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'*Nosce te ipsum*': An Italian national survey to explore choice's differences in End of Life (EoL) care between healthcare professionals and general public

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ABSTRACT

Background: The current debate regarding decision-making at the End-of-Life (EoL) is increasing remarkably and has spread all over the world. However, literature has paid little attention to describe choice's differences in EoL care between healthcare professionals and general public.
Objectives: The aim of this study was to explore the difference between choices in EoL care made by healthcare professionals and those of the general public within the Italian context.
Setting and participants: In 2017, an Italian widespread survey was conducted using a snowball sampling. A total of 2038 participants completed the survey, 55.64% of which were the general public.
Results: The main differences related to specific EoL choices made by healthcare professionals and the general public. In particular, healthcare professionals were more likely to avoid cardiopulmonary resuscitation and mechanical forms of breathing in terminal-stage conditions, and they were also more likely to be favorable towards the use of opioids to avoid suffering. Overall, healthcare professionals were also more likely to make a choice rather than express a 'not sure' answer.
Conclusion: The higher percentage of participants in the general public group that chose 'not sure' highlighted the importance of addressing and enhancing people's self-awareness. More cross-national investigation should help to frame the understanding of the choice's differences in EoL care between healthcare professionals and general public.

1. Introduction

The current debate regarding decision-making at the End-of-Life (EoL) is increasing remarkably and has spread all over the world (Beaty, 2015). In fact, in recent years, different international governments showed interest around the challenges brought about from EoL care (Berry, 2016; Thomas, 2016). Different governments established boards, reports and guidelines that aimed to improve the quality of EoL care (Julia Neuberger, 2016). Accordingly, EoL care encompasses the delivery of healthcare in the final stage of a person's life, considering the needs of patients and their families (Bone et al., 2018; Caruso, Di Pasquale, Lichosik, Dellafiore, & Pittella, 2013). In other words, EoL care embodies different spheres of the clinical practice, from the pain and symptom management to the education and support for patients and families.

The quality of EoL care involves the whole of society – not only people who are dying as well as their families – as a litmus test for the majority of contemporary people to express perspectives and thoughts about self-awareness (Thomas, 2016). Precisely, self-awareness refers to the ability to recognize oneself as an individual with peculiarities, being a determinant of the right to be independent in making a choice, described as self-determination (Ryan & Deci, 2006). For these reasons, the establishment of a genuine international debate about choices and personalized care for people in the final stage of their life is a significant step towards the awareness that is needed, along with self-determination related to the EoL (Davis-Berman, 2011).

Notably, about 1% of the world population in Western countries dies every year, demanding appropriate EoL care and the possibility of

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having a choice regarding care strategies (Clark et al., 2014). The causes of death changed in the last century, mainly represented by long-term diseases such as cancers and cardiovascular diseases, while the advances in medicine greatly improved the possibilities of treating ill patients (van der Heide et al., 2003). In this scenario, there is an increasing recognition that the health sciences have a duty to guide the decision-making in EoL, improving the quality of life of patients and families, and both preventing and relieving their sufferings (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002).

Autonomy in the decision-making regarding EoL is recognized by patients and their families as a high priority (Heyland et al., 2010), however, there is some divergence between their perspective and the data coming from studies on EoL care (Periyakoil, Neri, Fong, & Kraemer, 2014). For example, > 80% of patients would like to avoid hospitalizations and high intensity care during their EoL care, but they are often hospitalized in intensive care units (Truog et al., 2008). Different studies showed that the approach to delivering EoL care is closely linked to the characteristics of the local health care system, the institutional peculiarities and even the physicians' individual practice approaches (Kim et al., 2017; Periyakoil et al., 2014).

Accordingly, the possibility of appropriate decision-making regarding the EoL is very diverse around the world, and so are the regulations on this topic (Marcoux, Boivin, Arsenault, Toupin, & Youssef, 2015; Soto-Perez-de-Celis et al., 2017). For example, legal regulations about euthanasia and assisted suicide exist in Belgium, Luxembourg, Netherlands, Switzerland, Japan and in the State of Oregon (US) (van der Heide et al., 2003). Other countries – Germany, United Kingdom, the United States of America, France and Italy – approved the biological testament to allow patients' willingness to choose early on if they want to be kept alive on the basis of a treatment such as artificial feeding and hydration (Cogo, Lunardi, Cogo, & Lunardi, 2015).

Although some authors described the viewpoints of patients and their families related to EoL care, the attention towards the description of healthcare professionals' perspective about the choice for themselves in an EoL scenario is largely unexplored (Kim et al., 2017; Periyakoil et al., 2014; Periyakoil, Noda, & Kraemer, 2010). Some researchers showed that gender, ethnicity and specialty of physicians could be linked to their choice preference related to EoL care for their patients, but the description of what healthcare professionals want to choose for themselves is poorly investigated (Periyakoil et al., 2014, 2010). This gap could undermine the delivery of adequate education and information related to EoL care, due to the description of the healthcare professionals' viewpoints. This could help to address certain weaknesses within the current debate, especially when comparing their viewpoint with that of the general public, in order to identify the main areas of difference. So far, there are no studies that aim to explore the perceptions regarding the different choices in EoL care made by healthcare professionals and the general public. Therefore, this study aims to explore the difference between choices in EoL care made by healthcare professionals and those of the general public within the Italian context. In this regard, the discussion around EoL is very active in Italy, where the law related to the biological testament was recently approved (Italian Parliament Act, 2017). More precisely, the abovementioned law provides a roadmap for the advance directive in Italy, being the first Italian legislative act on this topic (Sulmasy, 2018). Therefore, this law establishes the right to refuse invasive tests and treatments, and the right to palliative care. The information from this study could improve the understanding of which aspect of EoL care varies between healthcare professionals and the general public, providing points for public debate and defining a clearer scenario to address the education needs around this topic.

2. Method

2.1. Design

This study had an exploratory and cross-sectional design to investigate the difference between choices in EoL care made by healthcare professionals and those of the general public in Italy. An online survey was created in January 2017, and it was administrated in the same year using the online tool SurveyMonkey®™. The sections of the survey were related to demographics, knowledge and choices in EoL care. More details about the rationale used to design the survey are described below. The decision to perform an online survey was based on the ease of use and the reach provided by internet access, which is often available to the broader public. People may answer more freely than they would with telephone or paper surveys, and there is no need for data entry, as the online form directly collects the participants' answers and effortlessly exports these as a dataset. The institutional review board of the coordination center has previously approved this study.

2.2. Survey development

The authors of this study developed the survey, supported by a panel of ten experts involved in bioethics studies and teaching. The authors designed a first draft of the survey considering the background given by the current debate in Italy around the biological testament law (Italian Parliament Act, 2017), while the panelists were involved in assessing its content validity to improve the quality of the final form of the same survey prior to its online administration (Polit & Beck, 2006). De facto, the panelists' involvement included assessment of their agreement regarding the pertinence of each item in relation to the objective of its measurement through the survey. They were asked to rate the survey's items in terms of relevancy (1 = not relevant; 2 = somewhat relevant; 3 = quite relevant; 4 = highly relevant). The Content Validity Index was calculated both for the items' level (I-CVIs) and for the scale-level (S-CVI) (Polit & Beck, 2006). Specifically, to obtain the relevancy of each item (I-CVIs), the number of those judging the item as relevant (i.e. ratings ≥ 3) was divided by the number of panelists. Furthermore, S-CVI was defined as the proportion of total items judged for content validity, and it was computed as the average of the I-CVIs. Those indices could range between zero and one, and the more the indices are closer to one, the higher the panelists' agreement that the content of the survey is adequate. All the items achieved adequate CVRs (CVR ≥ 0.75) and I-CVIs (I-CVIs ≥ 0.85) after three rounds of discussion with the panelists and their face validity assessment after each round.

Subsequently, the final survey consisted of two main domains: the first related to *knowledge* and the second related to *choices*. The knowledge domain was given by the following questions: (a) Have you ever heard the term 'euthanasia'? (b) Have you ever heard the term 'active euthanasia'? (c) Do you know what the term 'palliative sedation' means? (d) Do you know what the term 'assisted-suicide' means? (e) Do you know what 'biological testament' is? Conversely, the choices represented the main part of the survey, exploring three different scenarios. The first scenario referred to the '*need for information and to inform*', the second explored the '*general choices*', and finally the third scenario explored '*specific choices*'. Specifically, those scenarios are described in Table 1. Questions in the survey had a two-option's answer ('yes' versus 'no') for the knowledge domain, the 'need for information and to inform' (scenario 1), and 'general choices' (scenario 2). Conversely, the options for the 'specific choices' domain were three ('yes', 'no', 'not sure') to intercept those people who did not feel confident about making a choice in both a positive or negative sense.

Table 1
Survey administrated using SurveyMonkey®.

Knowledge
1. Have you ever heard the term 'euthanasia'?
2. Have you ever heard the term 'active euthanasia'?
3. Do you know what does 'palliative sedation' mean?
4. Do you know what does 'assisted-suicide' mean?
5. Do you know what 'biological testament' is?
Choices
Scenario 1 (need of information and to inform)
In full possession of my mental faculties, in total freedom of choice, I dispose as follows regarding the choices to be taken in case of medical treatment:
1. I would like to be informed about my health and life expectancy, even if I will suffer from a serious and unrecoverable disease
2. I would like to be informed about risks and advantages of diagnostic tests and therapies
3. I authorize my doctor to inform my family about my disease status (Yes versus No)
Scenario 2 (general choices)
In case of loss of the ability to decide or in the case of impossibility to permanently communicate my decisions to the doctors, I formulate the following indications regarding my medical treatments:
1. Medical treatments have to be started and continued even if their result was the maintenance in a state of permanent unconsciousness not susceptible to recovery
2. Medical treatments have to be started and continued even if their result was the maintenance in a state of paralysis with total incapacity to communicate verbally, writing or helped by technology
Scenario 3 (Specific choices)
If I had a terminal-stage disease, or a disabling and irreversible cerebral lesion, or an irreversible disease that requires the permanent use of machines (coma or persistent vegetative state), I dispose that:
1. All measures have be taken to alleviate my suffering, such as the use of opioid drugs
2. Cardiopulmonary resuscitation has to be used if deemed possible by healthcare providers
3. Mechanical forms of breathing have to be used (if necessary)
4. Artificial nutrition or hydration has to be used (if necessary)
5. Emergency surgery has to be used (if necessary)
6. Dialysis has to be used (if necessary)
7. Blood transfusion has to be used (if necessary)
8. Antibiotics has to be used (if necessary)

Note: All the answers could be 'Yes', 'No', or 'No Sure' (No Sure option was available for scenario 3 only).

2.3. Sampling and procedure

A snowball-stratified sample was generated among the Italian volunteer population (i.e., the general public) and healthcare professionals. The first initial public sample was enrolled by the sampling manager, who disclosed the survey invitation using social media to enroll the general public, creating a page ad hoc on the major social networks. In addition to the dissemination of the invitation to the survey via social media, the sampling manager also involves different region's referents to ensure a national widespread diffusion of the study invitation. Each region referent contributed to disseminate the survey using their own networks, using a snowball approach, where each involved volunteer that answered to the survey had the possibility to invite other eligible future volunteers from their networks of contacts. More precisely, this approach aimed to reflect the geographic, demographic and cultural diversity within the Italian context. The online tool used to manage the survey (SurveyMonkey®™) allowed the monitoring of the invitations, which were roughly 2000 and with a national broadcasting. Conversely, the group of healthcare professionals was also invited using a snowball sampling approach, where the sampling manager contacted the medical directors of different healthcare facilities to involve the healthcare professionals from their facilities.

Both the invitations for the general public and healthcare professionals contained information that related to the study such as aim, confidentiality disclosure and an online link to access the same survey. The incipit of the survey summarized again the aim of the study, also informing the participants that the completion of the same survey included consent for using their answers in an aggregated and anonymized form for analysis and the final study's scientific reporting. This approach was consistent with the Italian law and with the research protocol. The authors estimated that participants needed roughly 20 min to fill out the survey. This information, as well as a statement indicating that no form of remuneration would be provided for the study participation were indicated in the survey incipit. The link access was diversified for the two groups. Once the participants accessed the survey, a self-assessment check of eligibility was asked prior to proceeding with the questions. The eligibility check aimed to discriminate the two groups, where the general public had to state that their profession and educational background was not be related to healthcare such as medicine, nursing, and allied health professionals, whereas the healthcare professionals had to state their specific profession and educational background (e.g., MD, bachelor degree in nursing, master's degree). The survey was performed between January–August 2017.

2.4. Data analysis

Data were assessed for missing information, errors or outliers using the frequency check. A preliminary assessment of the internal consistency of the survey's domains was performed using Cronbach's alpha. Descriptive statistics were used to describe the sample and the survey answers, stratified by the two groups. The comparison between groups was performed through two steps. Firstly, the groups' answers were compared using Chi square (χ^2) test or Fisher's exact test, where appropriate. Secondly, the associations – between the answers ('yes' or 'no') and the groups, and between the will to make a choice for specific situations (scenario 3) (yes + no) and the groups – were assessed computing crude odds and adjusted ratios (ORs) with a 95% confidence interval (95% CI). Crude ORs (95% CI) were calculated in the univariate analysis by contingency table analysis. Then, adjusted ORs were calculated using a multivariable logistic regressions (MLRs) approach developed with the results of the contingency table analysis. MLRs were used for checking the conformity with a linear gradient for each included continuous variable, controlling the possible collinearity among the independent variables and generally assessing was done through the study of statistical significance using both the Wald's χ^2 and the likelihood ratio test and the assessment of the Goodness-of-fit measures – the Hosmer-Lemeshow test and the analysis of the Pseudo-R^2. Interferential analysis was performed setting $\alpha = 0.05$ and using a two-tailed hypothesis. All analyses were performed using IBM SPSS 22 (SPSS, Inc., Chicago, IL, USA) and R v 3.3.3 (R Foundation for Statistical Computing, Wien, Austria).

3. Results

3.1. Sample and survey's answers

Overall, 2038 participants completed the survey. All answers were mandatory to complete the survey. Thus, there was no missing data as participants who had not completed the survey were not considered in the final sample. The participants were mainly females (80.2%), with a university education (65.36%) and with an average age of 35.49 ± 14.09 years. Considering the group of the general public ($N = 1134$), the invitation reached 2589 possible participants, thus the response rate was equal to 43.8%. Conversely, the invitation for healthcare professionals ($N = 904$) reached 2356 possible participants, representing a 38.4% response rate. The online system to gather the answers recorded an average completion time of 16 min. In the overall sample, females had a higher response rate (80.2%), while the regions more widely represented were in line with the population distribution, being Lombardy (16.93%), Piedmont (14.18%), Lazio (14.08%), Emilia-Romagna (12.71%), and Campania (10.35%). The broadcast distribution in different Italian regions was obtained through the snowball sampling started in the different regional settings by the

Table 2
Demographic characteristics of the sample ($N = 2038$).

		N	%
Province	Abruzzo	104	5.10
	Apulia	116	5.69
	Basilicata	79	3.88
	Calabria	87	4.27
	Campania	211	10.35
	Emilia-Romagna	259	12.71
	Lazio	287	14.08
	Lombardy	345	16.93
	Piedmont	289	14.18
	Sicily	89	4.37
	Tuscany	88	4.32
	Veneto	84	4.12
Sex	Male	404	19.8
	Female	1634	80.2
Groups	General public[a]	1134	55.64
	Healthcare professionals[b]	904	44.36
Highest educational achievement	Lower than high school diploma	107	5.25
	High school diploma	599	29.39
	University education (under-postgraduate degrees)	1332	65.36
Age	Mean years (SD)	35.49	14.09

[a] General public were represented by (a) graduate professionals with university education (17.5%), (b) employees with high school diploma (73.1%) or lower than high school diploma (9.4%).

[b] Healthcare professionals were physicians (36.9%), nurses (54.8%) or other healthcare professionals (e.g., physiotherapists, technicians) (8.3%).

regions' referents who used the same online access link to invite possible participants and to gather the data. Among healthcare professionals, the main professions were nurses (54.8%) and physicians (36.9%). Table 2 shows the overall demographic characteristics of the sample.

Considering the answers to the knowledge domain (Cronbach's alpha = 0.876), the majority of participants gave a positive response by declaring that they knew the meaning of some terms, but with significant differences in the comparison related to 'active euthanasia' ($p = 0.000$), 'palliative sedation' ($p = 0.000$), 'biological testament' ($p = 0.009$), where healthcare professionals showed a greater distribution of the frequency in answering 'yes'. No differences were shown in the 'Need for Information and to inform', and the 'General choices' ($p \geq 0.05$). Conversely, all the 'Specific choices' showed significant differences. Table 3 outlines the frequencies stratified by the two groups and their comparison, and the Cronbach's alphas for the overall section of choices and each scenario.

3.2. Comparison of responses (yes versus no) between healthcare professionals and the general public

Healthcare professionals were roughly three times more likely than the general public to know the meaning of the term 'active euthanasia' (OR = 3.04; 95%CI = 2.38–3.88; $p = 0.000$; OR adjusted = 2.61; 95%CI = 1.97–3.46; $p = 0.000$) and 'palliative sedation' (OR = 5.32; 95%CI = 3.02–9.38; $p = 0.000$; OR adjusted = 3.16; 95%CI = 1.70–5.89; $p = 0.000$). Healthcare professionals were also more than two times likely to declare an understanding of 'biological testament' (OR = 3.45; 95%CI = 2.11–5.65; $p = 0.000$; OR adjusted = 2.38; 95%CI = 1.37–4.12; $p = 0.000$).

No differences were shown within the two groups between their likeliness to respond for the scenario of 'Need for Information and to inform' and 'General choices'.

Regarding the 'Specific choices', the univariate analysis showed associations for each situation. Specifically, healthcare professionals had 38% more likelihood than the general public to choose opioids to alleviate suffering (OR = 1.38; 95%CI = 1.04–1.85; $p = 0.020$), this likelihood increased to 43% in the MLR model (OR adjusted = 1.43; 95%CI = 1.06–1.93; $p = 0.010$). Moreover, within this scenario the likelihood to choose cardiopulmonary resuscitation was lower for healthcare professionals than the general public, from 53% less of the univariate analysis to 36% less showed by MLR model (OR = 0.47; 95%CI = 0.37–0.59; $p = 0.000$; OR adjusted = 0.64; 95%CI = 0.42–0.98; $p = 0.040$). Mechanical forms of breathing (OR = 0.52; 95%CI = 0.39–0.69; $p = 0.000$), artificial nutrition or hydration (OR = 0.76; 95%CI = 0.59–0.98; $p = 0.034$), emergency surgeries (OR = 0.70; 95%CI = 0.53–0.92; $p = 0.011$), dialysis (OR = 0.49; 95%CI = 0.38–0.62; $p = 0.000$), and blood transfusion (OR = 0.50; 95%CI = 0.39–0.63; $p = 0.000$) were less likely chosen by healthcare professionals. In addition, they were three times more likely than the general public to choose antibiotics administration if necessary (OR = 3.56; 95%CI = 0.39–0.69; $p = 0.000$). However, these last six situations showed the loss of their statistical significance in the MRLs analysis. Table 4 outlines the synopsis of the comparison of responses (yes versus no) between healthcare professionals and the general public.

3.3. Specific choices: to do a 'yes or no' choice versus 'not sure'

Healthcare professionals showed a more increased likelihood than the general public to make a choice related to: opioid use (OR = 1.59; 95%CI = 1.14–2.22; $p = 0.000$; OR adjusted = 1.39; 95%CI = 1.05–1.83; $p = 0.011$), cardiopulmonary resuscitation (OR = 1.83; 95%CI = 1.09–3.02; $p = 0.000$; OR adjusted = 1.72; 95%CI = 1.15–2.45; $p = 0.011$), artificial nutrition (OR = 154; 95%CI = 1.06–2.23; $p = 0.000$; OR adjusted = 1.39; 95%CI = 1.11–2.01; $p = 0.012$), emergency surgeries (OR = 3.56; 95%CI = 2.38–5.32; $p = 0.000$; OR adjusted = 2.98; 95%CI = 1.76–3.31; $p = 0.000$), and antibiotics use (OR = 1.75; 95%CI = 1.14–2.70; $p = 0.000$; OR adjusted = 1.14; 95%CI = 1.01–1.81; $p = 0.051$). Table 5 outlines the synopsis of the comparison of responses related to making a choice within the 'Specific choices' scenario (yes or no) between healthcare professionals and the general public.

4. Discussion

This research outlined the perceptions regarding different choices in EoL care made by healthcare professionals and the general public within the Italian context, where the debate around EoL is very active (Riccioni & Gristina, 2015). The results should be useful to frame insights and boost reflections, as this study helps to increase the awareness that choices related to EoL could vary between healthcare professionals and the general public. These differences could be linked to certain stereotypes or general familiarity with specific themes such as the use of opioids to alleviate sufferings (Darke, 2014). Overall, this survey received a large number of participants across the national territory. Considering the participant characteristics, there were more women than men. This gender distribution in the study participation may have a double reason: on one hand, the percentage of women working in healthcare in Italy is higher than men (Ministry of Health, 2013); on the other hand, women seem more likely to discuss EoL care than men (Sharma, Prigerson, Penedo, & Maciejewski, 2015). As it was expected, the overall high rate of participants with a university education was related to the presence of healthcare professionals. Accordingly, the university education in the general public group (see Table 2) reflected the Italian distribution of people with a university education, which is around 18% of the general population (Riccioni & Gristina, 2015).

The comparison related to the knowledge questions showed that the differences between groups were related to the meaning of the terms 'active euthanasia', 'palliative sedation', and 'biological testament'. Some authors described that levels of understanding around the legal options of EoL care is a current issue, due to the fragmented

Table 3
Descriptive statistics and comparison between general public and health professionals.

	General public (*N* = 1134)			Health professionals (*N* = 904)			*p*-Value
	Yes (%)	No (%)	Not sure (%)	Yes (%)	No (%)	Not sure (%)	
Knowledge *(Cronbach's alpha = 0.876)*							
Question 1	99.5	0.5	–	99.7	0.3	–	0.272
Question 2	57.7	42.3	–	80.6	19.4	–	**0.000**
Question 3	88.3	11.7	–	97.6	2.4	–	**0.000**
Question 4	88.6	11.4	–	90.3	9.7	–	0.312
Question 5	88.9	11.1	–	96.5	3.5	–	**0.009**
Choices *(overall Cronbach's alpha = 0.776)*							
Scenario 1 *(Cronbach's alpha = 0.881)*							
Choice 1	96.3	3.7	–	96.9	3.1	–	0.649
Choice 2	99.1	0.9	–	99.3	0.7	–	0.272
Choice 3	73.0	27.0	–	71.0	29.0	–	0.463
Scenario 2 *(Cronbach's alpha = 0.711)*							
Choice 1	14.9	85.1	–	15.1	84.9	–	0.926
Choice 2	10.5	89.5	–	13.8	86.2	–	0.432
Scenario 3 *(Cronbach's alpha = 0.793)*							
Choice 1	79.3	14.0	6.6	82.3	15.9	1.9	**0.005**
Choice 2	40.4	52.3	7.3	24.0	73.0	3.1	**0.000**
Choice 3	24.6	63.9	11.5	15.1	81.7	3.2	**0.000**
Choice 4	25.8	62.8	11.4	21.4	74.9	3.8	**0.007**
Choice 5	20.0	62.6	17.4	16.5	80.8	2.7	**0.010**
Choice 6	36.1	55.1	8.7	21.9	75.3	2.8	**0.000**
Choice 7	41.1	51.5	7.4	25.7	71.8	2.5	**0.000**
Choice 8	42.6	48.3	9.1	29.7	67.7	2.6	**0.000**

Legend: Significant associations are shown in bold.

Table 4
Comparison of responses (healthcare professionals versus general public).

	OR	95%CI	*p*-Value	OR adjusted	95%CI	*p*-Value
Knowledge						
1. Have you ever heard the term 'euthanasia'? (yes versus no)	1.55	0.30–8.01	0.59	–	–	–
2. Have you ever heard the term 'active euthanasia'? (yes versus no)	**3.04**	**2.38–3.88**	**0.00**	**2.61**	**1.97–3.46**	**0.00**
3. Do you know what does 'palliative sedation' mean? (yes versus no)	**5.32**	**3.02–9.38**	**0.00**	**3.16**	**1.70–5.89**	**0.00**
4. Do you know what does 'assisted-suicide' mean? (yes versus no)	1.19	0.84–1.67	0.31	–	–	–
5. Do you know what 'biological testament' is? (yes versus no)	**3.45**	**2.11–5.65**	**0.00**	**2.38**	**1.37–4.12**	**0.00**
Choices						
Scenario 1 (need of Information and to inform)						
In full possession of my mental faculties, in total freedom of choice. I dispose as follows regarding the choices to be taken in case of medical treatment:						
1. I would like to be informed about my health and life expectancy. Even if I will suffer from a serious and unrecoverable disease (yes versus no)	1.28	0.70–2.35	0.42	–	–	–
2. I would like to be informed about risks and advantages of diagnostic tests and therapies (yes versus no)	1.55	0.30–8.01	0.59	–	–	–
3. I authorize my doctor to inform my family about my disease status (yes versus no)	0.92	0.73–1.16	0.49	–	–	–
Scenario 2 (general choices)						
In case of loss of the ability to decide or in the case of impossibility to permanently communicate my decisions to the doctors, I formulate the following indications regarding my medical treatments:						
1. Medical treatments have to be started and continued even if their result was the maintenance in a state of permanent unconsciousness not susceptible to recovery (yes versus no)	1.01	0.75–1.35	0.92	–	–	–
2. Medical treatments have to be started and continued even if their result was the maintenance in a state of paralysis with total incapacity to communicate verbally. Writing or helped by technology (yes versus no)	1.14	0.82–1.58	0.42	–	–	–
Scenario 3 (specific choices)						
If I had a terminal-stage disease, or a disabling and irreversible cerebral lesion. Or an irreversible disease that requires the permanent use of machines (coma or persistent vegetative state). I dispose that:						
1. All measures have be taken to alleviate my suffering, such as the use of opioid drugs (yes versus no)	**1.38**	**1.04–1.85**	**0.02**	**1.43**	**1.06–1.93**	**0.01**
2. Cardiopulmonary resuscitation has to be used if deemed possible by healthcare providers (yes versus no)	**0.47**	**0.37–0.59**	**0.00**	**0.64**	**0.42–0.98**	**0.04**
3. Mechanical forms of breathing have to be used (if necessary) (yes versus no)	**0.52**	**0.39–0.69**	**0.00**	0.68	0.39–1.17	0.16
4. Artificial nutrition or hydration has to be used (if necessary) (yes versus no)	**0.76**	**0.59–0.98**	**0.03**	0.98	0.91–2.60	0.62
5. Emergency surgery has to be used (if necessary) (yes versus no)	**0.70**	**0.53–0.92**	**0.01**	1.26	0.76–2.11	0.81
6. Dialysis has to be used (if necessary) (yes versus no)	**0.49**	**0.38–0.62**	**0.00**	0.80	0.40–1.61	0.54
7. Blood transfusion has to be used (if necessary) (yes versus no)	**0.50**	**0.39–0.63**	**0.00**	0.60	0.27–1.32	0.20
8. Antibiotics has to be used (if necessary) (yes versus no)	**3.56**	**3.44–4.70**	**0.00**	1.14	0.71–1.81	0.59

Note: OR Adjusted were computed through a series of logistic regression models were the predictors were entered on the basis of the univariate analysis. All the models were checked for goodness of fit.
Legend: Significant associations are shown in bold.

Table 5
Comparison of choices: 'Do a choice' versus 'Not sure' (healthcare professionals versus general public).

	OR	95%CI	*p*-Value	OR adjusted	95%CI	*p*-Value
Choices						
Scenario 3 (specific choices)						
If I had a terminal-stage disease, or a disabling and irreversible cerebral lesion, or an irreversible disease that requires the permanent use of machines (coma or persistent vegetative state), I dispose that:						
1. All measures have be taken to alleviate my suffering, such as the use of opioid drugs ('do a choice' versus 'not sure')	**1,59**	**1,14-2,22**	**0,00**	**1,39**	**1,05-1,83**	**0,01**
2. Cardiopulmonary resuscitation has to be used if deemed possible by healthcare providers ('do a choice' versus 'not sure')	**1,83**	**1,09-3,02**	**0,00**	**1,72**	**1,15-2,45**	**0,01**
3. Mechanical forms of breathing have to be used (if necessary) ('do a choice' versus 'not sure')	1.17	0,77-1,80	0,44	–	–	–
4. Artificial nutrition or hydration has to be used (if necessary) ('do a choice' versus 'not sure')	**1,54**	**1,06-2,23**	**0,02**	**1,39**	**1,11-2,01**	**0,01**
5. Emergency surgery has to be used (if necessary) ('do a choice' versus 'not sure')	**3,56**	**2,38-5,32**	**0,00**	**2,98**	**1,76-3,31**	**0,00**
6. Dialysis has to be used (if necessary) ('do a choice' versus 'not sure')	**0,49**	**0,38-0,62**	**0,00**	0,80	0,40-1,61	0,54
7. Blood transfusion has to be used (if necessary) ('do a choice' versus 'not sure')	1,51	0,96-2,38	0,07	–	–	–
8. Antibiotics has to be used (if necessary) ('do a choice' versus 'not sure')	**1,75**	**1,14-2,70**	**0,00**	**1,14**	**1,01-1,81**	**0,05**

Note: OR Adjusted were computed through a series of logistic regression models were the predictors were entered on the basis of the univariate analysis. All the models were checked for goodness of fit.
Legend: Significant associations are shown in bold.

information currently available by the media and the diverse legislation among countries (Mercadante, Costanzi, Marchetti, & Casuccio, 2016). The debate around themes such as euthanasia is very active (Mercadante et al., 2016), but this study's results showed that the general public is little informed about the peculiarities related to specific EoL topics such as understanding the meaning of 'active euthanasia', 'palliative sedation', and 'biological testament'. This gap in public knowledge could undermine many debates, affecting the real awareness related to the options in EoL care, and it could generate stereotypes about the same EoL choices and meanings. These aspects should be addressed to increase knowledge and awareness by the general public. These results are also consistent with the confusion around the different possibilities of EoL choices and their meanings (Tuffrey-Wijne, Curfs, Finlay, & Hollins, 2018). The gap in public knowledge represents a challenge for healthcare professionals, who should improve the communication about these themes to build a more solid public understanding of the different and possible choices, using an education and information approach consistent with the national regulation. In this regard, there is a convergence of definitions where euthanasia could broadly be defined as the 'hastening of death of a patient to prevent further suffering at the patient's explicit request', and specifically, active euthanasia occurs when the healthcare professional performs an action to end the patient's life, such as the administration of a lethal drug (Davies & Higginson, 2004, p. 25). Conversely, passive euthanasia is intended as the omission of an act or a withdrawal of an act that was keeping a patient alive, such as removing a feeding tube (Davies & Higginson, 2004). Other important definitions to frame the magnitude of the debate around EoL care refer to the biological testament (bio-testament) and palliative sedation. The bio-testament encompasses the advance directives and living will, aimed to guarantee to patients the ability to make a choice in final moments of their lives, accepting or denying their consent to certain treatments, e.g. feeding and artificial hydration. Within the bio-testament, the living will is a document by which a person can register, consistently with his/her wishes, which treatments can be performed by healthcare professionals in the case of an incurable disease, to ensure the patients right to die with dignity, in accordance with their personal perspectives (Peicius, Blazeviciene, & Kaminskas, 2017). Palliative sedation refers to the relief of unremitting and intractable suffering achieved by sedation in EoL care (Olsen, Swetz, & Mueller, 2010). Particularly, palliative sedation differs from active euthanasia for its intent, which is not the termination of the patient's life but the relief from suffering.

The debate around EoL care is surely more complex than the one shaped by the differences arising from the knowledge domain's results of this study, even by acknowledging that the terms and EoL situations are numerous and often obscure for the same healthcare professionals (Dunlay et al., 2015). In fact, the knowledge domain of this study set out to be very generic and focused only on the terms more commonly used by media in the Italian context. In other words, if this study revealed a gap in the knowledge of EoL general terms between the general public and that of healthcare professionals, it would be argued that this gap was underestimated. This fact corroborates the necessity to improve the quality of information and education for the general public around all these topics.

An important novelty of this study is the direct exploration of the choices of the same healthcare professionals. De facto, an important peculiarity emerged: healthcare professionals are more likely to make choices in EoL care for themselves in a different way to that of the general public. This topic is largely unexplored by scientific literature. It is very likely that the reasons underpinning those differences could be related to the specific knowledge of healthcare professionals and their life experiences in caring for ill patients, influencing their self-awareness about the meaning of a more positive experience of death (Emanuel, Onwuteaka-Philipsen, Urwin, & Cohen, 2016). Many healthcare professionals improved their self-awareness through their work, which is also a key element to establish empathetic relations with patients, increase their communication skills, and self-evaluate the ability to deliver healthcare (Haley et al., 2017). Self-awareness is defined as the understanding of the self, allowing one to express attitudes and beliefs towards other people, being a sort of capacity to self-evaluate one's morals and become non-judgmental when different situations are assessed (Rogers, 2007). In other words, self-awareness is closely linked to the ability to know what oneself really wants, as an essential component to align the individual's choice within every healthcare setting (Goswami, 2013).

Another result confirming that the general public is less likely to decide for themselves in specific situations was given by the comparison between who made a positive or negative choice related to the items of scenario 3, and who preferred to state 'not sure'. Healthcare professionals were more likely to make a choice than the general public in many situations proposed by scenario 3, such as the cardiopulmonary resuscitation or the mechanical forms of breathing in the case of terminal-stage disease. Once again, it is reasonable to argue that the matter related to the participants' self-awareness could address the differences in this survey's results. Self-awareness, unlike general knowledge, requires a particular connection between one's mental representation of a specific situation – which could be defined as knowledge – and one's mental representation of the self as an agent to determinate choices and beliefs (Jacoby & Galak, 2016).

4.1. Limitations

Although this research represents an important glimpse of Italian choices related to EoL care, as it is also one of the first studies that aimed to provide an insight on the differences between the EoL choices of healthcare professionals and general public, it presents some important limitations. Firstly, the sample was non-probably estimated and the risk of oversampling some Italian areas was intrinsic to this approach, even if controlled by the presence of different regions' referents. Moreover, the absence of a randomization could affect the statistical inferences; for this reason, this study's results should be generalized with caution, even if the final study sample was very large. Another limitation was given by the high rate of females in the final sample. However, it was previously described that EoL themes could be gendered during the studies (Sharma et al., 2015). Finally, the participants were mostly young adults, which could be explained by their higher confidence than older generations to operate online systems to gather data. Overall, despite the intrinsic limitations of the snowball sampling approach, the authors followed the best recommendations to optimize the quality of the sample (Heckathorn, 1997). In fact, the final sample was well balanced regarding the regional distribution and also many socio-demographics characteristics were in line with the general Italian population, such as the participants with university education or the distribution of the ratio between healthcare professionals (Caruso, Pittella, Zaghini, Fida, & Sili, 2016). Another important limitation is represented by the cross-sectional data collection. In fact, many authors defined the EoL decision-making as a dynamic process that could vary throughout one's life (Kim et al., 2017). In other words, this survey represents a static glimpse of an Italian situation within a period of lively public debate on EoL care.

5. Conclusions

This study provides a snapshot of Italian choices related to EoL care, providing an insight that could describe the main differences between choices made by healthcare professionals and the general public. Healthcare professionals were more likely to avoid cardiopulmonary resuscitation and mechanical forms of breathing in terminal-stage conditions. These differences are not only related to the choices, but also to the general willingness to 'make a choice' or 'refrain from it', assigning a 'not sure' regarding specific scenarios. Accordingly, healthcare professionals were more likely to make a specific choice than the general public. All these differences could be related to the healthcare professionals' self-awareness, as they would be more confident in aligning their knowledge and their concept of self to frame their beliefs and possible choices due to their professional experience. De facto, these differences can be related to a plausible relationship between knowledge and self-awareness; however, we need more research to explore and define this potential relationship more deeply and precisely. The understanding of this phenomena should be deeply investigated to provide more elements to establish a sound education and information, aimed to help develop a culture where death and dying are not considered a sort of taboo, but a part of one's life. For this reason, healthcare professionals have the duty to promote a paradigmatic shift to sensitize the general public towards EoL care. Indeed, the choices on EoL care are not static, but dynamic and with important implications for the same patients' lives, but also for their caregivers and overall society.

Further, nurses represent the most prevalent group among the healthcare professionals involved in EoL care, being actively involved in the addressing of the most difficult healthcare challenges in these settings. This implies that the findings from this study provide the rationale for future nursing insights to deeply explore the peculiarities of the relationship between knowledge and self-awareness in EoL care. Further, nursing research should also describe the contribution of the nursing education towards families and patients in framing their self-awareness, which represents the base where the right to be independent in making a choice (self-determination) is laid.

In conclusion, the high percentage of participants in the general public group that choose 'not sure' suggested how important it is to address and enhance people self-awareness, which is the paramount way to express what oneself really wants in such particular situations. That capacity could be paraphrased using the ancient Greek aphorism 'know thyself', also known acknowledging the Latin quote: '*Nosce te ipsum*'.

Conflict of interest (COI) statement

The authors declare that there is no conflict of interest.

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