



Exploring health professionals' knowledge of end of life in Italy

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ABSTRACT

The evolution of medicine and technologies applied to medical knowledge has made it possible to extend patients' life expectancy by changing the prognosis of certain pathologies and often transforming their outcome. This has made it possible not only to keep a patient alive after acute events (e.g. cerebrovascular accidents, critical conditions linked to major traumas or road accidents) but also to 'chronicise' certain pathologies. These reflections are within the grasp of health professionals, legal scholars, politicians and ordinary citizens. This study aims to explore health professionals knowledge on terms pertaining to "end of life", that are often used improperly and interchangeably. It also offers an overview of the degree of knowledge and attitudes of health professionals and students of Medicine and Surgery and of the classes of the health professions, through a cognitive survey carried out by means of a digitalized survey on a Google platform administered by e-mail through the Order of Surgeons and Dentists of Salerno, Naples and Caserta, the Professional Order of Nurses of Naples and the student associations. The results point to the need for end-of-life organic legislation and for the implementation of training and continuing education programmes. It is desirable for the widest possible sample to take part in the survey in order to obtain more meaningful statistical information.

1. Introduction

The debate between the availability and unavailability of life came to the forefront of Western culture at the beginning of the medieval perception of man's destiny and with the gradual establishment of Enlightenment philosophy. With the swirling growth of scientific discoveries and the development of techniques capable of curing certain pathological conditions, a progressive "domination" over death has been achieved [1]. Quoting Seneca, "there is nothing on which one should meditate as on death' because, unlike what happens with all other experiences, on which 'one perhaps exercises oneself uselessly [...], that meditation is the only one that one day will have to be put into practice" [2]. It is not uncommon for the terms "euthanasia" and "assisted suicide" to be used interchangeably and far from their original meaning in everyday language, but also in specialist language [3–5]. Euthanasia is a polysemic term [6], i.e. it has different meanings, although etymologically related. In general, it is understood as the act whereby a doctor or other person administers drugs at the free request of the conscious and informed subject, with the aim of intentionally causing the immediate death of the applicant. The aim is to anticipate death on demand in order to eliminate suffering. The possibility of extending euthanasia in conditions of

depression, severe existential distress, loneliness, negative economic impact on the family, or even in conditions of not being fully capable of understanding, as in the case of minors or persons suffering from dementia, is a debated issue. Despite a generic conceptual orientation from a cultural point of view, there is no lack of conceptual "complications" in doctrine and among commentators that enrich the lexicon of the end of life and make it less easy to manage such a topic, that is still lacking stable references [7,8]. For a more detailed definition, euthanasia is distinguished, according to some commentators, into active and passive [5]. Passive euthanasia would consist of two possible types of conduct: interruption or non-initiation of vital treatments or the administration of drugs to limit the patient's suffering, even though these may accelerate death (also called "indirect active euthanasia" or "analgesic euthanasia"). This conduct aimed exclusively at relieving pain, such as the administration of analgesics at maximum dosage, which have the inevitable but accepted effect of the patient's death. The second, active euthanasia, consists of active conduct aimed at hastening or bringing about death, e.g. administration of a lethal drug. According to some orientations, providing a drug to the patient, who then ingests it (so-called assisted suicide), falls into the category of active euthanasia. It appears, in any case, that there are those who distinguish between active

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and passive conduct with reference to the doctor's role, and those who distinguish conduct on the basis of the actual action that results in death, shifting the adjectivization into active and passive as a qualification of the event. In fact, thanks to technology, use of machines can help the patient with reduced physical capacity to take the lethal product prepared (by the doctor or others). In the Italian legal system, it is not possible to find a regulatory framework specifically aimed at regulating the end of life, even though there have been several cases in the news that have influenced the current Italian regulatory scenario [9]. In the current state of legislation, it is possible to reconstruct a regulatory framework of reference that stands in the sense of an absolute unavailability of the right to life. Generally speaking, end-of-life practices represent crimes both in relation to Article 575 of the Italian Penal Code (murder), and in relation to the more specific provision of Article 579 of the Italian Penal Code (murder of the consenting person) and Article 580 of the Italian Penal Code (instigation or aiding and abetting suicide). To better understand the confusion of terms and the approach of health care professionals to the issue of end-of-life care, it is useful to review the news events that led to the pronouncements that also establish the duties and obligations of health care professionals called upon to intervene in end-of-life practices. Up until now, the efforts of the scientific community have focused on the knowledge of the phenomenon and the perception of medical personnel [10–17], without paying particular attention to the other figures in the care setting, an aim pursued by other research groups [18,19]. A relevant finding is that of a common lack of specific training dedicated to end-of-life practices and legislation together with the possible impact of such training [20]. In Belgium and Luxembourg, reflection has been opened on the possible limitation of palliative care development in the face of the legalization of medically assisted suicide practices [21]. Finally, there are other operational scenarios in which the role of telemedicine and teleassistance in end-of-life practices and in the candidacy and assistance procedures for medically assisted suicide is being questioned [22]. In Italy, following the death of Eluana Englaro, the entire scientific community began to question the perception of the medical profession regarding end-of-life issues. Subsequently, a further survey was conducted to investigate the perception and attitude of Italian doctors with regard to professional decisions on the end of life, and in particular the degree of knowledge of young forensic doctors on informed consent and advance treatment provisions, published in an article [23] by Bolcato et al. From a disciplinary point of view, the echo of the Cappato affair led to the inclusion of application guidelines in Article 17 of the latest version of the Code of Medical Ethics on 06/02/2020 [24]. Article 17, entitled 'Acts intended to cause death' states that: "The doctor, even at the request of the patient, shall neither perform nor favour acts intended to cause the death of the patient". The application guidelines of this article state that 'the free choice of the doctor to facilitate, on the basis of the principle of self-determination of the individual, the intention to commit suicide autonomously and freely formed by a person kept alive by life-support treatment, suffering from an irreversible pathology, source of intolerable physical or psychological suffering, who is fully capable of making free and conscious decisions (Constitutional Court ruling 242/19 and related procedures), must always be assessed on a case-by-case basis and entails, if all the above-mentioned elements exist, the non-punishment of the doctor from a disciplinary point of view'. The Investigating magistrate of the Court of Florence recently [25] raised a question of constitutional legitimacy in relation to the crime of aiding and abetting suicide (Article 580 of the Italian Penal Code), as amended by Constitutional Court ruling n. 242/2019. The case involves a well-known radical and activist being investigated for aiding suicide (Article 580 of the Italian Penal Code) for having organized and then materially carried out the accompaniment of a person to the Swiss clinic where, on the same day, he died following an assisted suicide procedure. The patient had been diagnosed with multiple sclerosis in 2017. In the Investigating magistrate's opinion, the conduct of the suspects does not fall within the hypothesis of non-punishment introduced into Article 580 of the Penal Code by

Constitutional Court ruling No. 242/2019, since the requirement of 'dependence on life-support treatment' does not appear to be integrated in the case at hand. In the face of the doubts of the Judge of Florence, which considered this delimitation discriminatory against those who were not subjected to such treatments, the judges of the Constitutional Court [26] definitively clarified that "the requirement of the patient's dependence on life-support treatment plays, in the absence of legislative intervention, a pivotal role in the logic of the solution adopted in Ordinance No. 207 of 2018, later taken up in Judgment No. 242 of 2019." In fact, the Court "did not recognize a general right to end one's life in any situation of intolerable suffering, physical or psychological, determined by an irreversible pathology, but only deemed it unreasonable to preclude access to assisted suicide of patients who – being in those conditions, and keeping their decision-making abilities intact – already have the right, recognized to them by Law No. 219 of 2017 in accordance with Article 32, second paragraph, of the Constitution, to decide to end their lives, refusing the treatment necessary to ensure their survival. Such a rationale clearly does not extend to patients who are not dependent on life-support treatment, who do not (or do not yet) have the option of allowing themselves to die simply by refusing treatment. Given the pronouncement of the Constitutional Court and in this context lacking a normative reference with a changing scenario with regard to jurisprudential orientations, it appears appropriate to investigate the perception of health professionals in this regard. The purpose of this study is to investigate and assess the level of training of health professionals and students of the Degree Course in Medicine and Surgery and of the Health Professions with respect to euthanasia, assisted suicide and advance treatment provisions with two very precise objectives:

- defining a background of knowledge to attest to the cultural training of health professionals and students who will be close to these issues in the course of their working life;
- tracing this knowledge back to a precise source of learning (professional experience, courses of study);
- assessing the possible training needs to be met for the future.

2. Materials and methods

In order to find out the state of the art on the end of life in Italy, a survey was administered, on a voluntary basis, to some categories of health professionals (doctors, nurses, etc.) to find out the level of training of these professionals on the subject of euthanasia, assisted suicide and advance treatment provisions. Recruitment was established on a voluntary basis with no exclusion criteria *a priori* decided. Being part of a medical/nurse/student association was the only inclusion criterion. People who decided to participate could answer the survey just once. In the present work, in order to obtain a greater degree of detail on the point, it was decided to widen the sample and include specialists (differentiated by branch), general practitioners, pediatricians of free choice, students in their final year of Medicine and Surgery, and students in the health professions classes, framing them as professionals in progress. Through a preliminary phase of evaluation of the sector's literature, a digitalized survey was subsequently carried out on a Google platform and administered by e-mail through the Ordinances of Surgeons and Dentists of Salerno, Naples and Caserta. Further support for diffusion was provided by the OPI (Professional Order of Nurses) of Naples. The invitation to participate was disseminated through online web platforms (institutional websites) and official mailing lists of the relevant professional bodies. The questionnaire remained published and still accessible. For widespread diffusion also among students on medical and surgical degree courses, as well as health professions classes, the instant messaging platform WhatsApp was chosen due to the fact that this segment of the sample is not otherwise surveyed by other institutional groups (e.g. orders). The questionnaire submitted consists of 10 questions. The first question is of a general nature and concerns gender, age, profession, place of practice (variables considered are listed in

Table 1
Variables considered in the survey.

Variables considered
Age
Gender
Profession
Place of practice/study
Medical specialty
Religion

Table 1). All questions aimed to explore different aspects of the matter and have been articulate with regard to education (questions 1 to 3), knowledge and terminological use (question 4), attitudes towards end of life issues (questions 7,8,9), organizations of the services (question 10). The 10-question questionnaire was designed to investigate relevant aspects that could be grouped, as best suggested by the reviewer, into aspects related to education (college pathway), continuing education (need for courses after completion of education), knowledge of the topic (differences in terminology), and own personal conviction. A “topic-based approach” within the same general issue was adopted to maximize the obtainable data. The answers were treated anonymously and according to the provisions of European Regulation 2016/67. Survey content is listed in Table 2:

After collecting the data anonymously, they were analyzed using the chi-square test statistical methodology for categorical qualitative variables. Statistical analyses were performed using SPSS software for Windows.

3. Results

First, the sample was analyzed through the description of general information. The total number of respondents to the questionnaire over

Table 2
Structure of the survey.

Statement/question number	Statement/question	Possible Answers
1	I believe I have received good training in terminal patient care during my training	yes/no/don't know
2	The notions I have learned about terminal care are the result of my professional experience.	yes/no/don't know
3	It is appropriate to provide training and refresher courses on end-of-life care	yes/no/don't know
4	I feel I know the difference between assisted suicide, euthanasia and palliative care	yes/no/don't know
5	I consider it necessary to have a regulation governing the end of life	yes/no/don't know
6	I believe I know how to explain the correct procedure to a patient with a terminal condition or their family members	yes/no/don't know
7	I am sympathetic to the implementation of euthanasic intentions expressed by the conscious patient	yes/no/don't know
8	I am sympathetic to the implementation of assisted suicide intentions expressed by the conscious patient.	yes/no/don't know
9	I believe that the DAT (advance directive on treatment) is a sufficient instrument to guarantee the implementation of the patient's intention in matters of end of life	yes/no/don't know
10	The structure in which I work provides for the presence of a dedicated figure to support the doctor/healthcare professional in the event of a patient's request for assisted suicide/euthanasia	yes/no/don't know

the diffusion period was 1507. The average age was 53 years, with a median of 49. As for the minimum answer value, this was 18 years, with the maximum age being 84. 56.7 % of the answers came from males, 43.1 % from women and 0.2 % other. As for the profession practiced, 33.4 % qualify as doctors employed by public structures, 18.5 % are specialized doctors, 6.4 % are doctors employed by private or contracted structures, 6.3 % are general practitioners or pediatricians, and 1.7 % are dentists. A minority is made up of retired doctors, freelancers and outpatient specialists. The extreme variability of the landscape of professional classification has generated a series of responses that can be classified as miscellaneous (UCA doctors, continuity of care doctors, doctors in pharmaceutical companies, GP trainees, freelance specialists, etc.). Other representative percentages are 1.7 % nurses employed by private facilities and 0.8 % nurses employed by public facilities. The majority of the respondents did not have a specialization. The most represented specializations are: Forensic Medicine, Pediatrics, Cardiology, Anesthesia and Resuscitation, Endocrinology, Geriatrics, Radiodiagnostics. 7.2 % of the sample are Medicine and Surgery students. Regarding religious orientation, 70.1 % of the sample stated that they were Catholic, 20.4 % that they were atheist, 4.7 % agnostic. There is a minority set of other religious orientations (non-oriented, orthodox, Buddhist). More than half of the respondents see the Campania region as a place to practice their profession; 61 % of the respondents believe that they did not receive good training in terminal patient care during their training, followed by 23 % who believe they received enough knowledge in this regard and 16 % who did not know. Sixty-nine per cent believe that they have derived their knowledge from their own professional experience, 23 % do not attribute their knowledge to this practice and 8 % did not know. The vast majority (96 %) consider it appropriate to

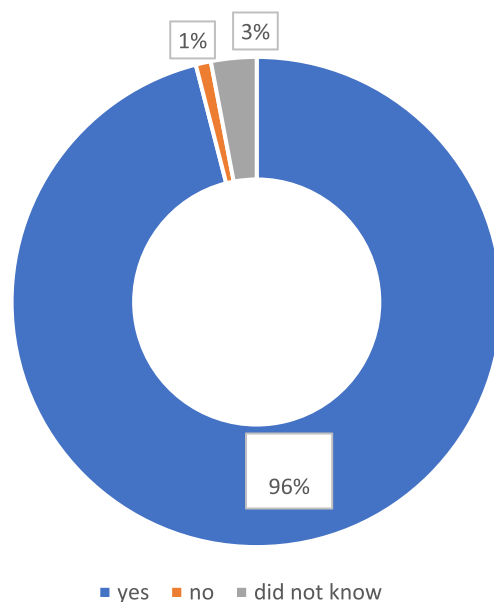


Fig. 1. Answers to the statement: “It is appropriate to provide training and refresher courses on the subject of end of life”.

provide training and refresher courses on end-of-life issues, 1 % consider such provision to be superfluous and 3 % do not know (Fig. 1). When asked about knowledge of an actual difference between the notions of assisted suicide, euthanasia and palliative care, 80 % of subjects gave a positive answer, 11 % negative and 9 % did not know (Fig. 2). With reference to the need to have in Italy a regulation governing the end of life, 91 % of respondents said yes, 5 % did not think it was necessary to regulate this further and 4 % did not know. In response to the question 'I believe I know how to explain the correct procedure to a patient with a terminal condition or his or her family', 47 % were in favor of no, 31 % were in favor of yes, and 22 % did not know. To the question "I am inclined towards the implementation of euthanasia intentions expressed by the conscious patient" 65 % answered yes, 17 % no and 18 % did not know (Fig. 3). To the question "am I inclined towards the implementation of assisted suicide intentions expressed by the conscious patient" 50 % answered yes, 26 % no and 24 % did not know (Fig. 4). As regards the qualitative assessment of the DAT, 35 % of the respondents believe that this instrument is enough to guarantee the implementation of the patient's end-of-life intention, 29 % did not and 36 % did not know, as shown in Fig. 5. As for the presence in the work structure of a dedicated figure to support the clinician in the event of a request for assisted suicide/ euthanasia, 2 % answered yes, 56 % no and 26 % did not know; the remainder are retired or work in private practices that do not require the presence of this figure. Based on the analysis of the comparison of categorical variables (correlation for categorical variables), the following results can be obtained:

- Age: this parameter correlates with question no. 5
- Sex: correlates with questions 1,5,6,7,8,9
- Region: correlates with questions 1,2,4,5,7,8,9,10
- Work: correlates with questions 3,5,9

Statistical significance was established for values above 0.5 by means of the Chi Square test Religious orientation did not correlate with any question.

Some of the most interesting results are shown in Figs. 1 to 5.

4. Discussion

The issue of the end of life continues to fuel a scientific production

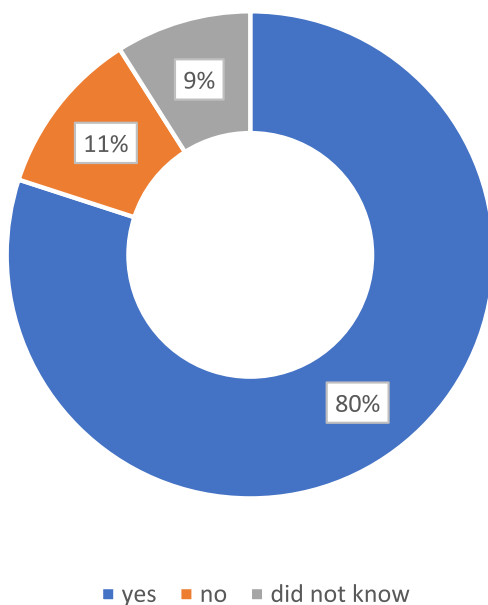


Fig. 2. Answers to the statement: "I think I know the difference between assisted suicide, euthanasia and palliative care".

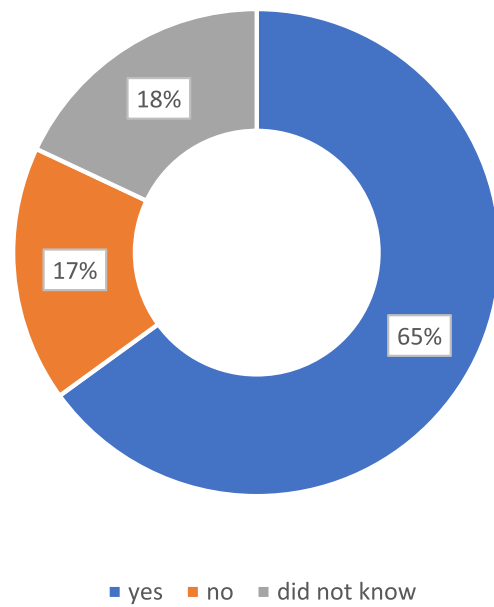


Fig. 3. Answers to the statement: "I am inclined to implement euthanasia intentions expressed by the conscious patient".

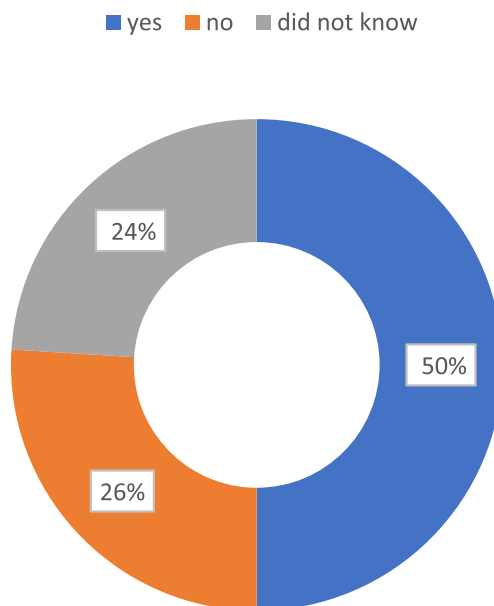


Fig. 4. Answers to the statement: "I am in favor of the implementation of assisted suicide intentions expressed by the conscious patient".

that is connoted by philosophical, legal, ethical and health policy elements [27]. Based on the results of the survey, it is possible to conclude that the first, most important (as well as rapidly measurable in its effects) step to be taken for a clearer awareness of entire categories of professionals called upon to protect the health and know the rights of citizens is to implement university training and adapt continuing education programmes. The vast majority of the sample, moreover, sees the need for systemic legislation on the end of life in Italy and for specific professional training in this regard. It is interesting to note that the majority of participants would more favorably implement a euthanasic intention than assisted suicide. This datum, which could apparently derive from the Catholic faith declared by the majority and the greater disvalue attributed to the term "suicide" might be attributed to the feared terminological confusion between euthanasia and assisted

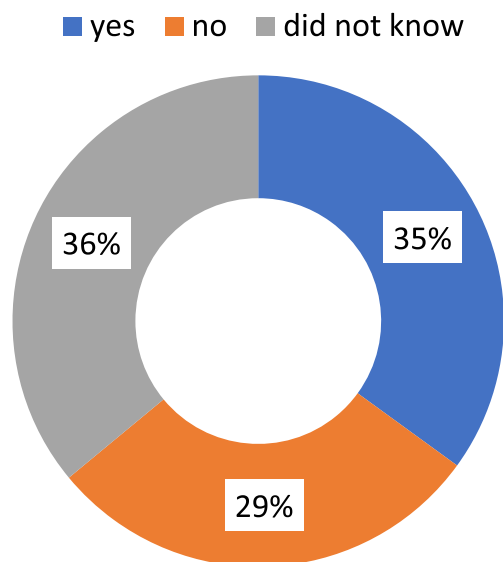


Fig. 5. Answers to the question: “Do I consider advance treatment provisions to be a sufficient instrument to guarantee the implementation of the patient’s end-of-life intention?”.

suicide. This is emblematic. Many of the healthcare professionals do not know how to explain the correct procedure to access assisted suicide to a patient requesting it, nor are they aware of the actual presence in the facility or company where they work of a dedicated figure to support the clinician in end-of-life practices. In relation to the limitations of the study, certainly one of them is the sample size. Certainly, the results obtained can be considered the result of a homogeneous sample of the entire population to be studied, but a nationwide dissemination of the questionnaire would be desirable. It is believed that the coverage should be expanded to obtain more meaningful data. Further limitation consisted in the contact of only one region of Italy (Campania) because of the ready and available direct contact with professional orders. Another aspect that would require more in-depth investigation is a survey targeting health care professionals working closely with end-of-life practices, in order to better explore thorny issues such as conscientious objection, also investigated in the present sample but in a generic way.

5. Conclusions

The vast majority of the sample interviewed sees the need for organic end-of-life legislation in Italy. What emerges as a clear, unequivocal and incontrovertible trend is the need to increase the training offer on end-of-life issues, taking advantage of the possibility of university courses and continuing education managed by the professional Associations. In addition to this, a clear and complete knowledge of already applicable provisions of Law n. 219/17 should be promoted and implemented starting from undergraduates to health professionals already dealing with end-of-life issues. An important impulse could be provided by the academic world, in particular by Medical Legal physicians, in collaboration with local professional associations. This objective could be achieved through the structural introduction of the end-of-life subject in degree courses and graduate training. The conclusion of this study constitutes only a starting point for future developments in research in this field, for which a growing contribution from the scientific community is desirable, with the aim of intercepting the needs not only of doctors but of all health professionals, whether already trained or still in training.

Research ethics and patient consent

Both child’ parents gave a written informed consent approving all performed treatments and analyses, conducted according to the World

Medical Association Declaration of Helsinki.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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