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ARTIGO DE INVESTIGAÇÃO (ORIGINAL)

Religion/spirituality and social support in improving the quality of life of patients with advanced cancer

Religião/espiritualidade e apoio social na melhoria da qualidade de vida da pessoa com cancro avançado

Religión/espiritualidad y apoyo social para mejorar la calidad de vida de las personas con cáncer avanzado

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Abstract

Background: The religion/spirituality and social support may improve the quality of life of patients with advanced cancer receiving palliative therapy or palliative care.
Objective: To determine if patients with advanced cancer receiving palliative therapy and/or palliative care use religion/spirituality and social support to cope with the disease, and assess if these aspects improve their quality of life.
Methodology: Observational, cross-sectional, and analytical study conducted in a hospital in southern Brazil from January to July 2018. A sociodemographic/clinical questionnaire and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 15 Palliative Care were used. The nonparametric Mann-Whitney test was used for comparative analysis.
Results: A total of 107 patients receiving palliative therapy and 19 patients receiving palliative care participated in this study. Religion/spirituality and social support were unanimously used. The presence of a family member as the main caregiver was significant (p = 0.014), predicting a better quality of life.
Conclusion: Nurses are responsible for promoting humanized care and the use of religion/spirituality and social support, namely the presence of family caregivers, with a view to improving the quality of life of patients with advanced cancer.

Keywords: quality of life; neoplasms; palliative care; spirituality; religion; social support

Resumo

Enquadramento: O constructo religiosidade/espiritualidade e apoio social sugere melhoria na qualidade de vida nos doentes com cancro avançado em terapêutica paliativa ou cuidado paliativo.
Objetivo: Verificar se as pessoas com cancro avançado que estão a receber terapêutica paliativa e/ou cuidado paliativo, utilizam a religiosidade/espiritualidade e apoio social para o enfrentamento da doença, e comparar o seu uso na melhoria da qualidade de vida.
Metodologia: Estudo observacional, transversal e analítico, realizado num hospital no sul do Brasil, de janeiro a julho de 2018. Dados recolhidos através de um questionário sociodemográfico/clínico e do *Quality of Life Questionnaire-Core 15-Palliative*. O teste não paramétrico de *Mann Whitney* foi utilizado para análise comparativa.
Resultados: Participaram 107 doentes na terapêutica paliativa e 19 no cuidado paliativo. O uso da religiosidade/espiritualidade e apoio social foi unanimemente utilizado. A presença de um familiar como cuidador principal teve significância (p = 0,014), predizendo melhor qualidade de vida.
Conclusão: Cabe ao enfermeiro promover o cuidado humano e viabilizar o uso do constructo religioso/espiritual e social, em especial a presença do cuidador familiar, para melhorar a qualidade de vida da pessoa com cancro avançado.

Palavras-chave: qualidade de vida; neoplasias; cuidados paliativos; espiritualidade; religião; apoio social

Resumen

Marco contextual: El constructo religiosidad/espiritualidad y apoyo social sugiere una mejora en la calidad de vida de los pacientes con cáncer avanzado en la terapia paliativa o en los cuidados paliativos.
Objetivo: Verificar si las personas con cáncer avanzado que reciben terapia paliativa y/o cuidados paliativos utilizan la religiosidad/espiritualidad y el apoyo social para afrontar la enfermedad, y comparar su uso para mejorar su calidad de vida.
Metodología: Estudio observacional, transversal y analítico, realizado en un hospital del sur de Brasil, de enero a julio de 2018. Los datos se recogieron mediante un cuestionario sociodemográfico/clínico y el *Quality of Life Questionnaire-Core 15-Palliative*. Para el análisis comparativo se utilizó la prueba no paramétrica de Mann Whitney.
Resultados: Participaron 107 pacientes en la terapia paliativa y 19 en los cuidados paliativos. El uso de la religiosidad/espiritualidad y el apoyo social se utilizó de forma unánime. La presencia de un miembro de la familia como cuidador principal fue significativa (p = 0,014), y predice una mejor calidad de vida.
Conclusión: Es responsabilidad del enfermero promover el cuidado humano y permitir el uso del constructo religioso/espiritual y social, especialmente de la presencia del cuidador familiar, para mejorar la calidad de vida de las personas con cáncer avanzado.

Palabras clave: calidad de vida; neoplasias; cuidados paliativos; espiritualidad; religión; apoyo social

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Introduction

Advanced cancer can be understood as a group of progressive, untreatable, metastatic or locally recurrent diseases (Gilbertson-White, Aouizerat, Jahan, & Miaskowski, 2011). Two types of treatment can be recommended: palliative therapy (PT) or palliative care (PC).

Palliative therapy can be defined as active systemic measures to minimize the symptoms of the disease and control its side effects, with the aim of improving the quality of life (QoL) of terminally ill patients, for example through chemotherapy, radiation therapy, cancer-directed therapy, hormone therapy, immunotherapy, surgery (Silva, Lenhani, Tomim, Guimarães, & Kalinke, 2019).

Palliative care can be used alone or combined with PT. It aims to improve the symptoms and relieve the suffering of both patients and their families. It also aims at the early detection and treatment of physical symptoms, as well as other psychosocial and spiritual problems with a view to improving QoL (THE WHOQOL Group, 1998).

The concept of QoL is broad, multidimensional, and subjective. WHO defines QoL as the "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1997, p. 1), a concept that permeates this study.

Religion/spirituality and social support are strategies used by patients to cope with the disease. They are used in situations of suffering and have an important protective role against disease-related psychological symptoms (Jaramillo, Monteiro, & Borges, 2019).

In order to determine if patients with advanced cancer use religion/spirituality and social support to cope with the disease, the following objectives for this study emerged: To determine if patients with advanced cancer receiving PT and/or PC use religion/spirituality and social support to cope with the disease, and assess if these aspects improve their QoL.

Background

Advanced cancer profoundly affects the physical, psychological, social, and spiritual well-being of patients and their families, which is often a challenge for the healthcare team. Many patients use religion/spirituality to guide their treatment decisions, cope with stress, maintain their spiritual well-being, and promote hope for a better QoL (Peteet & Balboni, 2013).

Religion and spirituality may or may not be associated and are two different expressions. Religion is a partial expression of spirituality, composed of a system of dogmas and doctrines shared by a group with specific social and doctrinal characteristics, behaviors, and values. Spirituality is a broad concept related to the transcendent, the search for the meaning and purpose of life, beyond what can be understood, and it may or may not extend to religious practices. Spirituality is individual, universal, dynamic, multidimensional, and inclusive (Damiano et al., 2016).

Religion/spirituality increase perceived control and independence from the effects of the disease and therapeutic adherence, and reduce stress and anxiety in the search for meaning while coping with the disease. The disease frightens, but spirituality renews (Jaramillo et al., 2019). In this way, cancer patients should receive holistic care that goes beyond the physical aspects to include the psychosocial, spiritual, and emotional aspects.

Another strategy to cope with the disease and prevent or reduce stressful effects in the long term is social support, which refers to interpersonal interactions that include emotional support, companionship, and counseling. Social support is associated with improved QoL and reduced anxiety and depression in patients with advanced cancer (Bradley, Lloyd-Williams, & Dowrick, 2018).

On the other hand, social isolation is associated with reduced well-being and increased depression, pain intensity, mortality, and cognitive impairment. The limitation in social relationships can result from the stigma associated with disease and death. Pain, fatigue, and other symptoms can prevent social engagement and lead to poorer physical function, which increases social restriction (Bradley et al., 2018).

Research question

Do patients with advanced cancer receiving palliative therapy or palliative care use religion/spirituality and social support as coping strategies to improve their QoL?

Methodology

This observational, cross-sectional, and analytical study was conducted at a university hospital in southern Brazil between January and July 2018. The nonprobability sample was composed of inpatients or outpatients receiving PT and/or PC. The inclusion criteria were: patients over 18 years of age; diagnosis of advanced cancer (stage IV), confirmed by histology, of any topography, previously communicated; and documentation in the medical records about PT and/or PC, with Performance Status classified by the researcher at the time of data collection using the Eastern Cooperative Oncology Group (ECOG): 0 (fully active); 1 (restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature); 2 (ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours); and 3 (capable of only limited self-care; confined to bed or chair more than 50% of waking hours; Oken et al., 1982). The exclusion criteria were: patients unable to maintain verbal communication.

Initially, the authors developed a questionnaire including variables on the following characteristics: sociodemographic (gender, age, marital status, number of children, education level, occupation, and family income); clinical (comorbidities, performance status, type of cancer, assessment by the PC team); spirituality/religion (religious belief, religious practice, religion, use of spirituality/religion/support from the religious community); and social support (support from family, friends, and healthcare professionals, participation in support groups).

QoL was assessed using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 15 Palliative Care (EORTC QLQ-C15-PAL) which had been validated for Brazilian Portuguese (Nunes, 2014). This shortened 15-item questionnaire assesses physical and emotional aspects, as well as the overall QoL in the past 7 days of patients with advanced cancer. Scores range from 0 to 100, where a higher score represents a better QoL (Groenvold et al., 2006).

Data (sociodemographic, clinical, use of religion/spirituality, and social support) were stored in electronic platforms and then analyzed on Microsoft Excel® 2016, using descriptive statistics and expressed in simple and absolute frequency (%). For analysis of the QLQ-C15-PAL, the raw score was calculated, which consists of summing each scale item and dividing by the number of answers (Groenvold et al., 2006). The nonparametric Mann-Whitney test was used to compare the overall QoL and the variables of social support and use of religion/spirituality, with a significance level of 5% for results with a *p*-value below 0.05, being considered as statistically significant ($p < 0.05$) because data were not normally distributed. Statistica version 7.0 was used for data analysis.

While planning this study, permission was requested from the Ethics and Research Committee of the institution where the study was developed (Opinion No. 2.461.307) and from the author of the QoL questionnaire for its use. Participants were informed about the reasons, risks, benefits, purpose, and objectives. They were given a document to express their informed consent to participate and informed that they could withdraw at any time. Data confidentiality was ensured, as well as the respect for privacy and anonymity, as established in Resolution no. 466/2012 of the Ministry of Health/Brazil.

Results

A total of 126 inpatients and/or outpatients participated in the study. They were classified according to the therapeutic intent described in the medical records: 107 were receiving PT and 19 were receiving PC (Table 1).

Table 1

Sociodemographic characteristics of patients with advanced cancer receiving PT and PC

Variable	Palliative Therapy		Palliative Care	
	(*n* = 107)		(*n* = 19)	
	n	(%)	*n*	(%)
Age in years (mean)	58.3		62.6	
Standard deviation (interval)	±12 (18-81)		±11.9 (35-82)	
18 to 49	24		2	10.5
50 to 59	29	27.1	5	26.3
60 to 69	38	35.5	7	36.9
70 to 82	16	15	5	26.3
Gender				
Female	66	61.7	11	57.9
Male	41	38.3	8	42.1
Marital Status				
Married/Cohabiting	63	58.9	10	52.7
Separated/Divorced	20	18.7	5	26.3
Single	19	17.7	2	10.5
Widowed	5	4.7	2	10.5
No. of children (mean)	2.8	3.5		
Education level				
Illiterate	5	4.7	-	-
Basic education	64	59.8	15	79
Secondary education	27	25.2	2	10.5
Higher education	11	10.3	2	10.5
Occupation				
Retired	56	51.9	11	57.8
Employed	16	15.1	1	5.3
Self-employed	18	17	1	5.3
Homemaker	10	9.4	3	15.8
Others/Absent from work	7	6.6	3	15.8
Income* in minimum wages**				
Up to 1 minimum wage	23	21.9	3	15.8
1 to 3 minimum wages	63	60	13	68.4
4 to 10 minimum wages	19	18.1	3	15.8
Household members (mean)	3		3.4	

Note. *Two participants did not answer. **The minimum wage in force in Brazil during the study was 954 BRL/Month.

In relation to the Performance Status using the ECOG, 81 patients receiving PT (75.7%) had ECOG 0 and 1, and 17 patients receiving PC (89.5%) had ECOG 2 and 3 (Table 2).

Table 2
Clinical characteristics of patients with advanced cancer receiving PT and PC

Variable	Palliative Therapy (*n* = 107)		Palliative Care (*n* = 19)	
	n	(%)	*n*	(%)
Comorbidities (Non-communicable diseases)				
Present	70	65.4	13	68.4
Absent	37	34.6	6	31.6
Performance Status (ECOG)				
ECOG 0	22	20.6	-	-
ECOG 1	59	55.1	2	10.5
ECOG 2	22	20.6	6	31.6
ECOG 3	4	3.7	11	57.9
Diagnosis of metastatic cancer				
Yes	68	63.6	14	73.7
No	39	36.4	5	26.3
Assessment by the PC team				
Yes	14	13.1	19	100
No	93	86.9	-	-

Note. ECOG = Eastern Cooperative Oncology Group.

The use of religion/spirituality to cope with the disease was identified in both groups: in 101 patients (96.2%) receiving PT and in 17 patients (89.5%) receiving PC. The support of visits and/or prayers from the religious community to cope with the disease was also identified in both groups: 66 patients (62.3%) receiving PT and 12 patients (63.2%) receiving PC. With regard to social support, 96 patients receiving PT (89.7%) and 17 patients receiving PC (89.5%) had a family member who was their main caregiver (Table 3).

Table 3
Religious/spiritual characteristics and social support of patients with advanced cancer receiving PT and PC

Variable	Palliative Therapy (*n* = 107)		Palliative Care (*n* = 19)	
	n	(%)	*n*	(%)
Religious Belief				
Yes	104	97.2	18	94.7
No	3	2.8	1	5.3
Religious Practice				
Yes	75	70.1	16	84.2
No	15	14.0	2	10.5
Eventual	17	15.9	1	5.3

Religion				
Catholic	66	61.7	9	47.4
Evangelic	28	26.2	7	36.8
Spiritist	4	3.7	1	5.3
Lutheran	3	2.8	-	-
Others/No answer	6	5.6	2	10.5
Religion/spirituality to cope with cancer*				
Yes	101	96.2	17	89.5
No	4	3.8	2	10.5
Support (visits and prayers) from the religious community*				
Yes	66	62.3	12	63.2
No/Eventual	40	37.7	7	36.8
Family member as the main caregiver				
Yes	96	89.7	17	89.5
No/Eventual	11	10.3	2	10.5
Family support to cope with cancer				
Yes	98	91.6	17	89.5
No/Eventual	9	8.4	2	10.5
Friends' support to cope with cancer*				
Yes	86	80.4	15	78.9
No/Eventual	21	19.6	3	21.1
Support from healthcare professionals				
Yes	100	93.5	18	94.7
No/Eventual	7	6.5	1	5.3
Participation in support groups				
Yes	1	0.9	-	-
No	106	99.1	19	100

Note. *Two participants did not answer.

The comparison between both groups revealed statistically significant differences in the group receiving PT for those who had a family member as their main caregiver (Table 4), thus suggesting that these patients had a better QoL (p = 0.014). The other analyses were not statistically significant.

Table 4
Comparison between overall QoL, use of religion/spirituality, and family support of patients with advanced cancer receiving PT and PC

Variables	Palliative Therapy			Palliative Care		
	Mean QoL	*SD*	*p*-value	Mean QoL	*DP*	*p*-value
Religion/spirituality						
Yes	72.50	25.33	0.13	60.78	32.24	0.57
No	45.83	28.46		50	0	
Eventual	75.00	11.79				
Belief						
Yes	71.36	25.40	0.57	60.19	31.38	1
No	77.78	38.40		50	0	
Family member as the main caregiver						
Yes	73.51	25.09	0.014	62.75	30.35	0.23
No	58.33	9.13		33.33	23.57	
Eventual	50	37.27				
Family support						
Yes	72.50	25.33	0.54	62.65	30.35	0.23
No	45.83	28.46		33.33	23.57	
Eventual	75	11.79				

Note. QoL = quality of life; *SD* = standard deviation.

Discussion

The care and treatment of patients with advanced cancer and their families is complex due to the diversity of multidimensional aspects, from the sociodemographic characteristics to the various dimensions of the human being, including the emotional, physical, biological, social, psychological, cultural, and spiritual domains, resulting in significant changes in the various areas of QoL (West et al., 2015).

Knowing the sociodemographic characteristics, such as gender, age, activities of daily living, number of children, and education level, is important and can contribute to improving the nursing interventions aimed at the multidimensional aspects of QoL. This is in line with a study conducted in the United States of America, with 185 patients, which concluded that the sociodemographic characteristics are directly associated with the perceived QoL and that women had lower scores in the physical, psychological, and social domains (West et al., 2015). A broader understanding of the individual as a whole will help the nurse to assess, plan, and prescribe individualized measures to improve the QoL.

In the present study, most of the patients with cancer receiving PT and PC were women, had a low education level, and were professionally inactive. Issues related to low education levels can lead to late-stage diagnosis (III and IV; Ribeiro, Eluf Neto, Luizaga, Lombardo, & Leite, 2015).

A factor of clinical significance both in the type of therapy and in QoL, the functional status was measured in this study using the ECOG. There was a predominance of ECOG 0 and 1 in patients receiving PT, whereas patients receiving PC were unable to carry out any work activities and capable only of limited self-care (ECOG 2 and 3).

In clinical practice, people with advanced disease and ECOG performance status ≥ 2 are frequently offered palliative chemotherapy to improve symptoms and QoL. A case-control retrospective study with patients receiving PT and PC showed the need for caution in the prescription of palliative chemotherapy in patients with EGOG greater than or equal to 2 because it seems to offer no benefits in overall survival and QoL (Caires-Lima et al., 2018).

With regard to religion/spirituality and social support, both PT and PC groups reported the use of these strategies in the course of the disease, such as the support of visits and/or prayers from the religious community and a family member as the main caregiver.

Results of a meta-analysis showed an association between spiritual interventions and better health outcomes in patients with cancer, as well as improved spiritual well-being and QoL and reduced depression, anxiety, and hopelessness (Xing, Guo, Bai, Qian, & Chen, 2018).

Religion/spirituality in the health-disease process can contribute to increased therapeutic adherence, QoL, and emotional and spiritual well-being, which can have an impact on the physical domain through sensations such as tranquility and peace. Religion/spirituality can influence the way people cope with adverse situations, promoting resilience and helping the patient to cope with the disease.

While caring for patients and families undergoing the palliative process, a way to provide holistic care is by recognizing the religious/spiritual dimensions and needs of the individuals. Therefore, the nurse should respect the autonomy and facilitate in a secular way the provision of spiritual assistance by the spiritual representatives and leaders involved in those activities, as according to the preference of the patient, family, and caregiver.

In this study, the participation of family members as main caregivers was highlighted by patients receiving PT and PC and it showed a positive significant association with QoL in patients receiving PT. It is common for patients with cancer to receive direct assistance from their relatives. Advanced disease affects the QoL of both the patient and the caregiver, and the burnout of the main caregiver can have a direct impact on patient care. Healthcare professionals should also pay attention to the caregivers' QoL due to possible changes in their well-being, including the physical, psychological, and social support dimensions, which can influence the QoL of cancer patients (Warapornmongkholkul, Howteerakul, Suwannapong, & Soparattanapaisarn, 2018).

Most of the social support to cope with advanced cancer is provided by family members, friends, and healthcare professionals, without evidence of participation in support groups, both in the PT and PC groups. The family contributes to various aspects of patient care, provides emotional support, maintains a reference of stability in relation to changes, pays for economic and social costs, shares the decisions about the proposed therapy, and assists in care delivery (Arrais, 2018).

Social support is associated with better overall QoL and functional status and lower depression symptoms. These were the findings of a study conducted in Minas Gerais, with 115 patients diagnosed with cancer eligible for PC at primary care. In addition, the study found that lower levels of QoL and a greater presence of physical symptoms are associated with lower levels of social support (Azevedo, Dias, Pessalacia, Lourdes, & Pavone, 2017).

Similar results were found in a systematic review, with a total of 1,668 patients with advanced cancer receiving PC in outpatient settings, which concluded that in the presence of intense discomfort, the opportunities and benefits of social support are higher, leading to improved psychological and physical well-being. Therefore, healthcare professionals should take into account and promote social well-being (Bradley et al., 2018).

In the present study, patients receiving PT or PC did not participate in support groups. A cohort study conducted with 66 patients receiving PT highlighted the participation in groups as coping strategies (psychoeducational and psychotherapeutic), when associating social support with the risk factor for hopelessness ($p = 0.007$), concluding that the lower the use of social support, the higher the level of hopelessness (Sorato & Osório, 2015).

For some families, it is hard to continue to care for the patient at the hospital and/or at home due to exhaustion, which stresses the importance of support groups. These groups are ways to cope with the disease, share experiences, feelings, difficulties, emotions, and seek support and information with other families who experience the same reality, besides being a favorable environment for health promotion and social support. Support groups evaluate and identify crisis situations and difficulties and are a source of help by assisting in autonomy and decision-making and empowering families and patients to deal with stress situations (Silva, Begnini, Stamm, Mistura, & Cogo, 2019).

Social support is a strategy used by patients to cope with advanced cancer and can be provided by the family, friends, and professionals who care for the patients, but also by support groups where they can come together and share experiences with people who are going through a similar situation.

The oncology team provides social support through home visits or via the phone or the Internet. The nurse can strengthen the caring relationships and the social support to patients and family members by providing adequate information to meet their needs. These interventions can improve the QoL of both patients receiving PT and those receiving PC.

One of the limitations of this study was the fact that it was conducted in a single service, thus data cannot be generalized. Another limitation was the lack of a reliable sample calculation that would represent the number of patients receiving PT, as well as the small number of participants receiving PC. In relation to the contributions of this study, it was possible to put forward some of the characteristics and needs of patients with advanced cancer. The nurse is responsible for assessing and intervening holistically to meet the care needs of patients and families treated with palliative intent.

Conclusion

The results of this study indicate that people with advanced cancer receiving PT or PC use religion/spirituality and are supported by the beliefs and prayers of religious leaders and communities. All of them have the support of a family caregiver, as well as social support from friends and healthcare professionals. Such strategies are used to cope with the disease and overcome its physical, functional, psychological, and emotional demands, with a focus on improving QoL.

The comparison between the mean overall QoL and the use of religion/spirituality and social support revealed a positive significant difference ($p = 0.014$) for patients receiving PT who had a family member as the main caregiver. The other comparisons showed no statistical significance. Therefore, nurses should provide humanized, comprehensive care to human beings in order to minimize their suffering and improve their QoL. Nurses should pay attention to the care needs of patients and their caregivers and promote and encourage the presence of the family and/or other social support groups throughout the disease process so as to improve the QoL of patients with advanced cancer.

Future studies should be conducted to clarify the influence of family caregivers in improving the QoL of people with advanced cancer, as well as the strategies to be implemented by nurses for the promotion of social, religious, and spiritual support in this caring relationship.

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