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ARTICLE CASE REPORT

TEACH NURSING CARE ABOUT PEOPLE IN THE END OF LIFE - EXPERIENCE REPORT

ENSINAR ENFERMAGEM SOBRE CUIDADOS DE PESSOAS AO FIM DA VIDA - RELATO DE EXPERIÊNCIA

ENSEÑAR ENFERMERÍA SOBRE LOS CUIDADOS DE PERSONAS EN EL FIN DE LA VIDA - INFORME DE LA EXPERIENCIA

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ABSTRACT

Objective: to introduce the teaching of nursing care to patients at end of life in the introductory discipline of the course. **Method:** application of the scale of fear of death in beginners of Nursing in introducing the discipline of applied psychology. **Results:** the assessment at the beginning of the course showed unanimity among students of having fear of death, with a slight variation by gender, predominating fear mostly in women, and due to age, less fear among more mature students. **Conclusion:** these results have provided subsidies in guiding selection of educational strategies in line with the characteristics identified in students. The authors propose necessary pedagogical practices to the conduct the teaching to students according to their own characteristics. **Descriptors:** Palliative Care; Fear; Death; Nursing Students; Nursing Education.

RESUMO

Objetivo: Introduzir os ensinamentos de cuidados de enfermagem a pacientes em final da vida na disciplina introdutória do curso. **Método:** aplicação da escala de medo da morte em alunos iniciantes de Enfermagem na introdução da disciplina de Psicologia aplicada. **Resultados:** a avaliação no início do Curso demonstrou unanimidade entre estudantes de terem medo da morte, com discreta variação por sexo, predominando mais medo no feminino, e quanto à idade, menos medo entre estudantes mais maduros. **Conclusão:** Tais resultados forneceram subsídios orientadores na seleção de estratégias educacionais que coadunem com as características identificadas no alunado. As autoras propõem necessárias práticas pedagógicas à condução do ensino de estudantes segundo suas características próprias. **Descritores:** Cuidados Paliativos; Medo; Morte; Estudantes de Enfermagem; Educação em Enfermagem.

RESUMEN

Objetivo: presentar a la enseñanza de los cuidados de enfermería a los pacientes en final de la vida en la disciplina del curso introductorio. **Método:** la aplicación de la escala de miedo a la muerte en principiantes de enfermería en la introducción de la disciplina de la psicología aplicada. **Resultados:** la evaluación al inicio del curso mostró una unanimidad entre los estudiantes de tener miedo a la muerte, con una ligera variación por sexo, predominando el miedo en las mujeres, y en edad, menos temor entre los estudiantes más adultos. **Conclusión:** estos resultados proporcionaron información orientadora en la selección de estrategias educativas que se adapten a las características identificadas en los estudiantes. Las autoras proponen prácticas pedagógicas necesarias para la realización de enseñar a los estudiantes en función de sus propias características. **Descriptores:** Cuidados Paliativos; Miedo; Muerte; Estudiantes de Enfermería; Educación en Enfermería.

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INTRODUCTION

Since the emergence of the profession of nursing has always included in their teaching practice care to people throughout the process vital care at end of life (earthly) in any circumstances the outcome of death.¹

This assertion can be found in the definitions of Nursing explained by pioneering theoretical and Nursing, as Virginia Henderson (1955), which thus defines the profession in his textbook: *"Nursing is basically the aid to the individual (sick or good condition) in carrying out those activities that promote health or its recovery (or peaceful death) that he would alone, if he had the strength, will or knowledge needed."* Madeleine Leininger (1991) defines nursing as *"a profession and a discipline learned scientific and humanistic focused on phenomena and activities of human care to assist, support, facilitate or enable individuals or groups to maintain or regain their well-being (or health) in culturally meaningful and beneficial ways or to help people cope with disability or death."*

On a more philosophical approach, Jean Watson (2002) showed that nursing as a profession suggests tenderness and it has several meanings for people. Such a concept is dynamic and changing knowledge, thoughts, values, commitment and action, with some degree of passion: *"a human science of persons and human health - illness experiences that are mediated by human transactions of caring professional staff scientific, aesthetic and ethical."* Doses of tenderness and passion suggested here certainly are accentuated in circumstances of suffering and death.

Was Wanda Horta (1976), nurse, teacher and theoretical Brazilian, who best defined the face of nursing terminally human: *"Transcending the be-nursing is to go beyond the requirement of" something to do". Being committed, engaged in profession, is to share with every human being under their care experience lived in each moment use therapeutically, is to give warmth, is to engage (without base neurotic) with each being and live each moment as the most important of his profession, transcendence. This assumes a more important binomial life-death".¹*

Drawn from the history of nursing, these examples confirm the traditional humanistic function of watching the outcome of life (earthly) people. Although the end of life care for patients fit to all members of the health team, the nursing staff (nurses, technical and

nursing assistant) is more responsible for the nature of their practical work, care for continuous surveillance, a duty to another, as required by ethical rules of the profession: only let the work shift when delivering to fellow patients under their care.¹⁻² Such a feature of nursing practice, from the perspective of human existence, is a peculiar privilege: attend the closest instance of living of people and accompany them on their farewell to life, sublime experience unconditional solidarity and amortization towards the person who dies, that part.

The reception of patients in a terminal condition by nursing therefore of special contours to meet the multiple needs be they human psychophysical, psychosocial, or psycho-affective spiritual/religious-philosophical in circumstances and contexts also multiple and complex.¹⁻³

The reception of patients or users in health services, current concept emphasized for the proper functioning of the Unified Health System (SUS), is defined as follows: The host should be understood as a guideline ethics, aesthetics and politics constitutive of ways to produce health and technological tool of intervention in listening skills, link building, ensuring access to accountability and problem solving. It is also understood as an action-technical assistance, as it allows analysis of the work process with a focus on relationships and requires the change of the professional / user and their social network, professional / professional by parameters, ethical, humanitarian and solidarity.⁴

Such a general precept, already embedded in nursing, in this particular case is about death, loss, grief and human suffering, a challenge to be overcome in the training of nurses and their professional practice. Even as the thematic part of the curriculum of academic curriculum, transcends the usual methods and instructional strategies for teaching nursing for peculiar situations of nursing practice in the care of people in the face of death, dying and suffering of family members.

Death involves existential philosophical questions of human life. Each being moves according to the values, beliefs, myths, rites, within their familial and cultural history. Anyway, the fact is that the death of people, the actual loss and consequent sufferings represent experiences dreaded, painful and for many people, almost insurmountable.

Philosophizing, reflect on human existence, on the finitude, confronting the desire of eternity and regret our own loss, finally think and rethink, talk about our destinations, as

bad as it seems to us, should still be more desirable than to deny it, hide it, in favor of a life experience more authentic and full.

In terms of training of health professionals, and here in particular of nurses, it is essential to start with the exercise of self-knowledge on the issue of human finitude, as part of education for the care of people suffering terminal. Some surveys of nursing students⁵⁻⁸ in Brazil showed that little is taught on the subject, both in workload as strategic teaching modalities used in three universities. Another cause for concern is the deficiency of faculty, teachers nurses (as), which in the view of students fleeing, possibly unpreparedness of actual teaching situations in practice care terminal patient, preventing students be given the opportunity of education incidental.⁹⁻¹¹ It is therefore urgent to include such training programs of continuing education for nursing faculty.

Aware of such a teaching situation, the authors nursing faculty, sought to introduce teaching of patient care at the end of life, the discipline of Psychology Applied to Nursing students of the 1st semester of Nursing, beginning with a diagnostic evaluation of class, for the purpose of adapting the syllabus to syllabus and teaching-learning strategies according to the characteristics of the students and their specific needs. It was applied a questionnaire assessment of fear of death because it is common among young nursing students fear death^{1, 12-3}, from which it infers their difficulty in drawing close to the patient to pay for his care.

The instrument scale created by Collet-Lester, includes the multidimensional concept of death and fear of death, a demonstration with several probable causes that leads an individual to react differently with attitudes and emotional reactions that can vary in the face of different situations. That said we feel the need to work initially this topic of fear of death in the introduction of thematic care in terminal illness.

In the following section we present the diagnostic evaluation done, their results and the deductions for the development of teaching-learning according to the context of the students and their characteristics and needs revealed.

♦ Evaluation of fear of death and initial proposition of teaching strategy

The scale of fear of death Collette-Lester. This scale originated in the English language, created in 1969 by the authors whose names identified Scale. Suffered successive enhancements to achieve adequate

validity and reliability.¹² This version was translated and validity in Spain, which in turn was subjected to analysis of validity and reliability by applying for nursing students in a city in Chile. The Chileans authors had to scale, adequate content validity and construct and good index of reliability, internal consistency, Cronbach's alpha coefficients between 0,7 and 0,9.

Article and Scale annex is published in a journal of Brazilian nursing.¹³ Is a scale that has four subscales that will provide ample and varied information on the fear of death itself, fear of death of others, fear of the process of death itself and fear of the dying process of others, containing a total of 28 items grouped into four subscales with seven items each and Likert responses can be given ranging from 1 (no fear) to 5 (very afraid). The assessment was based on the total score and partial scores of each of the four dimensions. The highest mean scores indicate greater fear of death or dying process.

Why have adequate psychometric property, the scale-Collette Lester, even only available in Spanish, the faculty authors translated in to Portuguese for didactic purposes and internal use for teaching practice (Annex).

♦ Evaluation of fear of death of nursing students

Nursing students participated in this experiment consisted of 108 students of two classes in the 1st semester of nursing two private colleges functioning in a large city in the north of the country. The data were collected in June 2012, distributing said Scale (attached) in the class at the beginning of a lesson Psychology applied to nursing, and whose completion by students, took around 15 minutes. Data were entered in Excel and its analysis by applying the procedures of descriptive statistics.

The results of this application among beginner students of nursing characterized regarding their distribution by sex in 79,3% of women and 20,7% men. As for age, we observed the distribution of the majority between 20 years and 40 years, with the frequency between 20 and 30 years for like 30 and 40 years. The fact that more mature students are attending the nursing program is a finding confirmed by the direction of the faculties, and is generally those already working as nursing aides or practical nurses, or is workers (occupational) areas related to health, and who seek nursing course for the rise of their professional *status*.

By average total scores obtained by students age stratum of 30 years and over,

representing slightly less afraid of death when compared with the younger students, the stratum of less than 30 years. Mean scores, when broken down by sex observed slight difference of greater indicates a fear of death among women than men although the students have answered the instrument with greater variability of responses than male students.

Deductions for the development of teaching in beginning students.

Timely and useful was the application of the Fear of Death Scale students. By high mean scores obtained indicated that students are afraid of death, regardless of gender, demonstrating that this topic is being worked in teaching primary care in the face of death, starting with the self-knowledge of the students themselves, the future of another caregiver.

When compared between the sexes, there was a slight difference in response less fear among men than women. Such a response, however, should be interpreted with parsimony; it may be masking a possible denial, withdrawal or desire to hide the real feeling of fear of death. With denial or not this feeling, the fear of death should be working with exercises self-providing the student a sense of reality and inner resources for coping with extreme situations such as death and human suffering.

The theme of "fear of death" is wide exploration and inexhaustible, as its complexity is inherent to human existence. However, it is necessary to limit it to specific situations and practices with educational purposes, to teach yourself nursing. Fear death can be seen as part of human survival. Insecurity is normal in situations of life-threatening diseases such as severe accidents, unhealthy or hazardous environments uninhabitable, among others. It is also normal to unrest in the presence of death, because the suffering and death of others to some degree reflect on who watches or observes, possibly causing a foretaste of death itself, hence the trend "natural" to move away from those who are about dying.

Trying to understand and distinguish "my death", "his death", "the death of others" are teachings Kubler-Ross¹⁴⁻⁵ sensitive to train professionals for the care of terminally ill patients and their families. Caring for others means caring for you. The care for themselves as personal exercise represents appropriation of knowledge and truth itself achieved through self-knowledge, skills reaching increasing government itself and away the mental suffering, which could be a reflection

of the suffering of patients. Once instrumented, the nursing faculty, the nurse and nursing student, may best to approach and care for patients who experience fear and pain on the verge of death, as well as their families by providing them sensitive guidance and support needed.

By this student evaluation, we have to consider the manifestations differ between sexes, because educational strategies should also address this. Also, regarding the age of the students, there was a slight difference in mean scores denoting less sense of fear among the age strata more mature than younger people. This finding implies that the experience of life given through the years, especially the more mature students here seem to have learned to face the fear of death, in the exercise of their own work. Therefore, in teaching practice, it is necessary to reveal the selection of appropriate strategies for each age group, as well as focus on horizontal learning and enjoyment by incorporating the experiences of others, in this case, the class of their own colleagues.

♦ The guise of contribution to nursing education in the care of people facing death, dying and bereavement.

The teaching of theories of the process of death and dying, palliative care theories and technologies for care available for the care of patients at end of life^{1,2,16}, is essential, and is routinely taught in classrooms, but are not sufficient. Teach young students about death and dying, pain and suffering, grief and mourning for the loss irreparable, and care about people in such situations, means big challenge for nursing faculty.¹⁶⁻⁷ It should be put at the service of educação¹⁶⁻⁸, their own life experiences moved necessarily conscious process of reflection about human life, the meaning of life, the fate of humanity and other existential questions that are each being different from the other in his way of being and experiencing life, until the last farewell to life (earthly). Such life experiences, however, be acquired at any time, in any stage of development.

It is possible; teachers and students in real engagement exercise self, a personal exercise deliberate reflection of the process of life including finitude. Exercise of self-knowledge leads people to position themselves so true to face existential questions according to their personal and cultural orientations and while humbly recognizing different positions of others. Caring for others means caring for you, the need to do justice to the care

offered. So work the fear of death, for example, in its various dimensions, is essential to become a good caregiver.

It is also appropriate learning experiences with others, so it should be taught seeking advice from professionals with vast experience successful, but also hear testimony from family members (those who accept volunteer for this) who experienced the most diverse circumstances of terminally required and appropriate care. Creating spaces to hear others experiences produces talks to exchange experiences resulting in rich teaching and learning.

What cannot be dispensed is teaching the incidental learning.^{1-2,14-5,17-20} Either by fear or denial of death, students and teachers often escape the real practical situations that require the care of a terminally ill patient, during the traineeship, losing a great learning opportunity actual field to what would be a "natural laboratory" teaching.

The incidental teaching provides opportunities in real time, revise theories appropriate to the situation, experience, share, accept and sympathize with sad or embarrassing own feelings that emerge in the context of caring relationships, discuss and conduct most appropriate channels for communications established between the team and the patient and family, and / or between the family and the patient, analyze and discuss the situation of care and designing early interventions possible and necessary nursing with unrestricted involvement of family members and the patient when possible.

To conclude, it is worth remembering Elizabeth Kubler-Ross¹⁴⁻⁵, pioneering studies on thanatology (1969), which emphasized the need and importance of speaking, listening and discussing death with patients and families and the health professionals that care, because he said it was convinced that the damage would be greater silencing about the real situation to the patient, making prevail the conspiracy of silence surrounding the death. Harmful to all involved, and may, in the future, for example, who was conducting a pathological mourning. Therefore, awareness of death is a fundamental part in the teaching of nursing students and the training of nurses and nursing faculty.

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Annex - Fear of Death Scale Collet-Lester. ¹³

Read each sentence and answer quickly. Don't spend time thinking about the answer. This is to express the first impression of how to think in this moment. Check the number that best represents your feeling.

Which level of concern or anxiety has in relation your own death?	MUCH	MODERATED			NOTHING
1. To die alone	5	4	3	2	1
2. The life be short	5	4	3	2	1
3. All things that you lose when die	5	4	3	2	1
4. To die young	5	4	3	2	1
5. How is it to be dead	5	4	3	2	1
6. Unable to think or try anything ever again	5	4	3	2	1
7. The disintegration of the body after death	5	4	3	2	1
Which level of concern or anxiety has in RELATION TO YOUR OWN PROCESS of DYING?	MUCH	MODERATED			NOTHING
1. The physical degeneration that assume the process of dying	5	4	3	2	1
2. The pain that accompanies the process of dying	5	4	3	2	1
3. Mental degeneration from aging	5	4	3	2	1
4. The loss of mental faculties during the dying process	5	4	3	2	1
5. The uncertainty about my Courage in addressing the process of dying	5	4	3	2	1
6. The lack of control over the process of dying	5	4	3	2	1
7. The possibility of dying in hospital away from friends and family	5	4	3	2	1
Which level of concern or anxiety has in RELATION TO THE DEATH OF OTHERS?	MUCH	MODERATED			NOTHING
1. The loss of a loved one	5	4	3	2	1
2. Have to see his corpse	5	4	3	2	1
3. Not being able to communicate with her ever again	5	4	3	2	1
4. Regret not having lived better with her when still alive	5	4	3	2	1
5. Age alone without the loved one	5	4	3	2	1
6. Feel guilty without the loved one	5	4	3	2	1
7. Feel alone without her	5	4	3	2	1
Which level of concern or anxiety has in RELATION TO THE PROCESS OF DYING OF OTHERS?	MUCH	MODERATED			NOTHING
1. Have to be with someone who is dying	5	4	3	2	1
2. Have to be with someone who wants to talk about death with you	5	4	3	2	1
3. See how that someone suffers from pain	5	4	3	2	1
4. Observe the physical degeneration of your body	5	4	3	2	1
5. Not knowing how to deal with the pain itself before the loss of a loved one	5	4	3	2	1
6. Watch the deterioration of their mental faculties	5	4	3	2	1
7. Be aware that some day also will live this experience	5	4	3	2	1

Note: translation into Portuguese by authors, for the purpose of internal use in teaching practices.