

Bioethics and palliative care: decision making and quality of life*

Bioética e cuidados paliativos: tomada de decisões e qualidade de vida

Bioética y cuidados paliativos: toma de decisiones y calidad de vida

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ABSTRACT

Objective: To evaluate the decision-making process and quality of life of adult oncology patients, hospitalized in a palliative care unit. **Methods:** A cross-sectional study, conducted over 12 months, which included 89 patients who agreed to participate by responding to the Psychological-Moral Development, WHOQOL-OLD and WHOQOL-BREF instruments. **Results:** In evaluating the Psychological-Moral Development instrument, patients demonstrated a capacity for making decisions in their best interest. In the domains of WHOQOL-OLD, the *social participation* had the lowest mean, and *intimacy* had the best. In terms of application of the domains of the WHOQOL-BREF instrument, the *physical* domain had the lowest mean, while the *environment* had he best performance. **Conclusion:** Patients demonstrated satisfaction with the capacity to establish social relationships, personal and intimate, even while hospitalized.

Keywords: Bioethics; Quality of life; Decision making; Palliative care; Vulnerable populations

RESUMO

Objetivo: Avaliar o processo de tomada de decisão e a qualidade de vida de pacientes adultos, oncológicos, internados em unidade de cuidados paliativos. Métodos: Estudo transversal, realizado ao longo de 12 meses, incluiu 89 pacientes que aceitaram participar respondendo aos instrumentos de Desenvolvimento Psicológico-Moral, WHOQOL-OLD e WHOQOL-BREF. Resultados: Na avaliação do Desenvolvimento Psicológico-Moral, os pacientes demonstraram ter capacidade para tomar decisões em seu melhor interesse. Nos domínios do WHOQOL-OLD, a Participação social teve a menor média, e a Intimidade, a melhor. Na aplicação do instrumento WHOQOL-BREF, o domínio Físico teve a menor média, sendo o Meio Ambiente o de melhor desempenho. Conclusão: Os pacientes demonstraram-se satisfeitos com a capacidade de estabelecer relações sociais, pessoais e íntimas, mesmo estando internados.

Descritores: Bioética; Qualidade de vida; Tomada de decisões, Cuidados paliativos; População vulnerável

RESUMEN

Objetivo: Evaluar el proceso de toma de decisiones y la calidad de vida de pacientes adultos, oncológicos, internados en una unidad de cuidados paliativos. Métodos: Estudio transversal, realizado a lo largo de 12 meses, que incluyó a 89 pacientes que aceptaron participar respondiendo a los instrumentos de Desarrollo Psicológico-Moral, WHOQOL-OLD y WHOQOL-BREF. Resultados: En la evaluación del Desarrollo Psicológico-Moral, los pacientes demostraron tener capacidad para tomar la mejor decisión. En los dominios del WHOQOL-OLD, la Participación social tuvo el menor promedio, y la Intimidad, la mejor. En los dominios del WHOQOL-BREF, el físico tuvo el menor promedio, siendo el Medio Ambiente el de mejor desempeño. Conclusión: Los pacientes se mostraron satisfechos con la capacidad de establecer relaciones sociales, personales e íntimas, a pesar de estar internados.

Descriptorres: Bioética; Calidad de vida; Tomada de decisiones; Cuidados paliativos; Poblaciones vulnerables

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Acta Paul Enferm. 2012;25(3):334-9.

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INTRODUCTION

Currently, there is a major effort to change the culture of care in the final phase of life. Palliative care is a philosophy and a way of caring that aims to enhance the quality of life of patients and their families facing problems associated with life-threatening illnesses. The objective of palliative care is the prevention and relief of suffering by symptom control⁽¹⁻³⁾ by integrating the Health Sciences with the Humanities⁽³⁾. This philosophy proposes that care should be conducted by a multidisciplinary team and is characterized by the acceptance of the limit of life, with a focus on care rather than a cure⁽³⁻⁵⁾. Thus, nursing professionals are essential in this process.

The palliative care movement as is it understood today began in England in the 1970s, when Cicely Saunders, who had received training in the areas of nursing, social work and medicine⁽⁶⁻⁹⁾, founded Saint Christopher's Hospice. Using the same framework of Saint Christopher's Hospice, a group of nurses from a public hospital in Porto Alegre (RS)⁽⁶⁾ suggested the creation of a palliative care unit (PCU). The PCU in Porto Alegre opened in November 2007 with six beds and was intended for the care of cancer patients without the therapeutic possibility of healing, with the inclusion of their families, to offer individualized care according to the needs of each patient. The unit has a trained multidisciplinary team and a private location that favors differentiated care⁽⁶⁾. Located at a university hospital, the PCU can offer training for professionals and assist in conducting research on palliative care.

Palliative care is defined by the World Health Organization (WHO) as "total and active care provided to the patient whose illness no longer responds to curative treatments and when the management of pain and other symptoms, psychological, social and spiritual, becomes a priority" (2). Presently, PCUs are being implemented in hospital environments in various countries.

In 1999, the WHO⁽¹⁰⁾ advocated the effective control of the pain and symptoms that are common in palliative care as a priority in the public health system. In Brazil, the provision of this type of care is a humanizing initiative that is in accordance with the National Policy of Humanization of Health Care of the Ministry of Health (8,10-12). The guidelines and goals of this policy establish the qualification and humanization of health care by seeking to ensure the connection between the user and the service and is characterized by the supportive care and accountability of the professionals who work in the teams. Thus, palliative care aims at improving the quality of life of patients and their families through humanization; the application of epidemiologic, scientific and management principles during treatment; and information and education for health and care management (10). However, little is known about the quality of life of patients in palliative care; thus, one can ask, how can we assume that all of these actions improve the self-perceived quality of life?

From the perspective of humanization and integrality in health care⁽¹¹⁾, the proposed model attends to the needs of patients who are beyond the therapeutic possibilities of cure, are in the process of death and dying, and are seeking individualized care. The palliative care team should consider the social context in which the patients live, become ill and die. The proposed care considers that a health professional qualified for the care of these patients should aggregate the individual and his family as subjects of death and dying and accommodate their beliefs and values while respecting the patient's autonomy to make decisions regarding his treatment^(7-9,10-13).

The principles of palliative care that provide the basis of this assistive model can be described as follows: Know when death is coming; Keep track of what happens; Preserve the privacy and dignity of the patients; Relieve pain and other symptoms; Choose the place of death; Provide spiritual and emotional support; Control who is present; Take the time to say goodbye; and Depart when the moment comes⁽¹⁴⁾. These principles reaffirm the patient's autonomy as one of the central points in the pursuit of excellence in the nursing care that is provided⁽¹²⁾ and fall into one of the main foundations of bioethics, which is the respect of the individual⁽¹⁵⁾.

Bioethics can be understood as a complex and shared interdisciplinary reflection on the appropriateness of actions that involve life and living⁽¹⁶⁾. Life is mainly understood in its biological dimension, whereas living comprises the relationships between people. Even when the discussion about the preservation of life is no longer the focus, living remains a key issue. Thus, palliative care (particularly the associated decision-making processes) lies entirely within the context of bioethical reflection.

The decision-making capacity of a person is based on several skills, such as the abilities to engage with the subject matter, understand or evaluate the types of alternatives, and indicate a preference. The decision-making process is composed of a number of factors, in particular, the willingness and the ability of the individual to make decisions⁽¹⁷⁾.

Little is known regarding the decision-making process of patients in palliative care, particularly regarding the autonomy of these people. We know that moral-psychological development, rather than chronological age, can determine the capacity for decision-making. There are several approaches to the characterization of psychological-moral development, the evolution of which has generated a proposal to categorize such development into seven different stages, ranging from pre-social to integrated stages (18-21).

Another important issue that is related to this short period of life of cancer patients in palliative care refers to their perception of quality of life^(22,23). Concern regarding the relationship between quality of life and health arose with the beginning of Social Medicine in the 18th and 19th centuries (24). Starting in the mid-20th century, the quality of life variable was used as a health indicator that could be measured by different instruments. In this sense, quality of life is the perception that the individual has of his position in life within the cultural context and the system of values in which he lives relative to his goals, expectations, standards, and concerns⁽²⁵⁾. Quality of life can also be defined as "the patient's perception of his physical, emotional, and social state⁽²⁶⁾". The evaluation of quality of life is personal, subjective, and complex. The individual assesses different variables or domains, such as their health, social relationships, autonomy, housing conditions, work, and other factors⁽²⁷⁾. Certain questions continue to merit a better understanding in the context of caring for patients in palliative care; for example, what is the decision-making ability of these patients? What is the self-perceived quality of life of these patients during their hospital stays? Faced with such questions, the objective of the present study was to evaluate the decision-making process and the quality of life of cancer patients in an advanced stage of the disease and the therapeutic possibilities outside of healing while interned in the palliative care unit.

METHODS

A transversal study with a quantitative approach was performed over a 12-month period with adult patients with advanced-stage cancer who were beyond the therapeutic possibility of healing and were interned at the PCU of the Porto Alegre Clinical Hospital (Hospital de Clínicas de Porto Alegre – HCPA). All of the patients were invited to participate in this study and authorized their participation by signing a term of free and informed consent. This invitation was extended to each new hospitalization.

A total of 89 patients were included in the study. The sample size, estimated at 86 patients, was obtained with the use of EPI-INFO 3.4.3 for a 95% significance level. In the study database, the names of the participants were not linked to the obtained results.

Demographic information such as age, gender, and years of study was collected, and instruments on the quality of life and decision-making capacity were applied during the patients' hospitalization. Due to the advanced stage of the patients' disease (Karnofsky performance status scale less than or equal to 40%), the patients were given the freedom to take breaks during

the application of the instruments and resume at will. Not all of the patients finished responding to the three instruments; thus, the incomplete instruments were excluded from the study. Previously trained research assistants performed the data collection.

The patients' decision-making ability was evaluated using the Psychological-Moral Development instrument (28). This questionnaire allows the classification of each person into one of six stages of psychological-moral development: Impulsive; Opportunist; Conformist; Conscientious; Autonomous; and Integrated (20). A person is regarded as morally unable to make decisions in their best interest when classified in the Pre-social, Impulsive, or Opportunistic stages. The Pre-social stage is not evaluated by this instrument because there is a continued presence of demonstrations by means of language at this stage.

The patients' quality of life was evaluated using the WHOQOL-BREF⁽²³⁾ and WHOQOL-OLD instruments ^(22,23). In these instruments, the evaluation of the scores is based on the results of each domain, which increase from 1 to 100; higher scores indicate a better perceived quality of life.

The WHOQOL-BREF instrument is the abbreviated version of the WHOQOL-100 instrument, which assesses the quality of life of young adults. Its structure comprises four domains: Physical (the patient assesses pain, discomfort, fatigue, sleep, mobility, drug dependency, and work capacity); Psychological (negative and positive feelings, thinking, learning, self-esteem, body image, and spirituality); Social Relationships (personal relationships, social support, and sexual activity); Environment (physical safety, physical environment, financial resources, health care, information, recreation, and leisure and transportation); and an overall score⁽²³⁾. Several analyses were performed during the validation of this instrument in which we emphasize the overlapping physical and psychological domains(23).

The WHOQOL-OLD instrument was developed to assess the quality of life in older people. Its structure comprises six domains: Sensory Performance (the patient examines the impact of sensory impairment in their daily quality of life and the extent to which such impairment interferes with participation in activities and the ability to interact); Autonomy (independence, the ability and freedom to live unattended and make their own decisions); Past, Present, and Future Activities (satisfaction with accomplishments in life and goals to be achieved); Social Participation (participation in the activities of daily living, especially in the community); Death and Dying (concerns and fears about death and dying); Intimacy (being able to have personal and intimate relationships); and a total score^(22,23).

All three instruments are validated for the Portuguese language spoken in Brazil, and the authors' consent for use in research was obtained.

The collected information was stored in a database, without identifying the subjects, in the SPSS (PASW) system, version 18. The data are described by their measures of central tendency and variability. Inferential statistical analyses were conducted. The significance level was established at 5% (P<0.05).

This research project was approved by the Ethics in Research Committee of the institution (GPPG 08215).

RESULTS

The sample was composed of 89 patients and contained 51 (57.3%) females with ages ranging between 25 and 83 years, a mean of 53.22±11.13 years, and a median of 52.0 years; the sample contained 38 (42.7%) males with ages between 25 and 85 years, a mean of 58.47±13.76 years, and a median of 62.5 years. The age of the men was significantly higher than the age of the women (F=3.97; p=0.049).

The mean number of years of schooling was 7.14±3.71 years, and the median was 8 years. Most patients (67.2%) presented between 1 and 8 years of schooling. An additional group of patients (21.4%) attended between 9 and 12 years, which is the equivalent to high school. The remaining patients reported no schooling (5.7%) or more than 12 years of school (5.7%).

In the evaluation of moral-psychological development, no participant was classified under the Pre-social, Impulsive, or Opportunistic stages. Patients were classified in the Conformist, Conscientious, and Autonomous stages at frequencies of 9.3%, 64.0% and 26.7%, respectively. No patient was classified as being in the Integrated stage.

In the evaluation of the WHOQOL-BREF domains, the Physical domain had the lowest mean (34.23%), and Social Relations had the best performance (67.87%). The other domains showed intermediate values (Table 1).

In the WHOQOL-OLD evaluation, the Social Participation domain had the lowest mean (45.71%), and Intimacy had the best performance (80.70%). The remaining domains presented intermediate values (Table 2).

Table 1. The measures of central tendency and variability of the WHOQOL-BREF domains in a sample of patients in palliative care (n=68)

| Domain | Minimum | Maximum | Mean | Standard deviation | Confidence interval |
|----------------------|---------|---------|-------|-----------------------|---------------------|
| Physical health | 0.00 | 67.86 | 34.23 | 15.28 | 30.65 – 37.81 |
| Psychological | 8.33 | 91.67 | 56.43 | 17.59 | 52.25 - 60.61 |
| Social relationships | 16.67 | 100.00 | 67.87 | 18.32 | 63.55 – 72.19 |
| Environment | 37.50 | 93.75 | 64.03 | 12.61 | 61.06 - 67.01 |
| Global | 0.00 | 100 | 54.16 | 25.44 | 48.29 – 60.04 |

Table 2. The measures of central tendency and variability of the WHOQOL-OLD domains in a sample of patients in palliative care (n=68)

| Domain | Minimum | Maximum | Mean | Standard deviation | Confidence interval |
|-------------------------------------|---------|---------|-------|-----------------------|---------------------|
| Social participation | 0.00 | 87.50 | 45.71 | 22.93 | 40.22 - 51.20 |
| Death and dying | 0.00 | 100 | 51.10 | 30.50 | 43.85 – 58.35 |
| Performance of the senses | 6.25 | 100 | 57.17 | 25.85 | 51.02 - 63.31 |
| Autonomy | 25.00 | 100 | 60.85 | 15.86 | 57.08 - 64.61 |
| Past, present and future activities | 18.75 | 100 | 67.37 | 16.41 | 63.47 – 71.27 |
| Intimacy | 12.50 | 100 | 80.70 | 18.60 | 76.28 – 85.12 |
| Total | 23.96 | 87.50 | 60.49 | 12.72 | 57.45 - 63.54 |

DISCUSSION

These results cannot be generalized because they relate to a particular situation and to a sample of patients.

In the results of the Psychological-Moral Development instrument, all of the inpatients in the PCU exhibited a full capacity to adequately make decisions regarding their best interest because they were classified in the Conformist, Conscientious, and Autonomous stages and were thus able to exercise their right to autonomy regarding therapeutic treatments and limitations⁽²⁸⁾.

Regarding the self-perceived quality of life, the results obtained for the **Physical** domain (34.23%) were predictable because it was expected that the perceptions of inpatients with very serious conditions, whose best Karnofsky performance status was 40%, would be unsatisfactory. We know that various physical signs and symptoms affect patients with a status of 40% or less, which explains this result. It is worth noting that this area was the only domain with a minimum value of 0.0% and a lowest maximum value of 67.86%, thereby confirming our expectations.

The results with respect to the **Psychological** domain (56.43%) were unexpectedly positive: the confidence interval did not overlap that of the Physical domain (22), suggesting that the seriousness of the health condition and the proximity of death did not have the expected effect.

The results regarding the **Social** domain (67.87%) were influenced by the following factors, all of which were implemented in the institution where the study was performed: the patients' autonomy; authorized visits, including those of children; the encouragement of visit by their religious leaders; aid in organizing commemorations of the patients' interests; and the fact that they consistently had a relative or a friend present.

The **Environment** domain result (64.03%) is justified by the physical structure of the PCU and the encouragement for patients to bring personal items that make their room an extension of their home. The PCU also offers a multi-purpose room, which is furnished for the use of patients and family members. We believe that these factors may have favored the perception of the quality of life of patients in this domain.

The **Global** score of the sample was of 54.16%, which represented the level of the patients' self-perceived quality of life based on the WHOQOL-BREF instrument.

The result of the **Social Participation** domain (45.71%) was the second lowest among all of the domains because it addresses the specific evaluation of daily life in the community, which was hampered by the hospital internment. However, the result could have been lower, and several patients were admitted for less than 2 weeks. At the end of the patient's life, relation-

ships tend to turn to an inner circle, which is typically the family unit⁽⁸⁾. Regarding the **Death and Dying** domain (51.10%), this result stands out as a positive result because, with the approach of death, the patients presented scores showing little concern about this topic. This attitude can be attributed to the fact that they feel free to talk with various professionals on the subject of death and the team's concern with promoting their comfort. Another important factor was the confidence in their desire not to be transferred to an intensive care unit, where they might die without the warmth of those close to them.

The good result obtained in the **Performance of** the Senses domain (57.17%) exposes a correlation with the proper management of pain and other symptoms. This issue deserves further study because this type of management might have allowed the patients to participate in activities and maintain the ability to interact with others. Thus, it was expected that patients would have a worse perception of this domain because the progression of the disease (Karnofsky performance status less than or equal to 40%) causes significant changes in various organs and senses. Several authors have noted that pain is the main complaint of patients and profoundly limits their daily activities (1-3,5,8,10,14).

The **Autonomy** domain (60.85%) demonstrates the extent to which patients feel free and respected to make their own decisions. Despite the seriousness of their health condition, the patients have the ability to make decisions about their treatment, which directly impacts his perception of autonomy. This autonomy may be facilitated by the flexibility of the care, particularly by the nursing staff, with regard to arranging visits from adults and children and the scheduling of working routines, which are organized jointly with the patient (12,27).

The domain **Past, Present and Future Activities** (67.37%) showed a great result, which can be related to the work with these patients to highlight their achievements, encourage them to engage in various activities and develop feasible and short-term objectives.

The best result was observed for the Intimacy domain (80.70%) and is likely related to the characteristics of the PCU, such as offering individual rooms, encouraging the presence of family members chosen by the patient, and determining the medication timetable by common agreement whenever possible.

The sample **Total** score was 60.49%, a result that represented the degree of the patients' self-perceived quality of life based on the WHOQOL-OLD instrument. Notably, although the patients were admitted due to the advanced and incurable state of their illness and, in most cases, without the possibility of returning home, they still experienced a good self-perceived quality of life.

The use of the two instruments, WHOQOL-BREF and WHOQOL-OLD, offered a broad evaluation of the patients' self-perceived quality of life. The WHOQOL-OLD instrument highlighted several important domains: Death and Dying; Performance of the Senses; Autonomy; Past, Present and Future Activities; and Intimacy. The WHOQOL-BREF instrument highlighted the Psychological and Environment domains as being important. The Global score of the WHOQOL-BREF (54.16%±25.44) and the Total score of the WHOQOL-OLD (60.49%±12.72) instruments presented consistent results, thereby strengthening the notion of complementarity between the instruments.

The involvement of palliative care patients in decision-making can be assessed by the capability shown by all of the study participants and the result obtained in the WHOQOL-OLD Autonomy domain, which presented a score of 60.85%. These data demonstrated the consistency of the results obtained in the two different research tools and of the proposal for palliative care, both in theory and in practice.

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CONCLUSIONS

The in-patients at the HCPA-PCU have the demonstrated capacity to make decisions in their best interest. On the quality of life assessments, the best results were in the Social Relations, Environment, and Intimacy domains, emphasizing the characteristics of the care provided to these patients. The results demonstrate the importance of offering this new type of care with the purpose of allowing patients to actively participate in decision-making and have the possibility of a suitable living experience in whatever little life remains.

The unit proposed and created by the initiative of the nurses in this hospital provides a differentiated service to facilitate results that are better than expected for the patients' self-perceived quality of life and thus achieve the goals of its implementation.

This study may offer a framework for different services that offer palliative care, thereby expanding this subject area, and it may be used for comparative studies between the results of this and other studies previously conducted using the same instruments.

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