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NURSES' PERCEPTION REGARDING PALLIATIVE PATIENT REFERRAL

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Abstract

In order to provide patients with the full potential of the National Integrated Continuing Care Network it is necessary for all professionals involved in the referral process to realize their true role and inherent competencies in order to provide rapid and effective response in view of the high number of patients requiring palliative care. The aim of this study is to analyze the difficulties that nurses face throughout the patients' referral process, in the hospital context. The study involved fourteen nurses who exert functions in wards where this process is used. We decided to conduct a descriptive exploratory study, the data was obtained through the use of semi structured interviews. The majority of nurses interviewed did not present training in palliative care (71.4%) or training to complete the referral survey (71.4%). The factors that compromise the effectiveness of the referral process are factors related to the multi professional team (57.1%) and factors related to the functioning of the National Network for Integrated Continuous Care (49.8%). In general, nurses find several difficulties in the process of referring patients, reinforcing the need for intra hospital training regarding multiple themes. Multiple difficulties regarding the communication between the professionals involved in the referral process were also observed.

Keywords: Referral and consultation, palliative care, nursing.

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1. Introduction

The increase in average life expectancy and incidence of chronic and degenerative pathologies has become a national reality, needing a special focus. In this context, palliative cares emerge, with a special focus on the patient, but also on the family and their social circle.

Despite the knowledge and acceptance of palliative care in the Health professional practice, the response capacity for the palliative patients is scarce, due to the unavailability of teams and units in the diverse health services and to the under sharing of palliative care related theoretical knowledge. The incapacity to provide answers is, mostly, related to the referral process where the multidisciplinary teams are integrated. The weak formation in palliative care ends up as a limitation, where the appointed health professional is the main barrier to the referral process, due to the partial or complete misunderstanding of the whole process or how to perform it effectively, quickly, rigorously and with quality (PNCP, 2010, p. 11).

The palliative care philosophy has been developed through the years as a response to the emerging needs of an ageing society, allied to the increase in chronic diseases as well as a depersonalization of the process of caring for the person/family at the end of life.

Terminal illnesses are associated to a set of problems that go beyond the physical symptoms, involving also psychological, social and spiritual aspects, the condition of suffering of different intensities to those who live it.

Palliative cares are an organised response to these problems, actively caring for and supporting the patients and family on the final step of their life with the main goal of ensuring their quality of life. In palliative care, the concept of quality of life is often associated with the concept of dignity, the last involving aspects ranging from physical comfort to the patients' consideration of their psychological, spiritual, cultural and social perspectives, being thus, a multidimensional, individual and subjective concept (Dias, 2012, p. 23).

Palliative cares affirm life and face death as a natural process, not aiming to provoke or delay it, either through euthanasia or inadequate "therapeutic obstinacy"; they have as a central goal, the well-being and quality-of-life of the patient; which is the reason why it should be made available to all who face that finality, without aggressive measures not focused on quality-of-life. (Barbosa & Neto, 2006, cited in Silva, 2014, p. 7).

According to the same authors, palliative care promotes a global and holistic approach to the suffering of patients, so more emphasis should be placed on the training of nurses to provide care, in all its dimensions, for the patient.

The doctor, the nurse and the social worker are the basic elements of the palliative care team, but other contributions are desirable, always being considered according to the needs of the patient - family binomial. Palliative care is offered based on needs and not only on prognosis or diagnosis and can be introduced at earlier stages of the disease, whatever it may be, when the suffering is intense and other therapeutics, whose purpose is to prolong life, are being used.

Palliative care aims to be a rigorous intervention in health care, so it uses scientific tools and is integrated into the health system and should not exist on the fringes of it (Barbosa & Neto, 2006 as quoted in Silva, 2014, p. 7).

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The same authors also mention that there are classically four areas or dimensions to be considered in palliative care, namely: symptom control; appropriate emotional support and communication; family support and multi and interdisciplinary teamwork.

These four strands should be viewed from a perspective of equal importance, as it is not possible to practice quality palliative cares if any of these are underestimated. It should then be emphasized that by properly controlling the symptoms, it may favour both quality and quantity of life. The rigor and quality of the work of the technicians will have an evident translation in the level of well-being of the patients (Neto, 2006 as cited in Silva, 2014, pp. 7-8).

The National Plan for Palliative Care (PNCP) is based on the need to provide adequate responses to the characterization of the Portuguese population, close to the patients' residence, in order to ensure care in view of the complex situation of the patient's clinical condition. Its general objectives are: easy access to palliative care; the provision of differentiated palliative care; ensuring the quality of the organization and providing care; the promotion of equity and the creation of conditions to increase the training offered in this area to all health professionals. It defends the principle of equity inherent to resources, access and use of services (PNCP, 2010).

To achieve these goals, the PNCP defines three types of responses: community support teams in palliative care, inpatient support teams in palliative care, and palliative care units.

Bernardo et al., (2016) analysed, through a SWOT analysis, palliative care in Portugal, identifying the main aspects related to it, defining the inadequate training of team professionals and bureaucracy as weaknesses and constraints in palliative care, and delays in the process of patient referral, among others.

The same authors also recommend that the referral should begin in the different hospital services, through the elaboration of programs or protocols that sensitize and facilitate the identification of criteria for the intervention of the intra hospital support teams in palliative care or community teams in palliative care.

Referral to palliative care units arises from the need to provide the best care to palliative patients, especially when curative treatment does not have benefits. This same referral should be made early, allowing these patients to be accompanied by the multidisciplinary team so that their real needs are met, as well as those of their family (Dias, 2012, p. 18).

Referral to palliative care units is fundamental to allow continuity of care, and lack of continuity results in a reduction in the quality of care provided.

One of the specific criteria for admission to these units is the dependency situation of a patient with severe and advanced or end-stage disease due to oncology or not, who do not present a favourable response to the therapy prescribed for the basic pathology (Directive Technique No. 1 / UMCCI / 2008).

It is addressed to all patients with severe, progressive and incurable pathology, with no possibility of a favourable response to a specific treatment, with intense, multiple, multifactorial and unstable signs, with a life prognosis of less than 6 months and that causes significant impact on the patient, family or caregiver (Dias, 2012, 36).

It is therefore recommended that the discharge of a hospitalized patient be prepared from the first day of hospitalization in order to allow continuity of care.

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According to Ribeiro et al. (2014), the experience of palliative care by professionals is essential to avoid incidents or errors in the process.

In order to achieve this goal, the identification of patients with an indication to integrate palliative care should occur as early as possible, allowing the patient to receive care in an appropriate environment, with material and human resources that promote their dignity and comfort. Currently, most patients in need of palliative care are referred to the team at an advanced stage of the disease, requiring a referral pattern focused on the disease rather than on the actual needs of the patient (Batista, 2016).

The process of referral can be affected by several factors, reducing the effectiveness of the process and reducing the chances of effective action on the patients and their family.

According to Batista (2016), two categories are evident regarding this process: facilitating factors and inhibiting factors of the referral process for palliative care.

Teamwork is a key aspect in the process of referral of patients to palliative care. This process is the result of an interdisciplinary work and the main groups of professionals involved present specific skills that complement each other, allowing a work of excellence with respect for the dignity and comfort of the patient. In this sense, good communication between team members is a facilitating factor. Relationships must be built on the basis of respect for each other's work, respecting the competencies and roles of each element.

Within the interdisciplinary team, all the elements have the same importance and each one provides differentiated contributions and of relevant importance for the referral process. The existence of communication failures among the team members may compromise the whole process of referencing, representing as an inhibiting factor (Fernandes, 2013, p.41).

The presence of ambiguities in the sharing of information may culminate in different interpretations on the part of the elements of the team, triggering conflicts within the team, compromising the quality of the care provided and the whole process of reference. For this reason, the communication within the team should be clear and appropriate to the different circumstances (Fernandes, 2013, p.45).

In order to avoid conflicts within the interdisciplinary team, it is fundamental that each element recognizes their abilities and their competences, valuing teamwork. Conflicts compromise effectiveness, efficiency and quality of the team, with negative repercussions for the team itself and for the patients (Fernandes, 2013, p. 46).

Still according to Batista (2016), one of the inhibitory factors of the referral process is the inadequate training of professionals in palliative care. In recent years, various associations and health institutions have been focusing on the training of their members in the field of palliative care, however, professionals working in non-specialized services in palliative care continue to present low literacy in palliative care.

The Development Plan of the National Network of Continued Integrated Care for the 2016-2019 four-year period advocates that training of all health professionals in the area of palliative care should be used. This training should focus not only on the medical aspects but essentially on the ethical, communicational and support areas of the bereavement process.

Part of this training need concerns the need for in-service training. In-service training includes all learning experiences that help nurses to acquire, maintain and / or increase their competence in

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performing their professional responsibilities, according to their expectations and those of the organization itself (American Nursing Association, 2002 as cited in Fernandes, 2013).

This training should meet the needs of the teams by promoting the implementation of new working methods, the development of new skills and the adaptation of attitudes and behaviours.

Within the multi professional team, the exchange of experiences and knowledge should be valued, taking advantage of these moments of reflection to promote better care (Fernandes, 2013, p.50).]

2. Problem Statement

The increase in the average life expectancy and the incidence of chronic and degenerative pathologies has become a national reality, with a special focus on this issue. It is in this context that palliative care emerges, giving special attention to the patient but also to his family and his social circle. In order to achieve this goal, the identification and referral of patients with an indication to integrate palliative care should occur as early as possible, allowing the patient to receive care in an appropriate environment, with material and human resources that promote their dignity and comfort.

3. Research Questions

[For a better understanding of the subject under study the following research questions were listed:

3.1. What kind of specific training in palliative care have nurses who refer patients?

3.2. What is the nurses' perception of the referral process?

3.3. What are the factors that hinder the referral process?

3.4. What is the perception of the nurses regarding the Intra-hospital Support Team in Palliative care?]

4. Purpose of the Study

[The study aims to identify the difficulties that nurses face throughout the patients' referral process, in the hospital context]

5. Research Methods

[For the development of this qualitative study, we delineated an exploratory descriptive study using a semi-structured interview script. The interview script was validated by an expert in palliative care, whose input served to adjust the script and to gauge the whole process.

Data collection took place from 10 April to 30 May 2017.

Using convenience sampling technique, a group of 14 volunteer nurses who practice in a hospital in the central zone of Portugal was obtained.]

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6. Findings

The findings are reported in the form of tables that provide the responses of the sample to the interview questions. Regarding the training in palliative care that the sample possesses, the responses highlight that 10 of the interviewees do not have any type of training in palliative care, while 2 of the 4 nurses who are trained in palliative care obtained this training in a postgraduate context in the area (see table 1). This shows that the majority do not have training in palliative care, and it is clear that those with training got it both in pré-graduate and post-graduate training.

Table 01. Training in palliative care

Categories	Subcategories	N
Training in palliative care	No	10
	Yes	4

Regarding the training received to fill out the referral survey, 10 of the nurses responded that they did not receive any training for this purpose, while 4 received training in the service context.

Concerning the bureaucracy of the referral process, 12 respondents considered the process bureaucratic; 3 associated this bureaucracy with factors related to its extension; 2 to factors related to filling delay of the survey and 7 mentioned other factors.

The remaining 2 nurses did not consider the bureaucratic process to be slow and time consuming (see table 2).

Table 02. Bureaucracy of the patient referral process for RNCCI

Categories	Subcategories	N
Bureaucratic	Factors related to the extension of the investigation	3
	Factors related to delay in filling	2
	Other factors	7
Non-bureaucratic		2

Analysing the factors that make it difficult to fill out the survey, we conclude that 4 of the respondents considered issues related to the multi-professional team to be the factors that make this process more difficult, since lack of time (1), lack of experience (1) and lack of clarification (1) are the mentioned inhibitory factors.

Of all respondents, 5 also mentioned factors related to the patient, such as lack of patient and family collaboration (2), lack of knowledge about the patient (1), disease progression (1) and difficulty in predicting hospitalization parameters (1).

7 of the respondents mentioned unnecessary information (2), the division into parts (1), the detail / complexity of the survey (1), unclear questions (1) and repeated parameters (1) (see Table 3).

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Table 03. Factors that hamper the referencing process

Categories	Subcategories	N
Factors related to the Multiprofessional team	Inherent to doctors	3
	Related to shift change of nurses	2
	Sick/family/health care professionals	1
	Lack of training in palliative care	2
Factors related to the operation of RNCCI	Extended hospitalization	1
	Excessive bureaucracy	1
	Progression of disease vs. lack of immediate response from RNCCI	1
	Geographical reference	1
	Significant number of patients vs. lack of vacancies	2
	Reference only for terminally ill RNCCI	1
	Absence of description of all symptoms of the patient in the referral survey	1

Regarding the factors that compromise the effectiveness of the referral process, 8 of the respondents considered issues related to the multi-professional team to be the factors that most compromise the process, such as the resistance in referral by the medical team (3) and lack of training of members of the multi-professional team in palliative care (2).

In addition, half of the sample (7) also considered factors related to the RNCCI's operation, except for the excess of bureaucracy in the survey (1) and late referral of patients to the network (1). 1 respondent also mentioned that the referral survey does not include an adequate symptom assessment (see tab.4).

Table 04. Difficulties experienced in completing the referral survey

Categories	Subcategories	N
Difficulties relating to the multidisciplinary team	Medical team	1
	Lack of time	1
	Lack of experience	1
	Lack of clarification	1
Patient-related difficulties	Little knowledge about the patient	1
	Lack of collaboration of the patient/family	2
	Progression of the disease	1
	Difficulty in predicting some parameters in hospitalization	1
Difficulties relating to the reference survey	division into parts	1
	Unnecessary information	2
	thoroughness/complexity	1
	Unclear issues	1
	Repeated parameters	1
Without difficulties		1

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In order to fill some of the gaps evidenced during research, our sample was asked to submit suggestions for improvement to the referral process (see table 5). 8 of the 14 respondents suggested improvements related to the multi-professional team such as: internal training of all professionals (5), palliative care teams (1) and creation of a working group for the completion of the survey (2).

Half of the sample (7) suggested improvements related to the admission survey, with 3 proposing to cancel replication of questions, the subdivision of the platform (1), greater accessibility to the survey by the nurses (1) and the restructuring of the survey (1).

3 respondents also suggested improvements in the functioning of the RNCCI, namely the increase in the number of vacancies in palliative care (1), the progressive evaluation of the potential for the patient to be palliated (1), and the reassessment of patient inclusion parameters in the network.

Table 05. Improvement suggestions for the referral survey

Categories	Subcategories	N
Suggestions regarding the Multiprofessional team	Internal training of all professionals	5
	Most awake teams for palliative care	1
	The inquiry be answered in partnership by the Multiprofessional team	1
	Cross-group creation	1
Suggestions regarding the admissions inquiry	Be more objective/annulment of repeated issues	3
	Stop being so bureaucratic	1
	Platform Subdivision	1
	Accessibility to the survey by nurses to put it directly on the platform	1
	Restructuring of the investigation	1
Suggestions regarding the operation of RNCCI	Increase in the number of beds in palliative care	1
	Initial assessment of the potential for the patient to be palliated	1
	Restructuring of some parameters for patient inclusion	1
Unaware		1

7. Conclusion

Palliative care is progressively expanding and constitutes a key pillar in the provision of health care to patients with this type of pathology. In recent years, a number of studies have appeared on the themes inherent in palliative care; however, the lack of training of health professionals in palliative care constitutes a major obstacle to their development, jeopardizing the whole process of referral and the quality of care that promotes dignity and comfort.

The results of the present study has made it possible to answer the research questions initially formulated and, consequently, to analyse the nurses' perceptions regarding the issues inherent in the referral process, concluding that:

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- Most nurses do not present any type of training in palliative care recognizing the difficulties that the lack of training entails for the provision of excellent care to the palliative patient and making it difficult to develop the entire referral process;

- Currently training in palliative care is being implemented both in the pré and post-graduate context. It is however, a very recent development which is reflected on the numbers.

- Most nurses consider that the referral process is a rather bureaucratic and time-consuming process, pointing out that one of the main factors that inhibits or prolongs the referral process is the resistance of the medical team to referral or the delay that these professionals present in completing the survey;

- One of the major concerns of nurses is the lack of communication between the multidisciplinary team, especially with the medical team;

- The In-Hospital Support Team in Palliative Care should continue to focus on training at the level of the various services in order to make known the objectives of their work as well as the added value of this type of services in the provision of care to the palliative patient.

Given the results obtained, it is a priority to review the entire referral process, namely the survey used, since most nurses consider that this survey does not allow a rigorous and objective evaluation of the patient's clinical situation and its real needs.

In light of this, it is necessary to evaluate the functioning and communication established within the various multidisciplinary teams. The lack of good relations between the team members compromises the entire process of caring and hinders the decision making regarding the treatment and referral of the patients.

It can be concluded that in today's world, with all the health developments and innovations, nurses must maintain a proactive position in the search for knowledge and in the capacity to provide nursing care that encompasses all aspects of patient care.

This investigation had some limitations, namely the sample size, the lack of validation of the interview script which was conceived only for the purpose of this study. Further investigation with more reliable sample numbers and instrumentation is needed to validate the findings of this study. However despite the limitations of the small size of the sample and the self-designed instrument, it is very clear that there is a serious gap in the clarification of the operation of routing networks. Palliative care has undergone several changes in recent years, including the creation and discontinuation of RNCP, which translates into a lack of knowledge on the part of professionals who are unaware of new developments in palliative care.

The issue of referral of palliative patients is currently under-explored and in the future, special attention should be given to the whole process in order to reduce the length of hospital stay in acute hospitals, to speed up the referral process and to allow patients, if this is their will, receive care that promotes dignity and comfort in their home.

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