



Comfort of formal and informal caregivers to palliative care patients in primary health care

Conforto de cuidadores formais e informais de pacientes em cuidados paliativos na atenção primária à saúde

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Objective: to analyze the comfort of formal and informal caregivers to palliative care patients, identifying the variables associated with the difficulties for home care. **Methods:** cross-sectional study involving 50 caregivers of palliative care patients attended in the Family Health Strategy, using the General Comfort Questionnaire. **Results:** most caregivers were women (86.0%), with a mean age of 52 years, with partners (68.0%) and practicing some religion (72.0%). The comfort scores ranged between 202 and 263, with a median of 235. An inverse relation was verified between the *General Comfort Questionnaire* score and caregiver reports of some difficulty in care delivery to palliative care patients (OR=0.90; 95.0% CI 0.81-1.01). **Conclusion:** the comfort level of the palliative care patients' caregivers was relatively good and was associated with the difficulties in home care.

Descriptors: Primary Health Care; Caregivers; Palliative Care; Nursing.

Objetivo: analisar o conforto de cuidadores formais e informais de pacientes em cuidados paliativos, identificando as variáveis associadas às dificuldades de cuidado no domicílio. **Métodos:** estudo transversal, realizado com 50 cuidadores de pacientes em cuidados paliativos, atendidos pela Estratégia Saúde da Família, utilizando o *General Comfort Questionnaire*. **Resultados:** a maioria dos cuidadores era mulher (86,0%), idade média de 52 anos, com companheiros (68,0%) e praticantes de alguma religião (72,0%). Os escores de conforto oscilaram entre 202 e 263, com mediana de 235. Constatou-se relação inversa entre os escores do *General Comfort Questionnaire* e o cuidador relatar ter alguma dificuldade no cuidado prestado aos pacientes em cuidados paliativos (OR=0,90; IC 95,0% 0,81-1,01). **Conclusão:** o nível de conforto dos cuidadores de pacientes em cuidados paliativos foi relativamente bom e esteve associado às dificuldades de cuidado no domicílio.

Descritores: Atenção Primária à Saúde; Cuidadores; Cuidados Paliativos; Enfermagem.

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Introduction

Palliative care, considered as the approach intended to promote the quality of life of patients and relatives in response to life-threatening diseases⁽¹⁾, initially developed among cancer patients. In the past decades, it was extended to patients with chronic, progressive and degenerative diseases, who do not respond to the curative treatment.

This scenario has made health professionals rethink the way they take care of these patients as, despite the preference for home care, countless difficulties are experienced in this environment, which often end up determining an institutionalized death, even in developed countries⁽²⁾.

In this context, the Family Health Strategy, implemented as a proposal to reorganize primary health care, plays a fundamental role in this process, due to the possibility of offering care closer to the patient and the relative, besides offering tightened bonds of trust and humanized monitoring in the death process⁽³⁾.

In palliative care, the patient and family binomial is always considered a target of care, being both a care provider and receiver⁽⁴⁾. In this process, besides the family members' need to adapt, certain roles are delegated to some people, such as the role of caregiver. This activity can be practiced formally, by a specifically trained or hired professional; and informally, by the family⁽⁵⁾.

At home, the informal caregiver is obliged to informally assume multiple tasks, becoming responsible for care⁽⁶⁾. In many cases, a moral obligation is imposed on the family to assume end-of-life care, without proper training or qualification to perform this function. In a study involving Canadian informal caregivers for advanced cancer patients, recruited at a palliative care services, it was shown that they presented emotional difficulties, besides the need for support and information⁽⁷⁾.

In the Brazilian context, the figure of the

informal caregiver has been hardly valued, in view of the lack of governmental and infrastructural strategies to intervene in the context of the patient's situation of dependence at home. In a study involving family caregivers to elderly users in the Family Health Strategy, it was evidenced that taking care of dependent elderly, besides the need to conciliate different tasks, demands physical effort, help from other people and emotional control⁽⁸⁾.

In this context, as the health professionals focus on the patient who requires specialized care, the informal caregiver's needs sometimes end up being neglected or hardly valued. Both the literature and practice appoint that these caregivers tend to experience a significant physical, emotional, social, material, financial and existential burden, mainly when the care time is long and the disease has reached an advanced stage^(1,5).

Measuring caregiver comfort, which is considered a synonym of wellbeing⁽⁹⁾, is an indicator that can influence the assessment of his/her quality of life and, consequently, support proposed interventions in this progressive phase of the disease⁽¹⁰⁻¹¹⁾.

Comfort is a holistic, subjective and multidimensional concept, influenced by the physical, environmental, social and psychospiritual contexts. Comfort Theory departs from the satisfaction of caregivers' needs in the context of relief, relaxation and transcendence (state of overcoming pain or a problem) in the different contexts of human experience⁽¹²⁾.

Despite the relevance of the theme, little attention has been paid in the literature to assessing the comfort of palliative care patients' caregivers. The assessment of burden and quality of life have been focused on, using instruments and domains that are unable to apprehend the trajectory of the death process, nor the need for interdisciplinary care.

In view of the above, the objectives in this study were to analyze the comfort of formal and informal caregivers to palliative care patients, identifying the variables associated with difficulties in home care.

Methods

A cross-sectional study was developed in the primary health care network of an interior city in the state of São Paulo, Brazil.

The study included a convenience sample of 50 caregivers to palliative care patients, attended by the Family Health Strategy, between May 2013 and December 2014, based on the following inclusion criteria: being a formal/informal caregivers to an adult palliative care patient, being available to answer the questionnaire and agreeing to participate in the study. Caregivers who did not comply with the preset inclusion criteria and whose home was not located were excluded.

It should be highlighted that, in the city where the study was undertaken, no information was available on the palliative care patients attended in the Family Health Strategy. The researcher undertook an individual survey at the primary health care services to obtain their addresses.

Two instruments were used to collect the data: the sociodemographic characteristics and the Portuguese version of the General Comfort Questionnaire, an instrument consisting of 49 questions, whose Likert-scale answers range between 1=I totally disagree and 6=I totally agree. The total scale ranges from 49 (very bad wellbeing) to 294 (excellent wellbeing). The questionnaire was initially developed and tested in the United States, involving 51 caregivers to cancer patients, with a Cronbach's alpha of 0.97 and evidences of excellent psychometric property⁽¹³⁾. In Brazil, its validation was undertaken recently and the Portuguese version reached a Cronbach's alpha coefficient of 0.83, indicating good internal consistency among the items⁽¹⁴⁾.

In this study, the reliability of the instrument was also assessed, using internal consistency analysis of the items, with a Cronbach's alpha coefficient of 0.80.

The quantitative variables were analyzed in terms of means and standard deviations and the qualifying variables were presented in tables with absolute (n) and relative (%) frequencies. The scores on the General Comfort Questionnaire were expressed as medians, maxima and minima. To present the results, the medians were used as, in an asymmetrical distribution, the median is much more representative of the results than the mean.

The multiple logistic regression model was used to analyze the caregivers' chances of reporting some difficulty in taking care of palliative care patients, in function of the General Comfort Questionnaire score and of sociodemographic variables. Statistical significance was set as $p < 0.05$ and, for the analysis, Statistical Package for the Social Sciences version 15.0 was used.

The study complied with the formal requirements of the Brazilian and international regulatory standards for research involving human beings.

Results

As regards the sociodemographic variables, most caregivers were women (86.0%), with an average age of 52 years, with partners (68.0%), who practiced some religion (72.0%). It was also observed that about half of the interviewees (46.0%) were illiterate or had not finished primary education.

Most caregivers were directly related (70.0%) to the patient, had been informal caregivers (92.0%) for at least three years and 78.0% indicated difficulties in home care (Table 1).

Most patients were male (80.0%), with a mean age of 49 years. The predominant baseline disease was neurological 30 (60.0%), followed by tumors 12 (24.0%), cardiac 5 (10.0%) and renal conditions 3 (6.0%).

Table 1 - Sociodemographic characteristics of primary caregivers to palliative care patients

Variable	n (%)	95% CI
Sex		
Female	43 (86.0)	76.4 - 95.6
Male	7 (14.0)	4.4 - 23.6
Age (years)		
	(16-82)	
16 - 26	7 (14.0)	4.4 - 23.6
27 - 37	7 (14.0)	4.4 - 23.6
38 - 48	7 (14.0)	4.4 - 23.6
49 - 59	16 (32.0)	19.1 - 44.9
Mean (\pm Standard deviation)	52 (\pm 5.63)	
Instruction level		
Illiterate/Unfinished primary	23 (46.0)	32.2 - 59.8
Finished primary/Unfinished secondary	10 (20.0)	8.9 - 31.1
Finished secondary/Unfinished higher	12 (24.0)	12.2 - 35.8
Finished higher	5 (10.0)	1.7 - 18.3
Having a partner		
No	16 (32.0)	19.1 - 44.9
Yes	34 (68.0)	55.1 - 80.9
Practicing some religion		
No	13 (26.0)	13.8 - 38.2
Yes	37 (72.0)	59.6 - 84.4
Degree of parenthood		
None or indirect	15 (30.0)	17.3 - 42.7
Direct	35 (70.0)	57.3 - 82.7
Remunerated caregiver		
No	46 (92.0)	84.5 - 99.5
Yes	4 (8.0)	68.9 - 91.1
Difficulties in home care		
No	11.0 (22.0)	2.3 - 19.7
Yes	39.0 (78.0)	25.5 - 52.5
Length of care (years)		
Mean (\pm Standard deviation)	3 (\pm 2.69)	
Income (Real)		
Mean (\pm Standard deviation)	1,257.04 (\pm 522.61)	

CI=Confidence Interval

In Table 2, the medians, minima and maxima are displayed for the General Comfort Questionnaire of caregivers to palliative care patients, according to the sociodemographic characteristics. As observed, female participants with a partner, practicing some religion and illiterate/unfinished primary education obtained higher scores on the General Comfort Questionnaire, although not statistically significant. Little variation was found in terms of the age range, degree of parenthood and remunerated activity. As regards the General Comfort Questionnaire score, the median was 235, ranging between 202 and 263.

Table 2 - Median, minimum and maximum for the General Comfort Questionnaire of caregivers to palliative care patients, according to the sociodemographic variables

Variable	n	Median	Minimum-Maximum
Sex			
Female	43	235	202 - 263
Male	7	230	212 - 255
Age range			
16-26	7	238	212 - 255
27-37	7	236	216 - 248
38-48	7	235	229 - 263
49-59	16	230	202 - 247
\geq 60	13	235	222 - 251
Having a partner			
No	16	233	212 - 255
Yes	34	238	202 - 263
Practicing some religion			
No	13	233	202 - 252
Yes	37	237	212 - 263
Instruction level			
Illiterate/Unfinished primary	23	237	225 - 263
Finished primary/Unfinished secondary	10	232	212 - 247
Finished secondary/Unfinished higher	12	231	202 - 255
Finished higher	5	232	224 - 235
Degree of parenthood			
None or indirect	15	235	216 - 263
Direct	35	233	202 - 252
Remunerated caregiver			
No	46	235	202 - 263
Yes	4	232	214 - 240

The analysis results inherent in the caregivers' chances of reporting some difficulty in care delivery to palliative care patients, in function of the General Comfort Questionnaire score and sociodemographic variables, are displayed in Table 3. Although no statistically significant results were identified in this analysis, an inverse relation was observed between the General Comfort Questionnaire score and the caregivers' chances of reporting difficulties in care delivery to palliative care patients (OR=0.90; 95% CI=0.81-1.01).

Table 3 - Multiple regression analysis of factors associated with difficulties in home care

Variables	Regression coefficient β	p-value	Odds Ratio	Odds Ratio (95% CI)
General Comfort Questionnaire score	-0.10	0.054	0.90	0.81(1.01)
Age of caregiver (years)	-0.02	0.387	0.98	0.92(1.03)
Male caregiver	-1.20	0.389	0.30	0.02(4.61)
Caregiver with partner	-1.74	0.100	0.18	0.02(1.40)
Caregiver practicing religion	-2.71	0.082	0.07	0.00(1.41)
Caregiver illiterate/unfinished primary education	0.65	0.487	1.92	0.30(12.17)
Directly related caregiver	-0.45	0.614	0.63	0.11(3.71)
Length of care	0.06	0.255	1.06	0.96(1.18)

CI=Confidence Interval

Discussion

The development of the research at a single health service with local particularities was a limitation in this research. In addition, the cross-sectional design should be considered, which does not permit the establishment of cause and effect relations⁽¹⁵⁾, as well as the difficulty to identify the palliative care patients in the city's primary health care network.

In this research, the caregivers were predominantly women, who possessed a low education level and worked informally. This finding is similar to the reality in other countries, including developed nations, in accordance with the literature^(6,16).

The participants assessed their comfort as satisfactory (median=235). Although the questions on the General Comfort Questionnaire were focused on caregivers to cancer patients, which was not the case for all participants included in this research, little difference was found in the study in which the comfort of 99 informal caregivers to patients attended at a specialized oncology outpatient clinic was assessed. In that research, the total score ranged between 140 and 263, with an average of 203⁽¹¹⁾. It should be

highlighted, however, that none of the studies analyzed the palliative care domains in the General Comfort Questionnaire, as the questions were not grouped in the elaboration of this instrument.

Nevertheless, the absence of significant associations between comfort and the sociodemographic factors was found in this research. Although these results cannot be fully explained, they are not considered to derive from selection biases or even shortages in the questionnaire. The use of qualitative research methods could enhance the capacity to explain these inquiries.

In a study involving ten caregivers to children and adolescents beyond therapeutic possibilities of cure, the scores on the General Comfort Questionnaire ranged between 144 and 252, with an average of 189. These data demonstrate the low prevalence of very low global comfort scores. The concern with the family, the patient's discomfort and his/her uncertain future were the factors that most negatively affected the caregivers' comfort, while the most positive influences were the belief in spiritual help and in the tranquility in the patient's room⁽¹⁷⁾.

In a recent study involving 96 relatives who took care of adults with malign tumors, the total scores on the General Comfort Questionnaire ranged between 168 and 255, indicating great individual variation. Higher scores were related to the items corresponding to spiritual beliefs and religious concepts⁽¹⁸⁾.

The range of factors that interfere positive and negatively in the perceived construct and the score range, as evidenced in the studies that used this questionnaire, make it difficult to compare the results. This instrument has no final stratification to rank the comfort levels, which simply appoint the items that contribute to the promotion and reduction of caregiver comfort⁽¹⁸⁾. It does not permit grouping the questions according to the multifactorial dimensions assessed either, which makes it difficult to identify and estimate the score for specific domains.

Other relevant information found in this research refers to the inverse relation between the General Comfort Questionnaire score and the care difficulties for palliative care patients. These results can be related with the subjective and multidimensional perception of comfort and with the repercussion of the difficulties faced in daily reality.

Hence, the multidisciplinary assessment of the patient in these conditions should also be extended to the caregiver, who is often invisible to the health system. In this context, one of the main potentials of the Family Health Strategy is the capacity for wide-ranging interventions in the complexity of the problems the caregivers experience at home. It is fundamental that the professionals in this program understand the family dynamics and the role the patient plays in this group, with a view to tightening the support actions through the establishment of bonds of trust and embracement⁽³⁾.

These data emphasize the need to bond with the clients the health teams attend to as a fundamental condition to put in practice the embracement of the family, and particularly the caregivers of palliative care patients, during the process of dying at home.

Therefore, the Family Health Strategy teams should be prepared for palliative care actions, such as the control of low-complexity symptoms, the prevention of problems and emotional support to the families, also during the mourning period⁽¹⁹⁾.

And, finally, the lack of studies on the comfort of caregivers to palliative care patients made it difficult to compare our results. On the other hand, it showed that future studies are needed in this area.

Conclusion

The caregivers' comfort in palliative care was relatively good, going against the expectation that the burden imposed on them could interfere negatively in the perception of the concept. In addition, it was identified that the comfort was associated with difficulties in home care.

These research results could contribute to the reorganization and local articulation of actions in the Family Health Strategy, with a view to the establishment of palliative care as a legitimate practice in the country at all health care levels. In this sense, it is fundamental to acknowledge the caregivers as care subjects and to provide them with the support needed to cope with the disease at home.

Collaborations

Meneguim S, Ribeiro R and Ferreira MLSM participated in the conception, analysis, writing of the article, relevant critical review of the intellectual content and final approval of the version for publication.

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