

Nurses' and physicians' opinions on end-of-life: a secondary analysis from an Italian cross-sectional study

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Abstract

Background. In daily clinical practice, healthcare workers face end-of-life issues, such as futility, which is generally defined as the provision of treatments that do not produce any meaningful benefit for patients.

Study design. To investigate the end-of-life issues according to Italian nurses' and physicians' opinions and to detect any differences between them, a secondary analysis of existing data from a cross-sectional study was conducted.

Methods. A validated questionnaire was used involving 351 nurses and 128 physicians from four hospitals in Central Italy.

Results. Regarding the definition of futility, nurses mainly focused on agony, suffering, and risks, while physicians paid more attention to the hope of healing. Nevertheless, both were distressed by different aspects of the treatments; in particular, nurses by the 'invasiveness of the treatments' and physicians by the 'over-medicalization of death'. Instead, nurses and physicians similarly recognized patients' right to seek to anticipate the end of life when they are terminally-ill and to express freely their desire not to be revived.

Conclusions. The description of experiences and opinions of health professionals could represent a valid basis to develop a 'regulatory system' aimed to guide and support daily clinical and nursing activities.

Introduction

In clinical and nursing practice, ethical issues increasingly occur because of advances in the biomedical sciences, technologies, and care practices. Ethical dilemmas arise from end-of-life situations, life-prolonging measures, non-beneficial treatment prescriptions, conflict-laden

professional relationships, and organizational policies (1). Individual values of health professionals, the clinical setting in which they act, and the diseases that they often treat, may also contribute to these concerns (2-5). To meet ethical health workers' needs and protect patients' dignity, autonomy, and rights (e.g. self-determination), some policies, laws, guidelines, and codes are now

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available (6-8). In 2015, the UK Department of Health tried to identify the main needs of people that directly or indirectly approach the end-of-life.

Important emerging themes for patients were adequate access to high-quality care, respect for the individual will, and guarantee for emotional, social, and spiritual support. Other themes included the involvement of family, important people, and patients themselves in decisions about care activities (9). However, healthcare professionals on one side, and patients with their families, on the other hand, frequently disagree about treatment decisions (10). Thus, some methods to reach mutually agreeable choices should be implemented (11), such as communication strategies actively involving families and professionals (12, 13). Furthermore, conflicts about end-of-life issues may occur among clinical team members, since their views about some topics could be different contributing to their moral distress (14, 15).

Currently, futility is one of the most debated ethical topics and, despite it is difficult to achieve a clear consensus over this concept, providing a treatment that does not produce any meaningful benefit for the patient is generally identified as the main feature of medical futility (16-18). However, the beneficence of a treatment and, consequently, its futility are subjectively perceived by people involved in end-of-life situations, and are related to several factors, such as the individual values of each health worker or patient's clinical conditions (17). In this context, to provide a shared definition of futility, in 2016 the Society of Critical Care Medicine performed a systematic review of empirical research and position statements, according to which life-prolonging interventions are futile in case of no reasonable improvements are expected for the neurological ability of the patient or there is no hope to survive outside the acute care setting (19).

In Italy, the debate on ethical issues in healthcare is mainly focused on the regulation of end-of-life care about which a law has been recently promulgated (Advance Care Directives - ACDs) (8). Previously, since no Italian laws about end-of-life care and futility were available, since 1995 the Italian Committee for Bioethics has been developing some recommendations and in 2003 it suggested the introduction of laws mandating physicians to respect the ACDs, through which patients could designate one or more persons to be involved in the decisional process about their end-of-life care (20). However, in 2001 a law had already provided a list of the services that the Italian National Health Service must ensure to all citizens (basic levels of care), also including palliative care (21), even if only nine years later detailed rules about access to palliative care were established (22).

Despite the broadness of the international debate about end-of-life issues (1, 17, 23, 24), in the Italian context few studies are available (25-27). However, understanding the healthcare workers' opinions about these themes could contribute to facilitate organizational changes in Italy, improve care for patients and face moral distress of health professionals (25).

The main objective of the study was to contribute to the international debate about end-of-life issues, investigating Italian nurses and physicians' opinions. Secondly, any difference between the two groups, in a period characterized by a legislative void, was explored.

Methods

Study design, setting, and sample

A secondary analysis of existing data (28) from a cross-sectional study, conducted between March and June 2014 was performed (25), involving 351 nurses and 128 physicians from four university

hospitals located in Abruzzo region with numbers of beds ranging from 40 to 317.

Three out of all hospitals offer ethically sensitive services, i.e. abortions, intensive therapies, oncological treatments, and palliative care.

The questionnaire

In the above-mentioned cross-sectional study, a semi-structured questionnaire was used. After a deep analysis of the literature, a group of experts had developed an *ad hoc* questionnaire which underwent a content and face validity analysis before being adopted (25). It consisted of 21 items grouped into 5 sections exploring: 1) demographic and occupational characteristics, 2) knowledge in the ethics field, 3) experience with ethical issues, 4) propensity to use ethics consultation, and 5) end-of-life issues. The first and latter sections, concerning 15

questions (Table 1), were examined in this study.

Ethical approval

Ethical board approval was obtained from the Professional Board of Nurses (IPASVI). Moreover, the Hospital Ethical Committee and the University Research Ethical Board were consulted. However, both recognized their ethical approval unnecessary for this type of study, since it did not interfere with patients' care provided by the involved healthcare workers.

Statistical analysis

Descriptive analyses were performed for all data. Regarding item 15 of the 'end-of-life issues' section of the questionnaire, answers provided by respondents have been coded to obtain categorical data. Afterwards, frequencies and percentages were calculated

Table 1 - First and fifth sections of the original questionnaire

Demographic and occupational characteristics	Type of question
1. Age (years)	open-ended
2. Gender	closed-ended
3. Job qualification	multiple-choice
4. Work setting	multiple-choice
5. Education	multiple-choice
6. How long have you been working? (years)	open-ended
7. How long have you been working in your current ward? (years)	open-ended
End-of-life issues	
8. What is futility?	multiple-choice
9. What treatments do you intend as futility for the terminally-ill patient?	multiple-choice
10. Did you ever disagree about the prescription of a treatment to a terminally-ill patient? <i>If yes, which aspect of the treatment was mostly distressing for you?</i>	closed-ended <i>multiple-choice</i>
11. Do you think that terminally-ill patients have the right to ask to anticipate their last moment of life?	multiple-choice
12. Do you think that it is right that patients can freely express their will to not be revived?	multiple-choice
13. Do you think that it is right that a healthcare worker can decide to intervene even in presence of the patient will to not be revived?	multiple-choice
14. What do you think about considering the opinions of the family members of the patient in decision-making about end-of-life?	multiple-choice
15. Indicate three elements that should be guaranteed to the terminally-ill patient	open-ended

Note: for multiple-choice questions, one answer only was allowed.

for all the categorical data and the χ^2 test was used for hypotheses testing. For all the analyses, a bidirectional test was used with a significance level of 0.05 through the IBM SPSS software version 19.0 (IBM Corp., Armonk, NY, USA).

Results

Demographic and occupational characteristics of the respondents

The characteristics of the analyzed sample are summarized in Table 2. Four hundred and seventy-nine participants completed the questionnaire, of whom 351 (73.3%) were registered nurses (RNs) and 128 (26.7%) were physicians. Among nurses, women prevailed (79.2%), as opposed to physicians (46.1%); only 20.8% of nurses had a post-graduate qualification, and the middle-age group (36-51) was more represented (56.4%). Instead, among physicians, the oldest age group (52-65) was more represented (48.4%). As regard the work setting, most of both nurses and physicians were employed in critical or medical area (27.9% and 31.3% vs. 32.0% and 32.0%, respectively). Finally, 34.5% of nurses had a professional experience ranging from 21 to 30 years, while 32.8% of physicians had a shorter professional experience (<10 years); at the moment of the survey, most of both nurses and physicians were employed in the same ward since less than 10 years (57.5% and 46.1%, respectively).

Opinions about end-of-life issues of the respondents

As shown in Table 3, among the 'futility' definitions proposed in the questionnaire, the respondents most frequently chose '*Insistence on the use of surgical and medical devices that do not significantly change the natural and irreversible course of the disease, sometimes worsening the patient's quality*

Table 2 - Demographic and occupational characteristics of the respondents

Characteristics	Nurses N (%)	Physicians N (%)
	351 (73.3)	128 (26.7)
Age		
20-35	41 (11.7)	17 (13.3)
36-51	198 (56.4)	48 (37.5)
52-65	101 (28.8)	62 (48.4)
Missing	11 (3.1)	1 (0.8)
Gender		
Male	57 (16.2)	61 (47.7)
Female	278 (79.2)	59 (46.1)
Missing	16 (4.6)	8 (6.3)
Job qualification		
Basic	312 (88.8)	38 (29.7)
Advanced	24 (6.9)	101 (70.3)
Missing	15 (4.3)	-
Work setting		
Critical area	98 (27.9)	41 (32.0)
Medical area	110 (31.3)	41 (32.0)
Surgical area	87 (24.8)	25 (19.5)
Other	18 (5.1)	18 (14.1)
Missing	38 (10.8)	3 (2.3)
Education		
Basic	275 (78.3)	-
Post-graduated	73 (20.8)	-
Missing	3 (0.9)	-
Years in practice		
<10	56 (16.0)	42 (32.8)
11-20	95 (27.1)	21 (16.4)
21-30	121 (34.5)	34 (26.6)
>30	70 (19.9)	28 (21.9)
Missing	9 (2.6)	3 (2.3)
Years in the current ward		
<10	202 (57.5)	59 (46.1)
11-20	75 (21.4)	31 (24.2)
21-30	35 (10.0)	22 (17.2)
>30	16 (4.6)	9 (7.0)
Missing	23 (6.6)	7 (5.5)

of life' (31.0%). However, the following definitions: '*Immoderate treatments that have the sole effect of extending the patient's agony and/or implying additional suffering and/or high risks*' and '*Provide treatments*

Table 3. Opinions about end-of-life issues of the respondents

	Total (%)	Nurses (%)	Physicians (%)	χ^2 test p-value
Definition of futility				
Provide treatments that prolong patient's life with no hope of healing	28.2	18.3	54.6	
Insistence to the use of surgical medical devices that do not change significantly the natural and irreversible course of the disease, sometimes worsening the patient's quality of life	31.0	30.0	33.6	
Treatments aimed to cause the patient's death	1.6	-	5.9	<0.001
Treatments disproportionate to the results	10.8	12.6	5.9	
Immoderate treatments that have the sole effect of extending the patient's agony and/or implying additional suffering and/or high risks	28.4	39.1	-	
Treatments intended as futile				
Invasive diagnostic test	44.5	45.3	42.5	
Mechanical ventilation	25.5	23.9	29.9	
Nutrition and hydration	16.6	16.6	16.5	
Cardiopulmonary resuscitation	5.0	5.1	4.7	0.810
Complex therapies	3.3	3.3	3.1	
Drug sedation	0.9	1.2	-	
None of the listed	2.6	2.7	2.4	
Other	1.5	1.8	0.8	
Disagreement about the prescription of a treatment to a terminally-ill patient				
Yes	51.6	52.1	50.0	0.679
The most distressing aspects of the prescribed treatments during end-of-life				
<i>Invasiveness of treatment</i>	57.4	65.9	39.0	
<i>Over-medicalization of death</i>	31.0	22.7	48.8	0.009
<i>Resource wasting</i>	9.3	10.2	7.3	
<i>Other</i>	2.3	1.1	4.9	
Patients have the right to ask to anticipate their last moment of life				
Always	58.6	58.4	59.3	
Sometimes	18.9	18.1	21.0	0.731
Never	22.5	23.5	19.8	
Patients have the right to freely express their desire to not be revived				
Always	72.0	71.6	73.2	
Sometimes	13.4	13.6	13.0	0.945
Never	14.5	14.8	13.8	
Resuscitation treatments provided to patients who had expressly requested to not be revived is right				
Always	18.2	18.7	16.8	
Sometimes	24.9	23.5	28.6	0.543
Never	56.9	57.8	54.6	
Considering the opinions of family members				
Crucial	19.0	22.2	10.5	
Recommended	52.5	50.5	58.1	
Useless	10.7	9.3	14.5	0.005
Sometimes	6.6	5.4	9.7	
I don't know	11.2	12.6	7.3	

What guarantee to patients during the end-of-life			
Pain treatment	50.7	44.2	68.8
Ensuring dignity in dying	32.8	33.6	30.5
Appropriate environment	27.3	26.5	29.7
Appropriate caring	21.5	19.9	25.8
Presence of family members	26.1	26.8	24.2
Nutrition, hydration, and ventilation	9.0	5.4	18.8
Psychological support	12.7	13.1	11.7
Listen to the patient	5.2	4.3	7.8
Religious support	12.5	15.1	5.5
Other	15.9	16.5	14.1

<0.001

that prolong patient's life with no hope of healing' were also frequently chosen (28.4% and 28.2%, respectively). The definition of futility identified by nurses and physicians was different ($p < 0.001$) since nurses mainly focused on themes such as agony, suffering and risks, while physicians paid more attention to the hope of healing. Nevertheless, about the identification of futile treatments, nurses and physicians agreed ($p = 0.810$). In particular, they identified mostly as 'futile' invasive diagnostic tests (45.3% and 42.5%, respectively) and mechanical ventilation (23.9% and 29.9%, respectively).

More than half of the total sample (51.6%) stated that in the past they had disagreed with a treatment prescribed to a terminally-ill patient (52.1% of nurses, 50.0% of physicians), with no significant differences between nurses and physicians ($p = 0.679$). In this regard, nurses and physicians were distressed by different aspects of the treatments ($p = 0.009$); in particular, nurses were distressed by the 'Invasiveness of treatment' (65.9%) and physicians by the 'Over-medicalization of death' (48.8%). Instead, nurses and physicians similarly recognized patients' right to seek to anticipate the end of life when they are terminally-ill ($p = 0.731$) and to freely express their desire not to be resuscitated ($p = 0.945$). Moreover, the two groups had similar opinions about the resuscitation treatments

provided to patients who had expressly requested not to be revived ($p = 0.543$). In this regard, more than half of both nurses and physicians considered performing undesired resuscitation treatments as never right (57.8% and 54.6%, respectively). As concerns the respondents' views on patients' rights during the end-of-life, nurses and physicians held different opinions ($p = 0.005$), since nurses believed, more often than physicians, that the consideration of the relatives' opinions is crucial (22.2% and 10.5%, respectively).

Finally, as regards what nurses and physicians would mainly ensure to patients during end-of-life, several differences emerged between them ($p < 0.001$), especially in relation to pain treatment (44.2% vs. 68.8%, respectively), ensuring life-sustaining measures (5.4% vs. 18.8%, respectively), and religious support (15.1% vs. 5.5%, respectively).

Discussion and Conclusions

Concerning the ethical issues related to the end-of-life phase, such as futility, the literature is still trying to provide clarifications. In fact, a highly shared definition of futility is still lacking (18). Similarly, in the present research the respondents gave different definitions

of futility. In particular, it seems that physicians dwelt on the uselessness and the outcomes of futile treatments while they paid little attention to some key themes highly considered by nurses, such as agony and risks. This is probably due to the different education of nurses and physicians, as far as to the role that they assume in daily clinical practice and to their engagement with patients (23, 29).

Interventions that generally provide an objective result (i.e. effective treatments), such as invasive diagnostic tests and mechanical ventilation, may be futile if they do not benefit patients through the achievement of a caring outcome (i.e. non-beneficial treatments) or improve their quality of life (30), and it seems that both nurses and physicians tried to emphasize this concept. In fact, more than half of the total sample disagreed with the treatments prescribed to terminally-ill patients. Thus, it would seem that nurses and physicians had witnessed treatments that they consider effective but not beneficial. However, when they were asked to identify the most distressing aspect of these treatments, nurses mainly focused on the invasiveness of treatments more than physicians. In this regard, the non-beneficial feature of treatments has been recognized as a risk factor for nurses' moral distress (31). Indeed, physicians were mainly distressed by the over-medicalization of death. According to such results, it seems that the term 'medicalization of death', apart from resulting in an improper and excessive use of technology, refers to the inappropriate use of hospital facilities in the management of terminally-ill patients, highlighting the need for improving alternative structures aimed at managing the end-of-life, such as hospices or palliative home care (32-34). This reveals another difference between the roles of the two professionals: even though all healthcare workers often face resource rationing, physicians, as managers of the treatment options, deal with the use of resources

more often than other professionals. Such a situation influences the clinical decision-making, gives physicians a different degree of responsibility towards health institutions, and could lead them to conflict with the wills of the patient/family (35). Nevertheless, besides the institutions' perspective, the patient's perspective, e.g. the demands for Do Not Resuscitate (DNR) and anticipate the end-of-life, should also be considered, as highlighted by the respondents. Instead, as regards the recognition of the specific right to not intervene, the sample was probably divided because of the lack of a standardized approach through guidelines and laws (27) during the period in which the study was performed.

Historically, little importance was paid to the opinions of relatives (36, 37). In this study, a recognition of the role of family members as trusted persons in decisions related to end-of-life treatments was shown, even if some differences between the responses of the two groups were pointed out. Nurses recognized a centrality of that role, while physicians perceived it as more nuanced, probably because nurses are very often in contact with patients and their families and can assume the role of mediators in clinical communication (38). These opinions agree with the recently promulgated law (Advance Care Directives - ACDs) (8, 28) that establishes the chance to involve a trusted person, not only a relative, who plays an active role in end-of-life decisions. Miscommunication can lead to safety hazards or to not respecting the wills of patients, who could receive unwanted care. At this regard, Italian nurses and physicians must guarantee the application of ACDs, i.e. that patients' wills have to be collected and satisfied correctly (8). Communication strategies aimed to minimize conflicts should be implemented to reach shared decisions about appropriate goals of care among patients, surrogate decision-makers, and physicians (11). In this regard, since curricula do not always include teachings

of psychology, ethics, and communication management techniques, it would be desirable to integrate them into basic and post-basic interprofessional educational pathways (39-41). Finally, ensuring life-sustaining measures was very important for physicians, while nurses recognized as essential to face not only biological needs, but also social, psychological, and spiritual needs, like religious support, shown to be oriented to holistic patient-centered care (42). Holistic care recognizes a person as a whole and the interdependence among one's biological, social, psychological, and spiritual aspects (43). It is interesting to highlight that life-sustaining measures, such as nutrition, hydration, and ventilation, have been indicated both as futility and as interventions to be ensured during end-of-life. This was probably due to an internal conflict perceived by health professionals who felt obligated to perform treatments they considered futile. In this case, health professionals could need an ethics consultation service (26). Anyhow, it seems clear that knowing patients as persons, listening to their needs and preferences, supporting their everyday's choices through advocacy, and maintaining their dignity are central themes surrounding end-of-life care (33).

To our knowledge, this is the first Italian study including nurses and physicians in regard to their experiences and opinions on ethical issues. This first experience could be a starting point to stimulate research activities on this issue and to provide input to consider healthcare providers' opinions when developing practical guidelines for end-of-life treatments. However, the study was carried out in a local context and with a limited convenience sample; moreover, the utilization of closed-ended questions regarding futility could have hidden some aspects of healthcare workers' point of view. Therefore, the generalization of the results should be cautious.

The results showed nurses and physicians considered ethically sensitive situations in healthcare activities with some differences, which were probably due to their different educational curricula, roles and level of responsibility towards health institutions. Since these curricula do not always include psychology, ethics, and communication teachings, it would be desirable to integrate these topics into basic and post-basic interprofessional educational pathways.

Concerning the definition of futility, physicians tended to have more consideration of treatment outcomes, while nurses mainly focused on such themes as agony, suffering, and risks, as requested by holistic care. Moreover, nurses are the usual mediators of communication and generally have a different level of engagement with patients and their relatives. Nevertheless, physicians, although with a different level of priority compared to nurses, agreed about the importance of considering the opinion of family members.

Both nurses and physicians recognized the need for respecting patient's will during end-of-life treatment, even though they demonstrated uncertainty about the possibility of guaranteeing the application of such a will. This is probably due to the legislative void in these issues in Italy at the time of the survey. Healthcare workers were distressed when they felt obligated to perform treatments that they considered futile. As this is quite frequent, the comprehension of experiences and opinions of health professionals could represent a valid basis to develop a 'regulatory system' aimed at guiding and supporting daily clinical and nursing activities. Furthermore, additional investigations are needed to design appropriate communication strategies both within the healthcare professional groups and between professionals and patients with their families.

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Riassunto

Opinioni di infermieri e medici sul fine vita: una analisi secondaria da uno studio trasversale italiano

Introduzione. Nella pratica clinica quotidiana, gli operatori sanitari affrontano questioni sul fine vita, quali l'accanimento terapeutico, il quale è generalmente definito come l'erogazione di trattamenti che non producono alcun beneficio significativo per i pazienti.

Disegno dello studio. Per investigare i temi del fine vita secondo le opinioni di un gruppo di infermieri e medici italiani e per rilevare le differenze tra di loro, è stata condotta una analisi secondaria di dati provenienti da uno studio trasversale.

Metodi. È stato utilizzato un questionario validato includendo 351 infermieri e 128 medici di quattro ospedali del centro Italia.

Risultati. Riguardo la definizione di accanimento terapeutico, gli infermieri si sono focalizzati maggiormente su agonia, sofferenza e rischi, mentre i medici hanno dato più attenzione alla speranza di guarire. Comunque, entrambi erano infastiditi da differenti aspetti dei trattamenti; in particolare, gli infermieri dall'invasività dei trattamenti e i medici dalla 'eccessiva medicalizzazione della morte'. Al contrario, infermieri e medici hanno riconosciuto ai pazienti terminali il diritto di chiedere di anticipare il fine vita e di esprimere liberamente il loro desiderio di non essere rianimati.

Conclusioni. La descrizione delle esperienze e delle opinioni dei professionisti sanitari potrebbe rappresentare una base valida per sviluppare un 'sistema di regolazione' finalizzato a guidare e supportare le attività infermieristiche e cliniche quotidiane.

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