 95% confidence level, resulting in a sample of 88 patients. Inclusion criteria for the caregivers were: over 18 years of age and serving as the principal caregiver for a cancer patient with functional capacity measured by Karnofsky scale less than or equal to 50.

Approval for the project was obtained from the Institutional Review Board at the hospital where data collection took place (process Nº. 0644/08). Caregivers who met the inclusion criteria and agreed to participate were informed about the research aims, the guarantees of anonymity, the freedom to participate in the research or not, and signed the Informed Consent Term.

Data collection procedures

Caregivers of patients with Karnofsky scores of no greater than 50 were contacted in the waiting room for outpatient care. Principal caregivers were identified by the patients when communication was possible, or by another companion present at the time of data collection. The researcher assisted the caregiver during data collection as needed such as reading the instruments to them, so as to deal with illiteracy, low education or reading difficulty problems.

Two demographic questionnaires (for patients and for caregivers) were developed for data collection. Patient characteristics were obtained from the patient's medical records, including data related to age, gender, marital status, tumor site, diagnosis date, current treatment and patient's functional capacity. The patients' functional capacity was described with the help of the Karnofsky Scale(9), which assesses the ability to perform activities of daily living. This score can range from 0 to 100, where 0 means death and 100 good health. The caregiver's questionnaire was completed during the interview with the caregiver, with questions on the subject's socio-demographic data, care time and other functions performed.

The version of the GCQ validated for Portuguese language was used(8) to assess comfort. This scale contains 49 items that assess the caregiver's comfort in the physical, social, psycho-spiritual and environmental dimensions. The GCQ is a multidimensional instrument to identify caregivers' different needs. Scores can range from 49 (very little comfort) to 294 (excellent comfort). Each item in the questionnaire includes a six-point Likert scale, with one meaning the caregiver totally disagrees and six that the caregiver totally agrees with the assertion in each of the questions.

Statistical analyses

For data analysis, SPSS (Statistical Package for Social Science®) software was adopted. Central trend measures were used for the quantitative variables. Comfort was analyzed through means and standard deviations (SD). The Mann-Whitney or Kruskal-Wallis test was applied to check the difference in mean scores for the study variables with significance set at 5%. Correlation of Spearman was used to the continues variables (age, familiar income, timing of care, time for diagnoses). Reliability of the GCQ was tested with Cronbach's alpha.

RESULTS

Characteristics of the caregivers

A total of 88 caregivers were interviewed. Female caregivers predominated (n=74; 84.4%), younger than 50 (n=54; 61.4%; range 18 to 81) and gaining less than three minimum wages (n=44; 50.0%). At the time of data collection, the minimum wage was about US$250. Approximately 76.0% (n=67) lived with a partner, 90.0% (n=79) were religious, 54.5% (n=48) had at least two children, 38.6% (n=34) were partners and 39.8% (n=35) the patients' children, 61.4% (n=54) received help from another person to deliver care, mainly siblings or children, 78.0% (n=69) did not have any leisure and 71.6% (n=63) did not have a paid job. Average time as caregiver was 20.3 months (median 27.2; range from 1 to 144), with half of them serving in this role for less than eight months.

Characteristics of the patients

Patients were mostly women (n=45; 51.1%), older than 50 (n=72; 81.8%; range 25 to 90) and living with a partner (n=62; 70.5%). Digestive (n=32; 36.4%), urological (n=13; 14.8%) and head and neck tumors (n=9; 10.2%) were the most prevalent cancer and 55.7% (n=49) had a Karnofsky functional capacity of 40. The diagnosis of 49.4% (40/81) of patients was reached in the last twelve months.

The reliability of the caregivers' GCQ scale was 0.814. Great variation was found in GCQ score (140-263), with an average of 203.9 (SD=22.4). The mean score for each item ranged between 1.2 and 5.8. The means and standard deviations for each item that was scored at 1 and 6 are presented in table 1.

Table 1 - Means and standard deviations for each item of the GCQ scale - São Paulo, 2009

(number) Statement	Mean (SD)
(23) I like his (her) room to be quiet.	5.8 (0.8)
(49) My God is helping me.	5.7 (1.0)
(8) I know that I am loved.	5.7 (1.0)
(33) I feel good enough to do some things to him	5.6 (0.9)
(47) He (She) is kept clean and dry	5.6 (1.0)
(5) My beliefs give peace of mind.	5.5 (1.2)
(21) I have special person(s) who make(s) me feel cared for.	5.5 (1.2)
(18) I am able to talk with people who I love.	5.4 (1.2)
(38) We are okay with our personal relationship.	5.4 (1.1)
(39) This room smells fresh.	5.4 (1.2)
(7) My life isn't worthwhile right now**.	5.3 (1.4)
(35) I feel confident spiritually.	5.3 (1.3)
(15) I feel guilty**.	5.2 (1.6)
(6) Nurse(s) gives me hope.	5.2 (1.3)
(25) The temperature in this room is fine.	5.2 (1.3)
(27) I can grow up with this situation.	5.1 (1.3)
(31) In retrospect, I've had a good life.	5.1 (1.4)
(3) There are those I can depend on when I need help.	5.0 (1.5)
(14) I am afraid to sleep**.	5.0 (1.7)

Continued...

Continuation...

(number) Statement	Mean (SD)
(41) I am able to tell people what I need.	5.0 (1.5)
(4) I worry about my family.**	1.1 (0.4)
(34) I think about his (her) discomforts constantly. **	1.4 (0.9)
(36) I need to be better informed about his (her) condition.**	1.9 (1.6)
(24) I would like to see the doctor more often.**	2.1 (1.6)
(45) His (her) emotional state let me sad. **	2.1 (1.8)
(46) I think for the future.**	2.1 (1.7)
(48) I worry about financial concerns.**	2.1 (1.6)

**inverted items

Items better scored that reached the score 6 were mainly related to environmental and spiritual aspects, while those with score 1 were preferably related to aspects in the social dimension of comfort. Considering the total of 49 items of the scale, in 40.8% (n=20) of them, caregivers signed in the Likert scale the higher score, while half of the caregivers assigned the lower score to only 14.3% (n=7) of items.

The correlation between the caregivers' score of GCQ and the age of the patient didn't show any significant result (r=0.083; p=0.083) even to the time for diagnoses (r=0.07; p=0.536) that ranged from 1 to 468 months. Statistically significant difference was not found between others patient and disease characteristics and the caregivers' mean GCQ score (Table 2).

Analyzing the mean GCQ scores according to caregiver characteristics (Table 3), a statistically significant difference was observed between the caregivers' mean GCQ score and current occupation (p=0.05) variable.

Table 2 - Mean and standard deviation of GCQ score of principal caregivers according to social demographic and clinical characteristics of the patients - São Paulo, 2009

Variable	N(%)	Mean (SD)	p-value
Gender of the patient			
Female	45 (51.1)	203.2 (24.7)	0.470
Male	43 (48.9)	204.6 (25.4)	
Marital status of the patient			
With a partner	62 (70.5)	201.4 (23.0)	0.225
Without a partner	26 (29.5)	209.7 (28.8)	
Tumor site			
Digestive System	32 (36.4)	201.6(24.4)	0.545
Head and neck	9 (10.2)	210.6 (24.6)	
Urological	13 (14.8)	204.1 (20.8)	
Other sites[1]	27 (30.7)	201.9 (21.4)	
Karnofsky (KPS)			
50	28 (31.8)	206.3 (25.5)	0.356
40	49 (55.7)	204.7 (22.1)	
30	10 (11.4)	197.9 (33.7)	
20	1 (1.1)	156 (0.0)	

[1] Bone, soft tissues, lung, breast, skin, brain, spinal cord, gynecologic and ophthalmologic tumors and lymphomas.

Table 3 - Mean and standard deviation of GCQ score of principal caregivers according to their social demographic characteristics - São Paulo, 2009

Variable	N(%)	Mean (SD)	p-value
Gender			
Female	74 (84.4)	207 (26.3)	0.276
Male	14 (15.3)	210 (15.3)	
Marital status of the patient			
With a partner	67(76.1)	201.7 (24.2)	0.212
Without a partner	21 (23.9)	211 (26.6)	
Religion			
Catholic	44 (50.0)	202.4 (24.1)	0.326
Evangelic	24 (27.3)	200.2 (25.3)	
Others[1]	11 (12.5)	217.4(24.4)	
Without religion	9 (10.2)	204.6 (27.5)	

Continued...

Continuation...

Variable	N(%)	Mean (SD)	p-value
Number of children			
Up to 1	40 (45.5)	205.8 (22.6)	0.580
2 a 5	48 (54.5)	203.3 (26.8)	
Familiar relationship			
Partner	34 (38.6)	201.6 (23.0)	0.782
Son (daughter)	35 (39.8)	203.6 (26.6)	
Other[2]	19 (21.6)	208.5 (25.9)	
Receive help to care			
Yes	54 (61.4)	204.4 (23.6)	0.781
No	34 (38.6)	203.1 (27.3)	
Leisure			
Yes	19 (21.8)	212.8 (21.5)	0.093
No	69(78.2)	201.4 (25.4)	
Work			
Yes	25 (28.4)	213 (26.5)	0.05
No	63 (71.6)	200.3 (23.5)	

[1]Adventist, buddhist, candomblé, espírita, umbanda. [2]Friend, formal caregiver, family member.

DISCUSSION

The instrument used to assess the caregiver's comfort showed a good internal consistency. The scale permitted a quantitative analysis of cancer patient caregivers' comfort, the identification of factors interfering in the caregivers' comfort and of needs that can be modified through health professionals' interventions.

The patients' socio-demographic and morbidity characteristics were not related to the caregivers' comfort, although the caregiver for the patient with the lowest Karnofsky functional capacity, i.e. the most care-dependent, obtained the lowest GCQ score. Descriptions in literature report that patients' decreased functional capacity can increase depression in caregivers(10).

Because of the patients' dependence level, most of the caregivers received help from another person for care. Other studies show that, when present, extra help always comes from a relative(11), similar to the present study results.

It was observed that timing of care positively affects caregivers' comfort. This finding reveals that, over time, caregivers gain coping mechanisms or ways of adapting to the disease and routines, which enhances comfort.

The lower GCQ scores in female and younger caregivers were also found among caregivers of breast cancer patients(8). Ages over 50 years favorably affected caregivers' comfort, as younger caregivers, perhaps due to their lack of life experience, faced greater difficulties to deal with the onus of care. Having a paid job also showed to be a positive factor for caregivers, in view of evidence that keeping up a productive activity in the job market enhances self-esteem and preserves individuality, contributing to greater well-being and quality of life.

Like in the present study, a research involving caregivers for cancer patients undergoing chemotherapy observed that most informal caregivers were also female, the patients' partners or children, and younger than 50. Although the study assessed caregivers' quality of life, the authors identified that male caregivers had a better quality of life, mainly in the psychological and social domains(12).

A study developed in a chemotherapy unit of a university hospital in Turkey with family caregivers found that 40.0% of them were younger than 35 years, 58.9% were female, 38.4% of caregivers were the son or daughter of the patient and 32.1% had been caring to the patient for over a year. Results of logistic regression analysis concluded that factors that had an effect on the quality of life were being under 50 years, having a low income and being the spouse and parent of the patient(13).

Great variation in income was found in this study. Half of the caregivers not only reported a low income, but also showed lower comfort. A Korean study with family caregivers of terminal ill cancer patients showed that the percentage of not working among family caregivers was almost two fold higher than in general population and the main reason was for caregiving; 32.3% of them reported extreme fatigue. Providing care for terminal cancer patients instead of working worsens the economic conditions of family caregivers with lower monthly incomes(14).

Religious beliefs can support people at times of crisis and, in this study, most caregivers mentioned being religious.

A study with caregivers of patients with advanced cancer in a palliative care outpatient clinic found that spirituality and religiosity helped them cope with their loved one's illness, and many reported that spirituality and religiosity had a positive impact on their loved one's physical and emotional symptoms(15).

The identification of positive aspects influencing caregivers' comfort reveals factors that can be encouraged during assistance to caregivers and families, permitting behavioral modifications, strengthening and stimulating caregivers to achieve the best possible comfort as the disease evolves and as patients' dependence increases.

Negative influences on caregivers' comfort were related to family and financial issues concern, communication difficulties and patients' discomfort. These results show the impact of care delivery to a cancer patient on caregivers' comfort, as well as efficient communication and support needs, factors that health professionals' interventions can modify through individualized actions. Trust, hope, availability and kindness need to be transmitted to the caregivers, contributing to a better comfort.

Caregivers' communication with their relatives and friends, and greater knowledge on the disease have been described as positive strategies for the caregivers(16). Caregivers want more attention from health professionals(17) and need to receive clear information on the patient(18). In this context, nurses can support patients and families by identifying and enhancing their strong points, mobilizing patients and families' coping resources(19).

Family caregivers of advanced cancer patients get involved in symptom management and are almost fully responsible for domestic routines. Caregivers' roles negatively affect their health and interfere in their anxiety and energy level. However, they find an important meaning in their role, and feel relatively well prepared to deliver care(20).

CONCLUSION

As time goes by, caregivers also experience an adaptation process to the transformations that the disease progression imposes and to the patients' increased care demands.

The small number of caregivers for patients with reduced functional capacity is one of the study limitations. Due to the patients' dependence and low purchasing power, they may have faced difficulties in attending outpatient follow-up. Follow up for the patients in this study was transferred to a new hospital specialized in oncology, which may have enhanced assessments of items related to the environment. Some interviewees, with low education levels, faced reading difficulties, needing help from the interviewer to fill out the instrument, which may have biased the answers.

Implications for nursing

The questionnaire used in this research enabled to identify caregivers' comfort needs, as well as positive and negative care aspects that can guide the construction of nursing interventions. The identified positive aspects should be stimulated and valued in caregivers, so as to enhance resilience and reduce suffering. Prevention and awareness-raising programs can be put in practice for cancer patients, addressing the use of their internal resources, stimulating them towards overcoming and adaptation to difficult situations.

The use of multidimensional holistic assessment instruments with cancer patients' caregivers can be useful in multi-professional teams' of clinical practice as they seek to improve care delivery to caregivers.

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ERRATUM

As published in Volume 48, number 2 of 2014,on pages 278 to 284, the published references of the article "Cancer patients caregivers comfort", should be excluded; therefore, the following list should be considered:

1. Wong RK, Franssen E, Szumacher E, Connolly R, Evans M, Page B, et al. What do patients living with advanced cancer and their carers want to know? – a needs assessment. SupportCareCancer. 2002;10(5):408-15.

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