Order of not resuscitating the terminally ill: nurses' ethical dilemmas

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Abstract

Order of not resuscitating the terminally ill: nurses' ethical dilemmas

The article discusses the do not resuscitate orders (DNR), a theme that has raised numerous ethical questions in the course of the provision of health care. Based on research undertaken in two hospitals specialized in oncology in North and South of Portugal, the study aimed to ascertain the main ethical dilemmas raised by the nurses because there is no uniformity on this decision in Portugal. From a sample of 231 professionals, was emphasized the position concerning the decision of performing DNR on the terminally ill, as well as issues about who has knowledge of it, and its recording and re-evaluation methods. In addition to characterizing this process, this study intended to show what was nurses' thought and attitude in relation to DNR patients.

Key words: Do not resuscitate (DNR). Terminally ill. Nursing. Right to die

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We live, currently, in techno-science world, whose evolution achieved extraordinary progress. A new dilemma arises, in consequence, the disthanasia, which affects health professionals' daily practice, nurses among them. This context motivated the present work, guiding it toward the topic: Order of not resuscitating (ONR) the terminal patient.

One felt the necessity to rouse discussion on this topic as well, and because one noticed the lack of guiding lines about ONR in Portugal. Thus, it was elected as objectives to identify nurses' major ethical dilemmas in face of ONR. Therefore, issues associated to decision-making, who has knowledge of it, where it is recorded, and its reevaluation was approached. The work elected as the core point of investigation the answer of the following question: which are the

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nurses' ethical dilemmas facing the Order of Not Resuscitating terminal patients?

Such concern justifies by argumentation already presented and, therefore, due to its pertinence and actuality. It is an issue of level I, whose replies were gotten through submission of questionnaires targeted to nursing professionals who work in internship (medicine, surgery, and continued care) and that, in this condition, often face such reality.

Fundament

With time and toward our more current reality, the vision of death has been changing because our own culture changed as well. In this context, current hospital itself, even in its physical structure, is vacationed essentially toward technological evolution aiming to actively treat the disease. Nevertheless, when this is not possible, and patients approaches death, this same hospital rarely is prepared to care of his suffering at the end of his life [1].

Thus, therapeutic obstinacy arises, although mistakenly, as consequence of the extraordinary progress achieved. This (…) *is considered as the employment or maintenance of diagnostic or therapeutical procedures without existing evidenced efficacy toward positive evolution and improvement of patient's conditions, either in terms of survival or in terms of quality of life* [2]. It is up to health professional who cares for the patient to evaluate his specific situation, and to act according the *leges artis.*

Thus, as Rui Nunes refers, (…) *within the frame of a irreversible and terminal disease, the Orders of Not Resuscitating are ethically legitimate if proposed maneuvers to resuscitate were interpreted as disproportional intervention* [3]. Patient's age seems to have some influence in making this decision also, as shows the work carried out

by Zigmond et all, who evidenced that ONRs are very little noticeable in younger patients (less than 1% in those less than 50 years old) [4].

According to previous description, it seems to be a decision that should be made by assisting physician with collaboration of medical team, nursing team, the patient, and his family. Araújo and Araújo advocate, in this issue, that *the decision of not resuscitate shall be always the competence of a physician, qualified by medical career, and his knowledge about the critical patient after analysis and discussion with other team members* [5]. Concerning patient's participation, Nunes refers that *decision of suspension or of abstention of treatment in a competent patient should be done by actively involving patient in the decision process (if that if his will)* [3]. Regarding nursing team's participation, Saraiva states that *probably they consider that more than power, they should participate in this decision-making because during 24 hours in a day, nurse and patient relate themselves in an intimate and close way, which leads them to feel that, although legally they cannot prescribe, ethically they should be listened* [6].

Other major steps complement ONR decision-making. It is the record, knowledge, and reevaluation of this decision, steps with own specificities. Laureano Santos explains that at *the end of irreversible diseases, there should not be place heart and respiratory resuscitation* (…)*When it is possible to know before hand the situation there is the advantage that the whole team knows the existence of instruction of not resuscitating, which will be decided together, in consensus, noting decision of "not resuscitate" in the clinical process* [7]. Regarding knowledge about ONR, one considers that after decision making, patient and his family should have knowledge of it as well [5]. It is imperative that ONRs should be renewed, documented, and justified daily [2].

This work approached, relatively to nursing role in face of ONR patient, three specific issues: a) conscience objection; b) silence conspiracy; c) nurses' attitude.

Theoretical knowledge accrual that fundament nursing practice has promoted greater autonomy to nurses amidst the multi-disciplinary team. Nowadays, they are acknowledged among peers and other professionals as partners that contribute a lot for patient's well being promotion. Thus, o their right to be conscience objector bases not only in conscience reasons, but, as well, in sound, deep, and updated knowledge [8].

Concerning *silence conspiracy*, the practice still noticed in many work places, the nurse is place in very delicate position, and with few weapons to help patient: in communication of bad news, and specifically in communicating a negative forecast, the information provided to patient is often "limited" by physicians for considering that patient does not desire to know this information or because they consider it as harmful [9]

In face of the diverse set of ethical dilemmas that the end of life evokes, the nurse often feels himself *cornered*. According to Pacheco, (…) *nurse's most common attitude is, then, quite often to distance from patient and from death itself, developing defensive mechanisms and the most diverse scaping behaviors. He limits himself, for example, to provide hasty care, which may help him to control his feelings or to have ritualized and blocking attitudes in the interpersonal relationship* (…) [10].

The unceasing search of denial of approaching death leads to isolation and silence in caring for patients, often isolated, ending, frequently, by dying alone. However, nursing care must go beyond patient's physical body, they must pass simultaneously for his follow up in this hard phase.

Therefore, one concludes that science evolves constantly and nursing, in its turn, has attempted to adapt itself to this evolution. However, ethical dilemmas persist, been often difficult to set an uniform guiding line for its daily practice.

Materials and methods

It is a level I exploratory-descriptive study. To this end, five investigation issues were arbitrated in order to answer investigation initial questioning. These are:

- When is ONR decision made?
- Which are the conditionings of ONR decision-making?
- Who makes the decision frequently, who participates/helps, and who has knowledge of the ONR?
- How ONR is recorded and reevaluate?
- Which are nurses' attitude related to ONR?

Chosen environment to carry out this study was inquired nurses' own working place. The sampling process used was intentional, and inclusion criteria were bases in census for studied group/location, that is, all nurses working in internship (medicine, surgery, and continued care) with terminal patients in a hospital specialized in oncology. It should be highlighted that hospitals specialized in Oncology were chosen for two reason. In one hand, one considered that sample would be very rich, since cancer is the second cause of death in Portugal[11]. One considered, as counterpart, the increase of patients in terminal phase occurring in these units in consequence of technological progress. Thus, two hospitals specialized in oncology were selected in the North and South of Portugal, while one may refer, therefore, that the study was developed in natural.

The sample comprises 231 nurses from these two Oncology centers who exercise functions in internship (medicine, surgery, and continued care). We used a questionnaire, presented in the end, as data collecting instrument. After data collection, we resort to its

treatment by the *Statistical Package for the Social Sciences* (SPSS).

Presentation and discussion of outcomes

Out of the 231 nurses comprising the sample, approximately 82% (190) are female, and 18% (41) male. These figures seem to be in conformity with what normally the literature refers: *majority of historians agreed that Nursing – or the nursing care provided to sick or wounded people – was practiced since human life's origin, and generally, this was a role attributed to women* [12]. It is a very young sample, either in age or in professional activity period, while minimum age is 22 years old, and maximum is 57 years old. Average age is around 30 years (29,93).

This decision, relating to ONR, frequently is made in relation to patients in terminal stage (184 replies). Majority of surveyed nurses (55,4%) considers that patient's age interferes in decision making.

According to literature, decision making should be done through scientific knowledge and complementary exams that show irreversibility of a terminal disease [13], while Bedell et all state that patients indicated to ONR were significantly older [14]. The major aspects considered in decision-making are the scientific confirmation of an advance and irreversible stage of the disease (95.2%; 220 replies), clinical status of patient in that specific moment (62.8%; 145 replies). Also, in accordance to mentioned by Souza (…) *decision should base in clinical and prognostic considerations* [15].

In reference to who makes and who helps in decision of ONR, the collected outcomes indicate that nurses consider that decision was made, in 43.3% (100) of cases, always by assisting physician, with participation and help from medical team (always = 64.1%), by patient when competent (always = 49.4%), from nursing team (always = 40.3%). These outcomes are detailed in tables that follow:

Table I – Frequencies and percentages referring to question *who makes the ONR decision*

Who makes ONR decision	Never		Little frequency		With frequency		With much frequency		Always	
	N	%	N	%	N	%	N	%	N	%
Service Director	88	38,1	90	39,0	30	13,0	17	7,4	6	2,6
Patient's assisting physician	7	3,0	4	1,7	28	12,1	92	39,8	100	43,3
Medical team	19	8,2	24	10,4	52	22,5	74	32	62	26,8
Nursing team	193	83,5	31	13,4	2	0,9	2	0,9	3	1,3

continues

Table I. continued

Other members of multidisciplinary team	202	87,4	21	9,1	3	1,3	4	1,7	1	0,4
Patient (when competent)	140	60,6	77	33,3	9	3,9	2	0,9	3	1,3
Patient's family	157	68,0	68	29,4	4	1,7	0	0,0	2	0,9
Other	228	98,7	0	0,0	1	0,4	1	0,4	1	0,4

These outcomes are in accordance with Araújo and Araújo description, who advocate that *the decision of not resuscitating will be always the competence of a physician qualified by medical career and by his knowledge about the critical patient after analysis and discussion with other team members* [5]. Nunes states, in face of patient's participation, that the *decision on suspension or abstention of treatment in a competent patient should be carried out actively involving patient in the decision process (if this is his will)* [3]. Ballin and Gjersoe verified, in this respect, in a work carried out in Danish nursing wards, that (…) *interned competent patients 'always' were asked in 20 cases (14%), 'frequently' in 34 (23%), 'rarely' in 59 (43%0) and 'never' in 12 (9%) before decision on ONR* [16]. These outcomes, however, are not in disagreement with the finding of our survey.

Table II – Frequencies and percentages referring to question *who participates in the ONR decision making*

Who participate in the ONR decision making	Nevera		With little frequency		With frequency		With much frequency		Always	
	N	%	N	%	N	%	N	%	N	%
Service Director	87	37,7	35	15,2	50	21,6	23	10,0	36	15,6
Patient's assisting physician	19	8,2	2	0,9	14	6,1	48	20,8	148	64,1
Medical team	28	12,1	4	1,7	15	6,5	58	25,1	126	54,5
Nursing team	45	19,5	13	5,6	34	14,7	46	19,9	93	40,3
Other members of the multi Disciplinary team	91	39,4	44	19,0	45	19,5	21	9,1	30	13,0
Patient (when Competent)	41	17,7	14	6,1	32	13,9	30	13,0	114	49,4
Patient's family	58	25,1	28	12,1	45	19,5	27	11,7	73	31,6
Other	229	99,1	0	0,0	0	0,0	0	0,0	2	0,9

Almost the totality of inquired nurses (92.6%) Considers that their opinion should be taken in consideration in ONR decision-making, justifying that:

- "Nurse is an element of the multidisciplinary team that may know better the patient and his family and social context (186 replies);
- "Nurse is an element of health professionals who renders direct care to patient, providing closeness between them (166 replies);
- "Nurse has conditions for patient to share most significant feelings and wills" (145 replies).

According to Susana Pacheco, *it is still the nurse, the health team person who is most concerned in attending patient as an individual, and who learn most from family, more than anyone else, generally knows well the patient, and knows which are his convictions, ideologies, and preferences*[8]. Besides remaining more time in company of patients, they are the team elements that render most direct care, adopting a privileged stand in the team [8]. Study carried out by De Gent verified that in order to make ONR decision appropriately, nurses should be involves since start [17].

Other question set was: *after ONR decision-making, who has knowledge of it. The outcomes collected suggest that majority of nurses consider that assistant physician* (73.6%), the nursing team (70.6%), and the medical team (55%) always have knowledge – however, the remaining members of the multidisciplinary team are informed about this decision with little frequency (30,3%). Regarding the service director, opinions are divided between *never*, with 26%, and *always*, with 21.2%.

According to the literature, in face of a patient in terminal stage, resuscitation is considered frequently as useless treatment [18], thus, the advantage of identifying this situation in due time, and of all team having knowledge of the ONR [7]. Nurses consider that, generally, patients, even when competent, never get knowledge about ONR decision (44.6%) or they have it with little frequency (40.3%), as well as their families. Araújo e Araújo advocate that (…) *the decision of not resuscitate or to suspend RCR measures is a medical judgment that, in our understanding, cannot dismiss information to family, and if possible to patient* [5].

According to majority of nurses (85.3%); 197 replies), ONR is written in medical records, indicating with 80 replies (34,6%) that it is in therapeutical prescription, outcomes that are in accordance to literature, that is, information about ONR should be in the medical records[7]. However, 33 replies (14.3%) indicate that it was *just oral communication*, what is not in conformity with the working standards internationally accepted. The non indication of the ONR in medical opens a gap in the approach to patient by other health professionals, either in an urgency or in the presence of someone that is not aware of this decision.

Such attitude is not considered adequate, since it raises many doubts, and it may lead to therapeutical obstinacy practices due to faulty information transmission, and because it not recorded. That is, the importance of appropriate record of the ONR information allows its use as guidance in view of approach to patient in a cardio respiratory arrest (PCR) by any professional in urgency cases when the professional may not know the patient, which leads him, in these situations, into doubts about patient's situation [2].

It is important to mention that 65.4% of the inquired, or 151 replies, indicated that this decision is not reevaluate a posterior. According to some authors, it is imperative that ONRs be renewed, documented, and justified daily [2].

In order to know nurses' attitudes in relation to ONR, some questions were made. The first questioned what is your acting in case a terminal patient gets a PCR and not have a ONR. The majority of nurses (74.9%; 173 replies) indicated that they counted on urgency/permanence physician, and 36 of the inquired (15.6%) replied that they would not resuscitate the patient. To this end, the majority of authors refer that physician must be the responsible about deciding on ONR. However, these extreme situations should be mitigated, in as much as attempted option of ONR could avoid the anguish of decision in the moment of PCR. Not resuscitating a patient in terminal stage would be possibly the most direct action that would avoid therapeutical obstinacy.

Nevertheless, nurses majorly opt for other attitudes, most probably for considering that they should not be responsible for decision-making. This is, without any doubt, one of the biggest ethical dilemmas connected to the non-resuscitation problematic [8].

It was questioned, also, if in any situation, nurse would have considered that ONR was inappropriate for a specific patient. To this regard, just 20.8% (48) stated yes. By restating the question, asking nurses if they considered that a patient should have ONR, and he did not have one, the picture inverts: 84.8% (196) replied yes. It was possible to perceive that those who stated yes, in both situation, had communicate with other nursing team members (in order to find out their opinion) or they had done it with the multidisciplinary team. Margarida Vieira refers, in this regard, that (…) *one will understand the decision of "not resuscitate", if taken unilaterally by physician who prescribes it, and it may place nurse in face of a dilemma to opt between the duty to comply medical prescription and the duty of acting safeguarding what, in conscience, understand to be the best interest of patient under his/her care* [19].

The majority of nurses (92.2%) considers that even when decision for ONR occurs are made, other disproportional therapeutical measure for the patient, what may be revealing instances that tend to therapeutical obstinacy. These attitudes, which should not taken in favor of the patient himself, are

referenced by a smashing number of surveyed nurses, who indicated use of disproportional therapeutical measures after ONR decision-making. Such situation reaffirms the difficulty that, in practice, one feels in determining what are disproportional, useless, or extraordinary measures for a patient, and the natural trend that there is all to do for maintaining his life, instead of letting the disease to follow its natural course [19,20].

In front of a patient with ONR, the main attitudes described by nurses are: to care for comfort often (58,9%; 136 replies) acting the same way with patient (57.6%; 133 replies), gets involved with patient, communicating with patient whenever possible (43.3%; 100 replies), attempting to provide privacy to patient through physical means (41.1%; 95 replies). Considering what literature evidences in this regard, it is important in these cases to pay attention to what one may denominate as *minimum care*, that is, hygiene and comfort, food, hydration, positions, and massage caring. It is necessary to attempt avoiding, at all cost, patient's isolation, referred in literature as a behavior frequently adopted in hospitals, in which patients are place in isolated rooms or, simply, sliding the curtain – which, often, finishes with patient dying alone [21,22].

Majority of nurses (64.9%) states that never having lied/omitted to patient ONR prescription. According Beauchamp and Childress there is basic obligation of never lying to patient [23]. The justifications of 33;8% of those who replied in opposite direction were: for considering to be the best for the patient - 45 replies; due to family' will, preferring that patient does not know about ONR - 41 replies; for not feeling comfortable to talk about ONR with patient - 26 replies; by patient physician's imposition on not talking about ONR - 11 replies; and because he thought that patient should not be informed about ONR – 11 replies. Actually, as Lanita Pires states, the core of nursing care seems to me been, effectively, the human being, presupposing a relationship based in truth[24], which one intends to be established always with the patient that one cares.

This variable was crosschecked also with the location where the nurse exercises his professional activity. All nurses who worked in continued care state never having lied/omitted to patient when questioned by him about this. As described in literature, the fact that there is greater information transparency in this service makes it easier open and true communication by nurses, as well.

Still, one wanted to know nurse's acting when physician does not communicate ONR to patient, since, according to Marie Hennezel, it is not always that physicians are partisans of truth, or at least, total truth [25]. In agreement with option that nurse stated the truth when questioned by patient, the majority of replies were toward that nurse sought for assisting physician

when he verified patient's insistency in knowing the truth. Such attitude reinforces the perspective that team communication is the best way to act in order to patient be aware of his situation correctly, and that he did not become aware of it by other means.

About this same questioning, it is important to consider, however, that, sometimes, nurse is not able to act in favor of patient, and that telling the truth may cause him problems with other professional classes that he works with [8]. In addition, it was questioned about the frequency with which the nurse used to speak with patient about ONR. In this context, 52.4% of the interviewees (121) replied that with little frequency, and 35.1% (81) that never. The dialogue about death is not easy, and ONR decision is based in this dialogue, which should be open, and information should be transmitted clearly and suitably [2].

Final considerations

Death is one of the most controversial topics in modern and western societies. Cultural, economic, and social nature reasons contribute for it [26]. Even health professionals who deal closely with death show severe difficulties in facing this phenomenon, maybe because they are not prepared to face their own death. This cultural constraint leads, often, to a distancing of health professional from the terminal patient. Such distancing, which in some cases may even be characterized as patient exclusion of terminality of life, associated to lack of dialogue and emotional support, ends up in changing into a vicious cycle of anguish, abandonment, and loneliness.

It is in this context that the Order of Not Resuscitating much be appreciated anew. Self, in one hand, this type of instruction finds ethical legitimacy in the principles of beneficence and of non maleficence (and in the principle of respect for autonomy when patient is involved also in the decision-making process), must pay attention that its concrete application is framed into a team spirit, involving all those that effective care for the terminal patient. If conditions allow for, this decision should be made unilaterally, without patient's knowledge, and without knowing his will. Despite all emotional reactions that death causes, health professional have the duty to allow patient to have a dignified death, most comfortably as possible, without pretending to postpone or delaying unduly.

In this work, one sought to evidence some of the health professionals' ethical dilemmas who care for terminal patients with ONR, aiming at contributing to an open, plural, and transparent discussion about ethical issues about the end of life. Two conclusions seem to stand out. In one hand, the necessity health professionals accrued formation regarding care to be rendered to patient in the terminality of life, namely by implementing good practices regarding suspension or abstention of disproportional treatments.

Thus, one may clarify society that the Order to Not Resuscitating is a dignified practiced, framed in current view of orthothanasia. In the other hand, it is fundamental to standardize ONR in order to any patient to have the right to usufruct the same kind of care and good practice, independently of the institution where he is sheltered. The different professional associations are charged with the task of defining guiding norms in this issue, so physicians, nurses, and other professional have clear notion about the referential of ethical action in terminal patients.

Resumen

Orden de no resucitar al enfermo terminal: dilemas éticos de los enfermeros

El artículo analiza la orden de no reanimar (ONR), una temática que siempre suscitó infinitas cuestiones éticas en el curso de la prestación de cuidados a la salud. Con base en investigaciones realizadas en dos hospitales, con especialidad en oncología en el norte y el sur de Portugal, el objetivo del estudio fue determinar los principales dilemas éticos planteados por el personal de enfermería porque no hay uniformidad en la presente decisión en Portugal. De una muestra de 231 profesionales se hizo hincapié en que su posición sobre la decisión de la ONR en el enfermo terminal y así como las cuestiones sobre quién tiene conocimiento sobre la misma, así como sus formas de registro y reevaluación. Además de caracterizar este proceso, este estudio pretende mostrar cuál es el pensamiento y cuál es la actitud del personal de enfermería de Portugal al enfermo con la ONR.

Palabras-clave: Orden de No Reanimar (ONR). Enfermo terminal. Enfermería. Derecho a morir.

Resumo

O artigo discute a *Ordem de Não Reanimar* (ONR), temática que tem suscitado várias questões éticas no exercício da prestação dos cuidados de saúde. Baseado em pesquisa empreendida em dois hospitais com especialidade oncológica no Norte e no Sul de Portugal, o estudo teve como finalidade conhecer os principais dilemas éticos invocados pelos profissionais de enfermagem pelo fato de não existir uniformização quanto a esta decisão naquele país. A partir de amostra constituída por 231 enfermeiros que atuam em serviços afins enfatizou-se o posicionamento a respeito da tomada de decisão de ONR no doente terminal, bem como as questões relativas a quem tem conhecimento sobre a mesma, assim como suas formas de registro e reavaliação. Além de caracterizar esse processo, este estudo pretendeu evidenciar qual o pensamento e atitude dos enfermeiros portugueses perante o doente com ONR.

Palavras-chave: Ordem de Não Reanimar (ONR). Doente terminal. Enfermagem. Direito a morrer

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