Interface between social support, quality of life and depression in users eligible for palliative care*

Interface entre apoio social, qualidade de vida e depressão em usuários elegíveis para cuidados paliativos

Las interfaces entre apoyo social, calidad de vida y depresión en usuarios elegibles para cuidados paliativos

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ABSTRACT

Objective: Analyzing the relationship between social support, quality of life and depression in patients eligible for palliative care at Primary Health Care of a municipality in the interior of Minas Gerais, Brazil. Method: A correlational cross-sectional study carried out with patients treated in six primary health care units. Data were submitted to descriptive statistical analysis, tests for differences between averages and medians, and correlation tests. The significance level was 0.05. Results: The sample consisted of 115 participants, and it was identified that the higher the social support, the better the global quality of life (p<0.001) and functional quality of life (p=0.035); the greater the presence of physical symptoms, the lower the level of social support (p=0.012) and the higher the level of depression (p<0.001); the higher the symptoms of depression, the worse the global quality of life (p<0.001), functional quality of life (p=0.035); the greater the presence of physical symptoms, the lower the level of social support (p=0.012) and the higher the level of depression (p<0.001); the higher the symptoms of depression, the worse the global quality of life (p<0.001), functional quality of life (p<0.001) and the lower the levels of social support (p<0.001). Conclusion: Levels of quality of life, social support and depression of patients eligible for palliative care are influenced by socioeconomic factors such as marital status, gender, age, income, education and presence of a caregiver.

DESCRIPTIONS

Palliative Care; Quality of Life; Social Support; Depression; Primary Health Care; Primary Care Nursing.

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INTRODUCTION

Nowadays, a process of demographic and population transition is occurring in the world context, mainly in developed countries, with rapid global aging and changes in disease prevalence\(^2\). Such a context has increased the need for palliative care (PC), whose focus is not only on patients in the terminal phase, but also on those who are beginning the course of the disease. It is known that PC offered early can provide numerous advantages, mainly regarding quality of life (QoL) of patients, caregivers and family members\(^2\).

It is also important to emphasize that although PC is traditionally offered to patients diagnosed with cancer, mainly due to the numerous symptoms caused by such a disease, it is currently believed that the great demand for PC is due to various chronic non-communicable diseases, and also not less important to some chronic communicable diseases, such as Acquired Immunodeficiency Syndrome (AIDS) and cases of resistant Tuberculosis\(^2\).

Although there are several specialized palliative care services, many patients with non-cancerous chronic diseases are assisted by the Primary Health Care (PHC) system. Thus, given the fact that most people prefer to die at home rather than in hospitals, the role of PHC in PC becomes increasingly important and significant\(^3\).

Palliative care is the care provided by a multidisciplinary team, aiming to optimize the QoL of patients and their families who are affected by a serious disease, regardless of its prognosis. PC can then be started at any stage of a chronic disease, and in conjunction with curative or life-prolonging treatments\(^4\).

While some studies have shown that PHC professionals consider PC as part of their responsibilities to their patients, it is still known that few patients with chronic diseases receive adequate and quality PC in this level of care\(^1,3,5\). An important challenge for implementing PC in PHC is the appropriate assessment of the patient, including identifying the parameters that scientifically and clinically support their diagnosis. It is also noticed that despite the advances, the complexity of the situations involving this care modality brings difficulties to health professionals regarding the management of physical, psychosocial and spiritual symptoms and suffering that directly interfere in the QoL. Therefore, assessment measures are necessary to identify the demands in evaluating the services and care offered, and mainly in the definition of more suitable and individualized conducts\(^6\).

Thus, the objective of this study was to analyze the relationship between social support, QoL and depression in patients eligible for PC attended by PHC of a municipality in the interior of Minas Gerais state, Brazil. We also propose to evaluate the relationships between QoL, social support, depression and the variables of functional capacity, age, gender, education and presence of caregiver, number of children, occupation, marital status, diagnosis and individual income. Studies such as this become relevant, since few studies are available in the literature on psychosocial aspects in PC\(^7-9\). Moreover, we believe that identifying the influence of psychosocial aspects can minimize emotional, spiritual and social suffering in these individuals, in addition to contributing to establishing real public health needs in face of the challenges that PC poses to the health system.

METHOD

PROCEDURE AND SAMPLE

A correlational cross-sectional study was carried out with patients eligible for PC attended at six PHC units (PHCU) of a municipality in the interior of Minas Gerais state, Brazil. The data were collected through individual interviews at the patients’ homes, from March to June 2015.

According to criteria proposed by the World Health Organization\(^10\), a previous study\(^10\) initially identified that the demand for PC-eligible patients in the six PHC units where the research was performed corresponded to 687 patients. Thus, after identification of this demand, the Karnofsky Performance Scale (KPS) was applied to the patients’ records in order to classify them regarding the need to receive early or exclusive Palliative Care.

KPS is an instrument used to measure the functional capacity of people affected by any disease. It is composed of a scale of 11 values distributed between zero (death) and 100% (complete functional independence). Users with performance values below 70% on the scale receive an early PC indication, and values below 50% correspond to exclusive PC. It is known that a patient’s functional capacity is determined by several factors such as age, gender, disease stage and the presence of physical symptoms; however, we believe that KPS is a useful form of evaluation in clinical practice, as it identifies the consequences of the physical and biological aspects in the daily life of the patient\(^11\).

In addition, it should be pointed out that this study also considered the KPS tripartite classification A, B and C, which is currently considered as the proposed algorithm for evaluating this instrument. Thus, three questions were answered, which were: (1) Is the patient able to work and develop his/her activities normally? If the answer was “yes”, we also asked: Does the patient have symptoms? According to this response the patient receives a classification between 80% and 100% of the KPS. If question (1) was answered negatively, question (2) was asked: Does the patient remain bedridden for more than 12 hours? If the answer to question (2) was “no”, we verified if: Does the patient need assistance, for example, to eat and get dressed? And thus, the patient received a classification between 50% and 70% of the KPS. Finally, if the answer to question (2) was “yes”, we asked question (3): What is the patient’s degree of disability? The patient then received a classification between 0% and 40% of the KPS\(^11\) according to the level of disability.

After applying KPS, the participants were selected according to the following criteria: age equal to or greater than 18 years; having early (Karnofsky scale < 70%) or exclusive (Karnofsky scale < 50%) indication for PC assistance, according to their functional capacity\(^11\); and having the cognitive ability to participate (application of the Mini Mental State Examination)\(^12\). Thus, of the 687 patients eligible for PC, only 183 had a KPS score equal to or lower than 70%, and 51 of these were unable to respond to the
Mini Mental State Examination, nine were under the age of 18, four moved, three died, two were hospitalized in the data collection period, and one refused to participate in the study. Therefore, the final sample of this study consisted of 115 participants.

The minimum sample estimate (n=44) was obtained based on the proposed criteria for correlation coefficient in a cross-sectional study\(^{(13)}\), considering the correlation between QoL and social support measures among the elderly (r=0.416)\(^{(14)}\), a significance level of 5% and a test power of 80%. We emphasize that Resolution 466/2012 was met and that the research was approved under CAAE 32864146.0000.5545, opinion number 742.851 by the Ethics Committee of the proposing institution, via Plataforma Brasil.

**Implemented instruments**

A questionnaire designed by the authors was used in order to characterize the participants, which included the following variables: gender, presence of caregiver, type of caregiver, age, ethnicity, marital status, number of children, education, current occupation, monthly salary income, medical diagnosis, presence or absence of comorbidities and which comorbidities. Thus, it was possible to address sociodemographic characteristics and the main clinical aspects of patients eligible for PC through this questionnaire\(^{(15)}\).

QoL was measured using the European Organization for Research and Treatment of Cancer scale (EORTC QLQ-C15-PAL), which has been validated for cancer patients. The choice of this instrument was based on the fact that no other validated instrument specific for QoL in PC was found in Brazil. This instrument is composed of 15 items distributed in three subscales or domains, which are: Functional Scale (five items), Symptom Scale (nine items), and finally, Global Health Status (one item). Validation in Brazil was performed in patients with advanced cancer\(^{(15)}\), and the answers to the first 14 questions are given on a four-point Likert scale, with the final question being evaluated on a seven-point Likert scale. The minimum possible score for this instrument is 15 points, and the maximum is 63 points. For interpretation, each subscale should be analyzed separately, with it being necessary to transform the raw scores into scores ranging from zero to 100. The higher the score for the functional subscale, the healthier the individual is, while a higher score for the subscale of symptoms indicates greater presence of symptoms\(^{(16)}\).

In order to assess the level of social support, the Medical Outcome Study (MOS) was used. A version has been translated, adapted and validated for Portuguese language and is composed of five dimensions of social support: material, affective, positive social interaction, emotional and information. The answers are given in a five-point Likert scale for all questions, with the minimum score being 19 points, and the maximum being 95 points. The final score is obtained by the sum of the total points from the questions of each of the dimensions, and divided by the possible maximum score of that respective dimension, where the higher the score, the higher the level of social support\(^{(17)}\).

Finally, the Depression Scale Center for Epidemiological Studies – Depression (CES-D) was used to identify symptoms of depression. A version has been translated, adapted and validated for Portuguese language and contains 20 items related to mood, somatic symptoms, interactions with others and motor functioning. The answers are given in a Likert scale that considers options of: never or rarely (0), sometimes (1), often (2) and always (3). The score is a simple sum ranging from zero to 60, and a score between 12 and 60 is indicative of the presence of depression symptoms\(^{(18)}\).

**Data analysis**

Data were processed and analyzed using the Statistical Package for Social Sciences (SPSS), version 21.0. Mean and median position measurements, standard deviation variability (SD) and interquartile range (p25-p75) were used for the descriptive analysis of the continuous variables. Simple frequency was used for categorical variables. Scalar variables were evaluated for internal consistency by Cronbach’s alpha. We investigated whether the assumptions of parametric statistics were present or not in the sample before verifying the relationships between the variables. Thus, the results of the Shapiro-Wilk test demonstrated that the variables have a non-normal distribution, with the only exception being the variable measurement of QoL.

Student’s t-tests and Mann-Whitney tests were performed according to the normality of the scalar variable to compare QoL means and social support, and depression medians according to the variables of gender, presence of caregiver, occupation, marital status and diagnosis.

The Spearman correlation test was used in order to identify possible relationships between the variables of QoL, social support, support and age, education, functional capacity, income and number of children. Correlation forces were analyzed considering that values between 0.10 and 0.30 were classified as having low magnitude, between 0.4 and 0.6 of moderate magnitude, and above 0.7 of strong magnitude\(^{(19)}\). Next, a partial correlation test controlled by gender, age, number of children, education, individual income, presence of caregiver, and marital status was performed in order to test the relationship between the variables of: social support and QoL measures, social support and depression measures, and QoL and depression measures. Scalar variables that had asymmetric distribution underwent logarithmic transformation for this analysis. The level of significance was set at 5% (p<0.05).

**RESULTS**

The study sample consisted of 115 participants with median age of 68 years (59.0-76.0), and the education median was four years of study (2.0-5.0). Regarding individual monthly income, the median was one minimum wage. In relation to gender, 64.3% of the participants were females and 35.7% were males, and 50.4% declared being white. Regarding marital status, 64.3% are married or in a consensual/stable union, and finally in relation to occupation, 62.6% are retired.

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Regarding clinical data, 60.9% of the participants had diabetes (34.8%) or diabetes associated with other pathologies (26.1%). In addition, 12.2% have cancer and 5.2% have stroke sequelae. Concerning the presence of comorbidities, 76.7% reported systemic arterial hypertension (SAH). Regarding the presence of a caregiver, 69.6% reported having caregivers, of which 31.3% were spouses and 24.3% were their children.

The result obtained by the QoL scale indicated a mean value in the functional subscale of 51.8 (SD=21.2). The subscale mean related to the presence of physical symptoms was 43.4 (SD=20.5), and finally the Global Health Status subscale mean was 68.1 (SD=29.3). Cronbach’s alpha of this instrument in the present sample was 0.6.

Regarding social support level, the median found was 78.0 (63.0-91.0), ranging from 27 to 95 points. Regarding an analysis of the results by social support dimensions, the following parameters were found: positive social interaction and affective support with a median of 29.0 (23.0-34.0), emotional and information support with a median of 32.0 (25.0-38.0), and material support with a median of 19.0 (14.0-20.0). The maximum scores for the respective dimensions are: 40, 35 and 20 points. Cronbach’s alpha of this instrument in the present study was 0.9.

Regarding an evaluation of the presence of depression symptoms assessed through the application of the CES-D, a median of 23.0 (14.0-32.0) was obtained, ranging from two to 49 points, meaning that 88.7% of the 115 participants had depression symptoms. Cronbach’s alpha of this instrument in the present sample was 0.8.

Comparison tests of the distribution of QoL measures (total score), social support and depression were performed with the variables of gender, presence of caregiver, diagnosis, occupation and marital status (Table 1).

Therefore, higher QoL scores were found among women. Men presented higher median scores for social support measure and lower depression symptoms. We also found that higher levels of social support were present in patients with presence of caregiver and in married patients (Table 1).

Table 2 presents the results of the Spearman Correlation test between the variables of QoL, social support, depression and age.

When analyzing the presence of possible relationships between the variables of Global QoL, functional QoL, symptom-related QoL, social support, depression and age, education, number of children and functional capacity as shown in Table 2, we found that the greater the age, the greater the Global QoL (weak correlation), whereas the shorter the education, the better the Global QoL (weak correlation), and the higher the income, the greater the Global QoL (weak correlation).

Table 3 shows the coefficients of partial correlation between the variables of social support, depression, Global QoL, symptom-related QoL and functional QoL, controlled by the variables: age, gender, number of children, education and functional capacity.

### Table 1 – Results of tests comparing the distribution of the measures QoL, social support and depression with the variables of gender and presence of caregiver – Minas Gerais, Brazil, 2015.

<table>
<thead>
<tr>
<th>Variables</th>
<th>QoL*</th>
<th>Social support**</th>
<th>Depression**</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>p</td>
<td>Median (p25-p75)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (n=41)</td>
<td>34.8 (6.9)</td>
<td>&lt; 0.001</td>
<td>86.0 (77.0-95.0)</td>
</tr>
<tr>
<td>Female (n=74)</td>
<td>39.7 (6.2)</td>
<td></td>
<td>72.5 (60.0-95.0)</td>
</tr>
<tr>
<td><strong>Caregiver</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (n=80)</td>
<td>38.1 (6.6)</td>
<td>0.821</td>
<td>85.0 (72.5-95.0)</td>
</tr>
<tr>
<td>No (n=35)</td>
<td>37.8 (7.4)</td>
<td></td>
<td>66.0 (58.0-95.0)</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer (n=18)</td>
<td>39.8 (6.9)</td>
<td>0.266</td>
<td>82.5 (67.0-93.0)</td>
</tr>
<tr>
<td>Not cancer (n=97)</td>
<td>37.8 (6.9)</td>
<td></td>
<td>77.0 (62.5-90.0)</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired (n=89)</td>
<td>37.9 (7.1)</td>
<td>0.671</td>
<td>78.0 (62.5-89.5)</td>
</tr>
<tr>
<td>Not retired (n=26)</td>
<td>38.6 (6.5)</td>
<td></td>
<td>79.5 (65.7-92.2)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married (n=74)</td>
<td>37.5 (6.6)</td>
<td>0.181</td>
<td>81.5 (66.7-93.0)</td>
</tr>
<tr>
<td>Not married (n=41)</td>
<td>39.3 (7.4)</td>
<td></td>
<td>72.0 (58.0-86.0)</td>
</tr>
</tbody>
</table>

Note: *Student’s t-test **Mann-Whitney test
The results of this study indicate that PC integrates PHC’s health needs and demands, and because they promote QoL of patients and their families in the process of coping with life-threatening diseases, it is necessary to prepare health units to deal with this new care scenario. Palliative Care prevents and alleviates patient suffering through early identification, evaluation and appropriate treatment of pain, as well as physical, psychosocial and spiritual problems, and it is essential to guarantee comprehensive care. Thus, an important challenge for implementing PC in PHC is adequate patient assessment, including identifying parameters to support diagnosis, incorporating methods and the team’s preparedness in order to increase the resolution capacity of PHC units. Therefore, the use of instruments to evaluate QoL, social support and depression constructs can be useful in assisting patients with the indication of PC in PHC services, expanding the clinical care and care reach, mainly by the nursing team.

The results regarding the clinical data and the characterization of the sample indicate that 88.7% of the patients that participated in the present study had depression symptoms. It is known that depression states, either due to prevalence or to their consequences, have significant importance as a public health problem. Specifically in the context of PC, studies indicate that the prevalence of psychiatric diseases is strongly associated with pain level and the functional capacity of patients. It is believed that psychological morbidity significantly impairs the patient’s activity, mood, sleep, and relationships, which reinforces the importance of assessing mental health in these individuals.

Regarding comparison tests that suggest a higher level of social support in patients with the presence of caregiver, no studies with similar results were found that have been performed in patients under PC; however, it is suggested that due to the fact that the diagnosis of a chronic disease causes life threatening, uncertain and stressful feelings in patients, the role of family members becomes paramount by encouraging psychological adjustment, as well as by helping to manage the symptoms caused by the disease. There is evidence that increased availability of social support positively influences biological systems, the overall health status, and psychological well-being of patients. Thus, the inclusion of other people in the care to support control of the adverse effects of the disease can benefit the patient’s adaptation and adjustment to the new health situation. Thus, it is important to stress that caregivers and family members are advised on the importance of their care in order to guarantee social support to the patient in PC, which is a function of the family health team, even when they are not directly responsible for the PC.

In this study, it was also found that higher levels of depression symptoms are associated with lower levels of QoL and social support. Corroborating the results found in another study that had the objective of investigating whether depressing mood had an influence on social support and QoL measures in elderly patients, it was found that those...
with better levels of social support present a lower number of depression symptoms, and therefore, social support is considered to be an important factor capable of protecting or predisposing a person to a depressing mood, consequently affecting their QoL\(^{[9]}\). Results such as this suggest the importance of new studies on the benefits of psychosocial assessment of patients under PC, in order to guarantee expanding care and thus improve the QoL of these patients\(^{[29]}\).

Regarding the association between depression symptoms and female patients, a study conducted to investigate the association between genetic factors and depression pointed out that women are on average twice as likely as men to have episodes of depression. However, despite the existence of justifications related to genetic, neuro-hormonal and psychobiological aspects, it is believed that due to the lack of data regarding the actual number of patients affected by this clinical diagnosis, investigations about the characteristics of this disease are limited, thereby highlighting the importance of new studies on this prevalence in the present day\(^{[23]}\).

Regarding the relationship between a higher level of social support in male patients and in married patients, a study with the objective to measure the social support available to cancer patients also found that men had a greater perception of support in most dimensions\(^{[24]}\). Still, it is important to point out that in dealing with patients with stable marital status, males are more likely to receive care and support from their wives than the opposite, meaning that men may feel more protected against a chronic illness compared to women\(^{[24-25]}\). In fact, 80.5% of the men in this study were married, and therefore more likely to receive care.

Regarding the results in which higher levels of QoL were identified in females participants, no studies with similar results were found. However, it should be noted that a study aimed at assessing the QoL of elderly people from different cultures including Jewish and Muslim subjects identified that men had a similar profile to women in most of the dimensions related to QoL, except for the physical and emotional functioning domains, where women presented lower levels\(^{[26]}\). Despite these results being different from those found in the present study, it is important to consider that the perception of health-related QoL is not only influenced by clinical symptoms such as pain and functional capacity, but rather by sociodemographic factors and cultural aspects, including the perception of health, illness and old age concepts\(^{[27]}\). This may explain the divergence of the results, evidencing the need for studies that comparatively evaluate QoL in different populations and cultures.

In relation to the association between higher levels of QoL and people with advanced age, a study with the objective to evaluate QoL in 625 patients with Acquired Human Immunodeficiency Syndrome (AIDS) found higher levels of QoL in patients aged over 47 years. These results may be justified, since due to their own experience of life, older people are less anxious about future events, including death and dying, and thus they suffer less impact from the chronic disease in their intimacy and QoL\(^{[28]}\). Still, although this study was not specifically performed with patients under PC, it is known that AIDS is a PC-eligible disease and has significant repercussion in young adults\(^{[29]}\).

As limitations of this study we can point out the difficulty in finding validated instruments in Brazil for patients who are receiving PC. Although the QoL scale used is specific for PC, it is focused on oncology patients. Thus, the importance of new methodological studies that aim at constructing and validating new instruments that are not specific for cancer patients, thus incorporating the broad concept of PC according to WHO.

**CONCLUSION**

It may be concluded through this study that higher levels of social support are related to patients with better global and functional QoL. On the other hand, lower levels of QoL due to the presence of physical symptoms are related to worse levels of social support. Moreover, worse global QoL is related to higher levels of depression symptoms. We can also conclude that higher levels of QoL are associated with female patients, people with higher age, lower education and higher income, as well as higher levels of social support to males, to patients who have a caregiver and who are married. Higher levels of symptoms of depression were associated with women. Thus, we believe that the present study contributed to define the profile of patients eligible for PC within the framework of PHC regarding psychosocial aspects, so that nursing can be holistic and not only considering the physical needs of the patients in PC, thus seeking greater PHC effectiveness.
RESUMEN

Objetivo: Analizar la relación entre apoyo social, calidad de vida y depresión en pacientes elegibles para cuidados paliativos atendidos en la Atención Primaria a la Salud de un municipio en el interior de Minas Gerais, Brasil. Método: Estudio transversal correlacional, realizado con pacientes atendidos en seis unidades de atención primaria a la salud. Los datos fueron sometidos al análisis estadístico descriptivo, pruebas de diferencias entre medias y medianas y pruebas de correlación. El nivel de significancia adoptado fue 0,05. Resultados: La muestra fue compuesta por 115 participantes, y se identificó que cuanto mayor el apoyo social, mejor es la calidad de vida global (p<0,001) y funcional (p=0,035); cuanto mayor sea la presencia de síntomas físicos, menor el nivel de apoyo social (p=0,012) y mayor el nivel de depresión (p=0,001); cuanto mayores los síntomas de depresión, peor es la calidad de vida global (p<0,001), funcional (p<0,001) y menores los niveles de apoyo social (p<0,001). Conclusión: Los niveles de calidad de vida, apoyo social y depresión de pacientes elegibles para cuidados paliativos son influenciados por factores socioeconómicos, tales como estado conyugal, sexo, edad, renta, escolaridad y presencia de cuidador.

DESCRIPTORES
Cuidados Paliativos; Calidad de Vida; Apoyo Social; Depresión; Atención Primaria de Salud; Enfermería de Atención Primaria.

REFERENCES


