

Attitudes, perceptions, and knowledge of the population on End-of-Life and Advance Treatment Declaration: an observational study in Southern Italy

*Antonino Calabro¹, Roberto Lupo², Iliaria Bernardini³, Ornella De Mitrì⁴, Cosimo Caldararo⁵,
Marcello Antonazzo⁶, Carmen Donadio⁷, Maicol Carvello⁸, Federica Ilari⁹, Maria Chiara Carriero¹⁰, Luana Conte¹¹⁻¹²*

¹"Nuovo Ospedale degli Infermi" Hospital, ASL (Local Health Authority) Biella, Italy

²"San Giuseppe da Copertino" Hospital, ASL (Local Health Authority) Lecce, Italy

³"Antonio Perrino" Hospital, ASL (Local Health Authority) Brindisi, Italy

⁴"V.Fazzi" Hospital, ASL (Local Health Authority) Lecce, Italy

⁵"A. Moro" University, Bari, Italy

⁶"V. Fazzi" Hospital, ASL (Local Health Authority) Lecce, Italy

⁷"Salvatore Peragine" Hospital, ASL (Local Health Authority) Stigliano, Italy

⁸"Brisighella Community Hospital, ASL (Local Health Authority) Romagna, Brisighella, Ravenna, Italy.

⁹"University of Piemonte Orientale Biella, Italy

¹⁰"Santa Chiara Institute, Rome, Italy.

¹¹Laboratory of Interdisciplinary Research Applied to Medicine (DReAM),

University of Salento and ASL (Local Health Authority) Lecce, Italy

¹²Laboratory of Biomedical Physics and Environment, Department of Mathematics and Physics,
University of Salento, Lecce, Italy.

Corresponding author: Luana Conte

luana.conte@unisalento.it

Abstract

In an advanced scientific and technological context, where it is now tangible the possibility of interfering indefinitely in the process of dying, it becomes necessary to disseminate knowledge about end of life that, for the great variety of areas that it invests, presents many controversial aspects. With the *Law no. 219/2017*, the right of self-determination and freedom of treatment of the patient is enshrined, aspects that to date still remain too little discussed. An online survey was conducted from December 2019 to February 2020, among the population residing in the provinces of Lecce and Brindisi, spread thanks to the collaboration of local authorities. A large part of the sample (82.4%, N=333) claims the right to self-determination, stating that therapeutic decisions are up to the patient who has signed his advance treatment dispositions, declared absolutely binding for 50% (N=205) of the sample. However, there is still a lack of information about how to draw up advance treatment agreements (AADs). 12.6% (N=51) of those interviewed stated that they knew nothing about it and only 32.9% (N=133) felt ready and adequately informed to make their own declarations. Another peculiar aspect is that topics such as euthanasia and assisted suicide seem to be considered at the margins of acceptability among End-of-Life instances. The results of the study show that knowledge on the subject has definitely improved over the years and that in most of the issues addressed, the population has an adequate degree of preparedness even though there is still some skepticism in dealing with issues such as assisted suicide and euthanasia. Future research could explore the possibility of identifying effective training tools and communication strategies that can be used by the widest possible segment of the population.

Keywords: End of life, Self-determination, Training, Information, Advance directive on treatment

1. Introduction

In Europe, and more generally in the Western world, the demographic transition has led to a prolongation of average life expectancy that has, however, coincided with a steady increase in chronic degenerative diseases (Riccioni et al. 2016). At the same time, in the health field, we are witnessing an impressive/impervasive scientific and technological progress which has allowed death to be transformed from a natural "event" into a medicalized "process" (Carlet et al. 2004; Lippo et al. 2014). In this context, in contemporary society, the most debated and controversial ethical issues are located, related to the end of life of the terminally ill person suffering from irreversible diseases, in conditions of discomfort and suffering. Moreover, as made evident by the dramatic case law cases presented in recent years, from Piergiorgio Welby to Eluana Englaro and Dj Fabo, have opened the political, social, and ethical debate on the end of life. Stories that have divided Italy, between those in favor and those against. The recognition of the right to refuse treatment as a correlate "*in negative*" of the principle of consent, has not prevented the emergence of various legal problems (Colacino et al. 2015), from the qualification of the interruption of medical treatment when it requires a phenomenologically active conduct, to the problem of representation and relevance of the will of the patient in a state of unconsciousness, which, in the continuing absence of legislative solutions, have been addressed by case law through the application of constitutional principles. The issues at the center of the discussion concern the limitation of care, therapeutic overkill, palliative care, advance declarations of treatment - DAT (*Law no. 219/2017*), medically assisted suicide, euthanasia; terms, meanings and contents that are often not distinct, thwarted by the excessive spectacularizing/emphasizing/media distortion that empty them of the complexity, depth, and morality with which they are imbued. To engage in a discussion on the issues of Life, Death and Suffering is to highlight the fundamental

bioethical principles and consider the diversity of views that arise from the analysis of them (Beauchamp et al. 2001). *Law no. 219/2017* ("Rules on informed consent and advance treatment dispositions") recognizes everyone is right to know their health conditions and to be informed in a complete and comprehensible way not only about the diagnosis, prognosis and benefits and risks associated with health checks and treatments, but also regarding the alternatives and consequences of any refusal of health treatment. Refusal of health treatment is part of the freedom of self-determination in health care, a freedom with respect to which the issue of the "end of life" emerges. The discipline on the rights of the person in end-of-life decisions, as also indicated in *Law no. 219/2017 (art.1)*, "protects the right to life, health, dignity and self-determination of the person and establishes that no health treatment can be initiated or continued if lacking the free and informed consent of the person concerned" (Cattorini et al. 2011). Every person who is capable of acting is recognized the right to refuse, in whole or in part, any diagnostic test or health treatment related to the disease from which the person is affected. The freedom of self-determination in the field of health care assumes such importance as to be recognized, in fact, even to those who are in a state of incapacity and it can also be exercised at a time prior to the onset of the disease or the situation that determines the state of incapacity through the *advance directive of treatment*. The ethical revolution of Biotestament has laid the foundation for the creation of a therapeutic alliance relationship between the one who provides care and the one who chooses to receive it, whereby the physician and/or the nurse can act according to the beneficial principle "only when the patient consents to his action and accepts it" (Garini et al. 2018). The recognition of the right to refuse treatment, however, is not equivalent to the recognition of the right to die, which is why it is important to know the meaning of the terminology that comes to the fore when discussing the end of life. The lack of training and information on

these aspects could generate confusion and reduced compliance; there are few studies conducted in the literature on these aspects.

2. Aim of the study

Survey of attitudes, perceptions and knowledge of the Italian population living in the provinces of Lecce and Brindisi with respect to the contents related to ethical issues of the end of life.

2. Methods

2.1 Design and Settings

The study was conducted among the population residing in the provinces of Lecce and Brindisi from December 2019 to February 2020. Before the start of the study, all participants were informed about the modalities and aims of the study. Only after their consent, the enrollment of study participants was carried out. The entire population in an age range of 18-80 years was included, who decided to take part in the survey on a voluntary basis. Each participant was given the data collection tool, the ad hoc constructed questionnaire consisting of a socio-demographic section and one relating to the actual survey on terms, content and attitudes related to the ethical issues of the end of life. To conduct this study, we chose to enlist a non-probabilistic sampling. The first items (1-12) inquire about the quality of the information related to the terminology concerning the ethical issues of the end of life, items 13-16 question and ask the respondent to express an opinion regarding the choice to suspend life treatments in cases of permanent vegetative state and regarding advance treatment dispositions related to adult and/or pediatric patients. Items 17-22 aim to explore in depth knowledge and attitudes about ART. Finally, the last two items (23-24) ask the respondent to express an opinion about the legalization of assisted suicide and euthanasia.

2.2. Statistical analysis

Analysis Descriptive analyses were conducted for all qualitative and quantitative variables using Statistical Package for Social Science (SPSS) Software version 17. Continuous variables were summarized by mean and standard deviation (SD) and categorical variables by frequencies and percentages.

2.3. Ethical consideration

Data were collected with respect for confidentiality and anonymity of the participants. Questionnaires were administered only to athletes who agreed to participate by signing the informed consent. The study project was illustrated and presented in advance to the facility managers of the centers involved; only after their consent was the survey started.

3. Results

3.1 Socio-demographic characteristics of the sample

The descriptive measures show that the population examined is evenly distributed between the provinces of Lecce (N=218, 54%) and Brindisi (N=186, 46%). The sample has an average age of 32 years (SD 13.14) More than half of the sample (n= 221, 54.7%) has a High School Diploma, the remainder (N=165, 40.8%) has a Degree. From the study, 52% (N=210) of the sample had never had the opportunity to train in bioethics, 46% (N=180) stated that they had done so through conferences and seminars, personal readings and through continuing education courses. (Table 1)

Table 1. Social-demographic data	N (%)
Age (average, DS)	32 (13.14)
Gender	
Male	156 (38,6)
Female	248 (61.4)
Civil Status	
Single	289 (71,5)
Married	89 (22.0)
Cohabitant	19 (4.7)
Divorced	7 (1.7)
Religious Creed	

Agnostic	56 (13,9)
Believer	254 (62,9)
Non-believer	94 (23,3)
Qualification	
No title	1 (0,2)
Elementary	3 (0,7)
Lower Middle	14 (3,5)
Superior	221 (54,7)
Under/post-graduate	165 (40,8)
Profession	
Physician	11 (2,7)
Nurse Practitioner	127 (31,4)
More	266 (65,8)
Children	
Yes	93 (23)
no	311 (77)
Have you had the opportunity to curate his education in bioethics before?	
No, never	210 (52)
Yes	180 (44,6)
Yes, through training courses	2 (0,5)
Yes, through conferences and seminars	6 (1,5)
Yes, through personal readings	6 (1,5)

3.1 Attitudes and knowledge with respect to living wills and end-of-life issues

Participants were asked to judge their own level of knowledge regarding ethical end-of-life issues. With respect to the regulatory aspect of three different clinical conditions such as "terminal illness" (47.8%), "irreversible coma" (36.6%) and "permanent vegetative state" (42.8%) it emerged that most of the participants have heard of them, so more than 40% in all three questions. 28.7% declared to know enough about terminal illness, while 40.1% declared to know enough about irreversible coma and 34.4% about permanent vegetative state. Despite what could be imagined, the analysis shows that the sample declares to feel quite knowledgeable in the field of Informed Consent (33.2%) in the same measure in which it affirms to have very good knowledge (33.2%), data that are subsequently confirmed since 57.2% are able to identify the correct expression of the meaning. For the Biological Will, as many as 85.8% of those interviewed would be able to define it and this could testify that the informed population is increasing, and *that Law 219/2017* has

contributed to fill gaps on informed consent and to redefine the physician-patient relationship. Regarding the therapeutic field, which concerns both therapeutic abandonment and palliative care, the percentages show that the sample is well informed (44.5% and 35.6%). About palliative care, 28.5% of the sample felt they had very good knowledge. The majority of those interviewed chose the correct definitions, and the same situation was repeated for life-support treatments, which appear to be well known to almost all the sample, for which there were no doubts about the terms Nutrition and Artificial Ventilation (items 9-10). It is also noteworthy that, when asked to consider as fair the choice of a patient to refuse life-saving treatments, the sample agreed absolutely in 63.10% of cases, in line with the request to identify the most suitable figure to act in the place of the patient who cannot express his or her wishes: it is significant that 82.4% of the sample affirmed that therapeutic decisions are up to the patient who has signed the Living Will, while 5% believed that life-support treatments should never be suspended (item 13). It is also important that the participants believe that it is right that the will of minors in the clinical choice should no longer remain unheard, as shown by the percentages; in fact, there is a propensity on the part of the sample to listen to the opinion of the minor and to involve him/her in the choices that concern them. The figure that rises in the second case concerns the percentage of participants who consider the opinion of the minor to be irrelevant, which is almost 10%. One aspect that needs to be taken care of regarding advance treatment provisions is that of the way they are signed. The option chosen by 68.8% of the participants regarding the way to express the DAT is the written form authenticated by signature. Another part of the sample (16.1%) believes that the DAT can be communicated to a trusted person, while 12.6% (item 20) state that they do not know of any method. From an attitudinal point of view (item 21), the scenario is not homogeneous: 32.9% of the participants state that they feel sufficiently prepared, 31.4% that they have partial knowledge of the subject

and 23.3% that they do not feel sufficiently informed, together with 12.4% (N=50) of the sample who do not feel sufficiently informed at all. Regarding Euthanasia and Assisted Suicide, 50% of the population was in favor of the legalization of these two practices, respectively 50.7% for assisted suicide and 53.7% in favor of euthanasia. Those against are 5.4% for assisted suicide and 5.9% for euthanasia. The rest of the population is most likely to state that they are in favor with percentages of 32.9% and 29.7% and probably unfavorable for 10% (items 23-24) (Table 2).

Table 2. "Living will and end-of-life issues"	
1: Have you ever heard of irreversible conditions of illness with an inauspicious course, or physical/cerebral injuries where there is an inability to express one's own will and which force the patient to depend on people and machines?	N (%)
Yes, I heard about it on television.	160 (39,6)
Yes, through the internet.	128 (31,7)
Yes, through acquaintances.	101 (25)
No	8 (2)
Yes, through personal readings	6 (1,5)
Yes, through conferences and seminars	1 (0,1)
2.1 Terminal illness:	19 (4,7)
Very poor	193(47,8)
I have heard about it	116 (28,7)
I know enough	76 (18,8)
Very good	
2.2 Irreversible coma	29 (7.2)
Very poor	148 (36.6)
I have heard about it	162 (40.1)
I know enough	65 (16.1)
Very good	
2.3 Permanent vegetative state	31 (7,7)
Very poor	173 (42,8)
I have heard about it	139 (34,4)
I know enough	61 (15,1)
Very good	
3: How do you rate your knowledge with respect to the following ethical issues and related standards governing the physician-patient relationship? (likert scale)	

3.1 Informed consent	
Very poor	43 (10,6)
I have heard about it	93 (23)
I know enough	134 (33,2)
Very good	134 (33,2)
3.2 Biological testament	
Very poor	46 (11,4)
I have heard about it	144 (35,6)
I know enough	154 (38,1)
Very good	60 (14,9)
3.3 Therapeutic abandonment	
Very poor	38 (9,4)
I have heard about it	104 (25,7)
I know enough	181 (44,8)
Very good	81 (20)
3.4 Palliative care	
Very poor	56 (13,9)
I have heard about it	89 (22)
I know enough	144 (35,6)
Very good	115 (28,5)
3.5 Assisted Suicide	
Very poor	59 (14,6)
I have heard about it	155 (38,4)
I know enough	141 (34,9)
Very good	49 (12,1)
3.6 Euthanasia	
Very poor	26 (6,4)
I have heard about it	137 (33,9)
I know enough	171 (42,1)
Very good	70 (17,3)
4: When we talk about a living will, what document are we referring to?	
To a document in which a patient asks for an end to their suffering, as painlessly and quickly as possible, in the case of incurable diseases.	59 (14,6)
To a document in which a patient asks to prolong his or her life by extraordinary technological means, in the case of incurable diseases	0
To a document, produced by a person in a lucid state of mind, regarding the possible care or treatment to which he or she wishes to be subjected at the time he or she becomes unconscious or loses decision-making capacity	345 (85,8)
To a document in which a patient asks to intentionally procure their own death if their quality of life is irreversibly impaired.	0
5: What is meant by euthanasia?	
It is a medical approach that aims to treat a patient through experimental treatments.	1 (0,2)
It is a medical and administrative aid that enables a patient to commit suicide independently and voluntarily, through an act performed by the patient.	113 (28,2)

Attitudes, perceptions, and knowledge of the population on End-of-Life and Advance Treatment Declaration: an observational study in Southern Italy

It is a medical intervention intended to intentionally bring about the death of a patient, at his or her request and without causing pain, when his or her quality of life is irreversibly impaired.	284 (70,1)
I don't know.	6 (1,5)
6: What is palliative care?	
They are a medical approach that aims to treat a patient through experimental treatments.	10 (2,4)
These are treatments aimed at hastening the death of a terminal patient.	16 (4)
These are treatments aimed at delaying the death of a terminal patient as much as possible.	40 (9,9)
They are an approach that improves the quality of life for a terminally ill person and their family through prevention and relief of suffering.	338 (83,7)
7: What is meant by therapeutic overkill?	
It is the administration of medical treatment without the consent of the patient.	27 (6,7)
It is the administration of medical treatments that may not significantly benefit the patient.	323 (80)
It is the administration of treatments that are extraordinary but can provide significant benefits to the patient.	26 (6,4)
I don't know.	28 (6,9)
8: What is meant by assisted suicide?	
It is death brought about by the discontinuation of a medical treatment that keeps a patient alive.	60 (14,9)
It is the implementation of extraordinary treatments that expose the patient to a high risk of death or aggravation of his or her suffering.	9 (2,2)
It is suicide accomplished in person by a patient who has decided to die, with medical and administrative support.	206 (50,9)
It is the act of procuring the death of a patient at his or her request and with the direct intervention of a third party.	129 (31,9)
9: What is meant by artificial nutrition?	
It is the administration of saline by venous administration.	13 (3,2)
It is the washing of the intestinal or gastric walls with a saline solution.	3 (0,7)
It is the administration of nutrients by vein or through gastric or intestinal probes.	388 (96)
It is the help to take in food through feeding.	0
10: What is meant by artificial ventilation?	

It is a health care treatment that replaces or supplements the activity of the respiratory muscles.	308 (76,5)
It is a health care treatment that allows for the administration of oxygen intravenously.	14 (3,5)
This is a health care treatment whereby a flexible plastic tube is inserted into the pleural space.	59 (14,6)
I don't know.	0
11: Would you know how to define irreversible coma?	
It is a state of unconsciousness that could be modified because of a painful stimulus.	282 (69,8)
It is a state of brain death with the cessation of all brain function but with the persistence of cardiac activity.	117 (28,9)
This is a state of bedside immobilization of a quadriplegic patient.	4 (1,0)
I don't know.	1 (0,2)
12: Would you know how to define informed consent?	
It is the physician's obligation to have the patient read the medical record to let him or her know his or her medical condition and possible treatments to which he or she may be subjected.	98 (24,3)
It is the physician's obligation to inform the patient clearly about his or her medical condition and the possible treatments to which he or she may be subjected.	232 (57,4)
It is the physician's obligation to make a patient's family members aware of the medical condition and treatment they may be undergoing.	34 (8,5)
I don't know.	40 (9,9)
13: In your opinion, if a person has a brain disease or injury that prevents him or her from expressing their wishes and forces them to depend on machines, who should be responsible for any decision not to administer or suspend life-sustaining treatment?	
To the patient who has expressed his or her wishes through a living will, when it is available.	333 (82,4)
To immediate family members.	33 (8,2)
To the physician and health care provider treating him or her.	7 (1,7)
To an ethics committee.	4 (1)
To a legal guardian.	3 (0,7)
To a judge or magistrate.	4 (1)
Life support treatments should never be suspended.	20 (5)
14: In your opinion, if a person has not made their Advance Treatment Statements and is no longer able to	

express their wishes, who should make the decision to stop or continue treatment?	
To immediate family members.	242 (59,9)
To the physician and health care provider treating him or her.	46 (11,3)
To an ethics committee.	54 (13,4)
To a legal guardian.	32 (7,9)
To a judge or magistrate.	10 (2,5)
Treatment should never be suspended.	20 (5)
15: In your opinion, in the case of a minor patient over the age of 14, how involved should they be in decisions regarding their end-of-life in the event of a terminal or permanently disabling illness?	
Very much, the minor must be put in the condition to understand what his health condition and the possible developments of the disease and his will must be considered.	264 (65,3)
Partially, the minor must be put in the condition to understand what his health condition and the possible development of the disease is and to express his opinion, but the decision is up to others (family members, legal guardians, doctor).	112 (27,7)
Not at all, the child does not need to be informed and the decision rests solely with others.	28 (6,9)
16: In your opinion, in the case of a minor patient under the age of 14, how involved should they be in decisions regarding their end-of-life in the event of a terminal or permanently disabling illness?	
Very much, the minor must be put in the condition to understand what his health condition and the possible developments of the disease and his will must be considered.	217 (53,7)
Partially, the child must be put in a position to understand what his or her health condition is and the possible developments of the disease and to express his or her opinion, but the decision is up to others.	148 (36,6)
Not at all, the child does not have to be informed and the decision is solely up to others (family members, legal guardians, doctor).	39 (9,7)
17: The approval of the law on living wills introduces the Advanced Treatment Arrangements, which allow the patient to decide which treatments to undergo and their possible interruption. Are you in favor of this possibility?	

Absolutely.	289 (71,5)
Probably so.	102 (25,2)
Probably not	6 (1,5)
Absolutely not.	7 (1,7)
18: Do you think it is fair that a patient can choose, after being fully informed about the course of his or her illness, to refuse artificial nutrition and hydration?	
Absolutely.	255 (63,1)
Probably so.	105 (26)
Probably not	31 (7,7)
Absolutely not.	13 (3,2)
19: In your opinion, should Advance Treatment Arrangements be binding on the health care providers treating the patient?	
Absolutely.	205 (50,7)
Probably so.	145 (35,9)
Probably not	36 (8,9)
Absolutely not.	18 (4,5)
Item20: What ways are provided by law to express Advance Treatment Arrangements?	
They can be communicated to a trusted person.	65 (16,1)
They may be communicated in writing by authenticating the text.	278 (68,8)
They can be reported to the primary care physician.	7 (1,7)
They can be communicated through a video recording.	2 (0,5)
I have partial knowledge about	1 (0,2)
I don't know.	51 (12,6)
21: Do you feel prepared enough to write your own advance directive?	
Yes, I feel quite prepared.	133 (32,9)
I possess partial knowledge on this subject.	127 (31,4)
I am not sufficiently informed.	94 (23,3)
No, not at all.	50 (12,4)
22: How would you like to be documented about Advance Treatment Arrangements?	
I prefer to document myself (through the internet or books).	135 (33,4)
Through themed television programs.	44 (10,9)
Through flyers or newspapers.	10 (2,5)
Through your primary care physician.	54 (13,4)
Through conferences with experts.	154 (38,1)
Through university lectures.	6 (1,5)
I prefer not to document.	1 (0,2)
23: Do you support the legalization of assisted suicide?	
Absolutely.	205 (50,7)
Probably so.	133 (32,9)
Probably not	44 (10,9)

Absolutely not.	22 (5,4)
24: Do you support the legalization of euthanasia?	
Absolutely.	217 (53,7)
Probably so.	120 (29,7)
Probably not	43 (10,6)
Absolutely not.	24 (5,9)

4. Discussion

The objective of the study is to detect the qualitative degree of knowledge of the population under consideration with respect to the terminology and content related to the ethical issues of the end of life. To analyze the contents of this study, it is necessary to examine the constitutional reference point that is in Articles 2, 13 and 32 of our Constitutional Charter (Colacino 2015). The Italian Constitution has margins of pliability that allow it to be current even at time from its initial writing. The reference to art. 2 for the issue of health treatments consists in the affirmation of the existence of fundamental rights. We are always looking for a balance between the needs of the individual and the community, even if there are several factors that can alter the balance. The first knot to unravel is the misinformation on end-of-life issues as it emerges from the study by Lippo et al. (Lippo 2014) where about half of the respondents report not having enough information on some aspects such as irreversible coma and permanent vegetative state. Our study shows that more than half of the sample (52.0%, N=210) has never had the opportunity to educate themselves in the field of bioethics and almost the entire sample has been educated through the mass media or through the internet.

The task of the law is to try to provide a balance between the different opinions and compared to the past, the current era enhances this trend. A contribution in this sense has been made by jurisprudence, thanks to the entry into force of (*Law no. 219/2017*) (Rules on informed consent and advance treatment provisions) to which a not indifferent media explosion has followed, demonstrating how it has entered, before in our

system, in the collective culture, drop by drop, through a series of cases widely documented in the press. The results of our study, show that 82.4% (N=333) of the sample, claim the decision to refuse, in the presence of certain conditions, a treatment potentially able to artificially extend his life, in contrast to what emerged from the study conducted by ISPO 2009 (Lippo 2014) in which only 50% of respondents recognized the right to self-determination of the subject. Another important aspect is certainly the end of life regarding the minor of age or incapacitated. *Law no. 4/2006*, instituted the figure of the support administrator, erasing the idea that the incapacitated person, if he reached a certain threshold of inability, should be deprived of any faculty of self-determination, replacing it with the principle of enhancement of every, even if minimal, possibility of autonomous exercise of the rights and faculties that pertain to him (De Filippis et al. 2018). Legislative and jurisprudential developments have enhanced the minor's capacity for discernment. From our study emerges a clear position of the sample to listen to the opinion of the minor and to involve him/her in the choices due to him/her. However, in the case of minors aged between 14-18 years, the percentage is 65.3%, which drops to 53.7% in the case of children under 14 years of age; this trend is reversed regarding the percentage of participants who consider the opinion of minors under 14 years of age as irrelevant, which is almost 10% higher. What emerges from the Biotestament law, obstinacy (the rule does not use the term overkill), which the physician must refrain from practicing, is configured in the case of an inauspicious short-term prognosis or imminence of death (Choi et al., 2015). In the public opinion, therapeutic overkill is identified in the administration of care that has no logical reason pe be practiced or continued, accompanied by suffering and / or risks to the patient, unnecessary or disproportionate. In this regard, the sample is well informed (80.4%, N=325). In any case, it is not insignificant that about a quarter of participants (N=104) still have only heard about

therapeutic obstinacy. It also does not go unnoticed that 5% (N=20) believe that life-support treatments should never be suspended, a fact that is not in line with what emerged from the ISPO Survey (Lippo 2014), namely that 20% of the sample believes that the decision to suspend should not be made by anyone. Paragraph 5, art. 1 (*Law no. 219/2017*), has central importance in defining the discipline of the law, puts an end to the age-old question of whether artificial nutrition and hydration are health treatments or should be otherwise defined. The prescription, in order not to be pleonastic, must be understood as an additional obligation, valid also for the case in which the information has already been provided. Physicians and/or nurses must inform patients of the consequences of such a decision and of possible alternatives, as well as promote supportive actions, also making use of psychological assistance services. In the context of these "life-sustaining" therapies, it was found that almost 100% of the sample responded correctly about artificial nutrition, while ideas appear less clear for artificial ventilation, where a small percentage of participants (15%, N=73) compared to the total sample provided an incorrect definition. Regarding Advanced Treatment Arrangements, 71.5% were fully in favor of their introduction, and 50% of the sample felt that the DAT were absolutely binding. This confirms that the population is increasingly concerned about the right to self-determination in the field of healthcare. The option chosen by most participants regarding the method of expressing DAT is the written form authenticated by signature. Not to be overlooked is the fact that 12.6% of the participants declare that they do not know of any method. The respondents were asked once again about their aptitude for writing their own Anticipated Treatment Arrangements: 32.9% (N=133) of them stated that they felt well prepared, 31.4% (N=127) that they had partial knowledge of the subject, and 23.3% (N=94) that they did not feel sufficiently well-informed, together with 12.4% (N=50) of the sample who did not feel well-informed at all. A large part of

the sample affirms that it would like to broaden its knowledge about DAT through conferences with experts or by seeking information on its own and from general practitioners. The DAT (Declaration of Anticipated Treatment) can be drawn up by the citizen without any support, even if, as for the will, the collaboration of a lawyer may be opportune, as well as the help of a physician, a nurse, to ensure that they are clear and comprehensible and do not give rise to problems of interpretation. In the absence of a DAT, the norm regulates the conflict between the representative of the incapacitated person and the physician, should the former refuse the treatment proposed by the latter. While in the case of a capable subject or DAT, the physician is obliged to respect the expressed will, as established by paragraph 6 of art. 1. As far as assisted suicide is concerned, the sample is almost evenly distributed between those who claim to be well-informed (34.9%, N=141) and those who have only heard of it (38.4% N=155), and those who, to the extent of 14.6% (N=59) have very little knowledge about it. In any case, 50% (N=206) of the respondents were able to give the correct answer. With respect to the condition linked to euthanasia, 42.1% (N=170) of the sample believe they are well informed. Even in this case, however, it should be underlined that 33.9% (N=137) have only heard about it. Regarding the possibility of legalizing assisted suicide and euthanasia, more than 50% of the sample were fully in favor of the legalization of these two practices. It should be emphasized that euthanasia and biotesting differ in the same way that action differs from omission, as well as differing by having the one aim to oppose nature, the other to indulge it. Closer to active euthanasia is assisted suicide, which consists of life-ending activities carried out directly by the person concerned, with the assistance or help of a third party. Health care professionals have a key role in clarifying some aspects of this new legislative framework for citizens. They work with people in a high state of dependency and need, in a situation made even more difficult by the presence of numerous hierarchies and cultures. Nurses have a

responsibility towards institutions and citizens, finding themselves in the ambiguous, but unique and potentially rich position of arriving at a collaborative choice. It should be noted that, due to the small size of the sample (although not negligible) and the minimal territorial extension, the results cannot be generalized at the national level.

5. Conclusions

The objective of the study was to detect the knowledge, perceptions and attitudes of the Italian population living in the provinces of Lecce and Brindisi with respect to the contents related to the ethical issues of the end of life. The results of the study showed that knowledge on the subject has definitely improved over the years and that in most of the issues addressed, the population has an adequate degree of preparation even if there is still some skepticism in addressing issues such as assisted suicide and euthanasia. Regarding the perception of knowledge about certain clinical conditions at the end of life (terminal illness, irreversible coma, and permanent vegetative state), it was found that most of the participants are aware of these situations thanks to the news conveyed to the public by the mass media such as TV and Internet, demonstrating that there is a greater awareness of the issue of the end of life. The deficient aspect to be taken care of in the field of advance treatment provisions is the one concerning the modalities of subscription; considering that the sample under examination declares not to know any modality and that one person out of 404 would prefer not to inquire, it becomes a challenge to identify strategies for the dissemination of information that can be used by the widest possible portion of the population. About euthanasia, it should be emphasized that a large part of the sample has only heard of it, confirming the fact that in Italy we are still far from considering it an acceptable practice, even though there is a large percentage, equivalent to more than half of the sample, in favor of its legalization. The situation is identical regarding the legalization of assisted suicide. The End of

Life is part of the path of every individual and for the same reason it is right that it should become the object of conscious choices. A reasoned and shared approach would be necessary to clarify the accuracy of the terms to make "meditated and conscious individual choices in light of the principle of Self-determination (autonomy) (item 4)". It is necessary to promote information campaigns that can guide the population to the correct approach to the End of Life through the introduction of training tools and effective dissemination strategies for the correct drafting of one's DAT, to shed light on realities that, in the light of medical and scientific progress, prove to be of crucial importance and allow the patient to expand his or her *HABEAS CORPUS* now more than ever.

6. References

- Beauchamp, TL., Childress, JF 2001. "Principles of Biomedical Ethics". *Oxford University Press, USA*.
- Carlet, J., Thijs, LG., Antonelli, M., Cassell, J., Cox, P., Hill, N., Hinds, C., Pimentel, J. M., Reinhart, K., and Thompson, BT. 2004. "Challenges in end-of-life care in the ICU". *Intensive Care Medicine*, 30(5), 770-784.
- Cattorini, PM. 2015. "Bioetica. Metodo ed elementi di base per affrontare problemi clinici". Elsevier.
- Choi, Y., Keam, B., Kim, TM., Lee, SH., Kim, DW., and Heo, DS. 2015. "Cancer Treatment near the End-of-Life Becomes More Aggressive: Changes in Trend during 10 Years at a Single Institute. *Cancer Research and Treatment: official Journal of Korean Cancer Association*, 47(4), 555.
- Colacino, G. 2015. "Autonomia Privata e Direttive Anticipate". A. Giuffrè Editor, Milan, Italy.
- De Filippis, B. (2018). "Biotestamento e Fine Vita". CEDAM.
- Garini, G. 2018. "ALCUNE RIFLESSIONI SU PRINCIPIO DI AUTONOMIA, CONSENSO INFORMATO E DISPOSIZIONI ANTICIPATE DI

TRATTAMENTO". *I mercoledì della Bioetica*.
<https://www.normattiva.it/urires/N2Ls?urn:nir:stato:legge:2017;219>.

- Lippo, L., Zenobi, C., and Amato, MG. 2012. "Il Testamento Biologico: Una scelta consapevole? Sondaggio sulle conoscenze degli italiani".

PROFESSIONI INFERMIERISTICHE, 65(3), 171–178.

- Riccioni, L., Busca, MT., Busatta, L., Orsi, L., and Gristina, GR. 2016. "La limitazione dei trattamenti: Una forma di eutanasia? Un approccio scientifico al dibattito sulle decisioni alla fine della vita." *Recenti Progressi in Medicina*, 107(3), 128.