UNIVERSIDADE BEIRA INTERIOR

Withhold, Withdraw, and Futility. When Should Doctors Stop and When Treatment Is No Longer Beneficial?

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Dissertação para obtenção do Grau de Mestre em
Medicina
(mestrado integrado)

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Dedication

To my parents, who have always been there to pick me up and encouraged me to pursue the dream.

Acknowledgment

I would like to thank the following people who without whom it would not be possible to complete this dissertation and without whom I would not have been able to make it through my master's degree.

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To all my family for the support that they have shown during this long and interesting process.

Finally, to my dog Kiara.

Thank you all!

Preface

"How people die remains in the memory of those who lived on" – Cicely Saunders[1]

The role of the modern physician is to balance the technoscientific advance with the art of healing, humanizing the process of death and demystifying the journey to be taken by the patient, family, and friends.

The process of withdrawing, withholding, and the avoidance of futility treatment is, in short, an attempt to dignify the human being.

To understand these terms and their implication, it is necessary to develop critical thinking focused on the user in all its facets (personal, family, religious, and social), dignifying and empowering them/decision-makers of correct scientific information, and most importantly, in an inclusive comprehensive way.

Resumo

Esta Revisão sistemática sobre: reter, retirar e futilidade terapêutica é de grande importância para todos os profissionais de saúde e não apenas médicos, enfermeiros ou estudantes. A procura de cuidados individualizados que permitam um melhor tratamento é a base da medicina moderna, mas só pode ser alcançada com o pensamento crítico que cria uma melhor compreensão do quadro jurídico e ético imprescindíveis para formar melhores profissionais.

O principal objetivo deste trabalho claramente não é responder a questões como “Quais são as maiores dificuldades que os médicos enfrentam na decisão da melhor gestão destes doentes, de um âmbito legal e ético?” ou "Quais são as fronteiras morais e éticas das decisões dos médicos" ou mesmo "Este tratamento é benéfico?". O principal objetivo desta dissertação é criar uma onda de pensamento crítico sobre o tema dos cuidados em fim de vida. Só aprendendo e formulando o pensamento crítico poderemos evoluir como sociedade, e seremos capazes de criar o quadro legal em que poderíamos, em teoria, fornecer os melhores cuidados de saúde possíveis para o paciente, entes queridos e a família.

Para a realização desta dissertação foram utilizadas duas bases de dados (PubMed e Cochrane Library), a pesquisa foi limitada de 1992 até 2019 de forma a evitar estudos relacionados com a pandemia de Covid-19. A decisão de excluir estudos durante a pandemia baseia-se na tentativa de evitar o *stress* causado pela mesma nas unidades de cuidados intensivos, assim, modificando o padrão de atuação das mesmas.

Para navegar na PubMed e Cochrane Library foram usados termos MeSH aplicando uma estratégia Booleana com combinação de “AND” e OR”(tabela 2). A estratégia de Pesquisa não ficou limitada às palavras-chave (pagina x), frequentemente sendo usados sinónimos ou variações das palavras.

A pesquisa foi limitada a publicações de artigos peer-reviewed publicados em inglês, português e espanhol. Foram excluídos estudos em idade pediátrica. Após aprovação do estudo pelo título e abstrato, os mesmos foram analisados na integra tal como as suas bibliografias para possíveis estudos de interesse. Alguns dos autores principais foram contactados através do site https://www.researchgate.net/, sempre que possível, para informação complementar.

Para evitar o risco de viés de informação foi utilizada a ferramenta "The Cochrane Collaboration's toll for assessing risk of bias in randomized trials"[2]. Os artigos foram classificados em risco baixo, alto ou incerto. Apenas foram usados artigos com risco baixo.

Foi possível identificar uma variabilidade significativa em relação à retirada de tratamento de suporte de vida nas unidades de cuidados intensivos. Essa variabilidade existe dentro da própria unidade, das regiões, países e continentes indicando uma causa multifatorial.

Palavras-chave

Fim de vida; Decisões clínicas em fim de vida; Retirada de Cuidados; Retenção de cuidados; Retirada de tratamentos de suporte de vida; sonegação de tratamentos de suporte de vida.

Abstract

This systematic review about: withhold, withdrawal, and therapeutic futility is of great importance for everyone working on healthcare and not alone doctors, nurses, or students. The search for individualized care enabling a better treatment is the foundation of modern medicine but it can only be achieved by the critical thinking of the matter at hand. Better professionals with a better understanding of the legal and ethical framework are a must.

The main goal of this paper is clearly not to answer questions like “What are the utmost difficulties faced by doctors when deciding the finest management for these patients, from a legal to ethical scope?” or “What are the moral and ethical boundaries of doctors' decisions” or even “Is this treatment beneficial?”. The main purpose of this dissertation is to create a tidal wave of critical thinking about the topic of end-of-life care. Only by learning and formulating critical thinking will we be able to evolve as a society and create the legal framework in which we could, in theory, provide the best health care possible for the patient, loved ones, and the family.

To accomplish this dissertation, two databases were used (PubMed and Cochrane Library), the research was limited from 1992 to 2019 to avoid studies related to the Covid-19 pandemic outbreak. The decision to exclude studies during the pandemic time is based on an attempt to stay away from the stress caused by it on ICUs, thus modifying their pattern of action.

To navigate PubMed and Cochrane Library, MeSH terms were used, applying Boolean strategy with a combination of “AND’ and “OR” (table 2). The search strategy was not limited to keywords (page xii), often using synonyms or variations of the word or term.

The search was limited to publications of peer-reviewed articles published in English, Portuguese, and Spanish. Studies that included pediatric age were excluded. After analyses of the title and abstract, the approved studies went a full analysis as their bibliographies for possible studies of interest. Some of the main authors of the study were contacted via https://researchgate.net/, whenever possible, for additional information.

To avoid the risk of information bias, the tool "The Cochrane Collaboration's tool for assessing risk of bias in randomized trials" [2] was used. Articles were classified as low, high, or uncertain risk. Only low-risk articles were used.

It was possible to identify a significant variability concerning the withdrawal of life-support treatment in ICUs. This variability exists within units amount their doctors, between regions, countries, and continents, the reason seems to be multifactorial for this result.

Keywords

End of life; Clinical decision at the end of life; withdraw care; withhold care; withdrawal of life-support; withhold of life-support.

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Acronym List

CDS-PP	Centro Democrático Social - Partido Popular
CNECV	Conselho Nacional de Ética para as Ciências Vivas
ERS	Entidade Reguladora da Saúde
ICU	Intensive Care Unit
INE	Instituto Nacional de Estatística
IT	Interventional trial
M.D	Doctor of Medicine
MeSH	Medical Subject Headings
N.	Number
O	Observational
P	Prospective
PICO	Population/Patient/Problem/, Intervention, Comparison and Outcome
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
Prof.	Professor
R	Retrospective
RENDAV	Registo Nacional do Testamento Vital
Std.	Standard
WHLST	Withhold of life-sustaining treatment
WLST	Withdraw of life-sustaining treatment

Chapter 1

Introduction and theoretical framework

There is a well-known saying "In this world, nothing can be certain, except death and taxes", I cannot debate about the taxes portion of the saying but long goes the days were patients lost their lives from uncomplicated heart arrest, pneumonia, or simply because they become unable to eat or drink. The right to life[3] complicates the ethical and legal pertinence of withdrawing or withholding life-support treatment in end-of-life care.

Doctors can now prolong the patient's life beyond its normal threshold bringing up the question about treatment futility and under what considerations may someone stop life-sustaining treatment, we must never forget about the patient dignity that must include but is not limited to a multifaced interaction with the patient regarding its autonomy, empowerment to make decisions, safety, communication, privacy, acceptance, acknowledgment, fairness and so much more[4].

The rationale for the study

The main driving forces for the resolution of this study were:

The contemporary of the thematic: The evolution of the human species is intrinsically connected with medicine's advance. This makes notions like withdrawal, withhold, and futility treatment a contemporary subject even more with the media's attention and the spread-out of medical knowledge throughout the internet.

Self-professional and personal realization: as a medical student, I felt the urge to develop a paper that helps to spread the grotesque reality about the final moments of a beautiful life and intoning the critical thinking in the name of those who inordinately have to deal with death.

End-of-Life

A person at end-of-life is more than a patient, he is a member of the community, a family member, someone's son, and his/her dignity should be considered every step of the way. Should a patient have a voice? If so, is this possible? How? Should it be considered homicide? Suicide?

Without a shadow of a doubt that medicine is more advanced than ever and with it, an entirely new ethical and legal territory.

Portugal and Europe status

Even today, in 2022, we can find in Portugal and Europe hundreds of families in social discomfort and deep anguish. This reality stems from several aspects: Lack of knowledge about the natural course of the disease, precariousness in medical education, difficulty in transmitting scientific knowledge, inefficiency in creating a solid doctor-family bond, among others. These difficulties result in unacceptable unsupported families. [5–7]

The main point towards

The future is uncertain but has said in the draft law by CDS-PP "to defend and promote human dignity is to reaffirm that each human being has an intrinsic, unique patrimonial value, not subject to transaction and not dependent on external circumstances, which may justify a lower value for that human being."[8]. Health professionals and students have an abundance of fertile ground on which to open the debate, study these issues, and develop critical thinking. The variability in ICU Withdraw and withholding of life-support treatment must be studied as well as its conditionings.

Chapter 2

Methodology

Study goal

The main goal of the carried systematic review was to identify (if any) the variability in withdrawal of life-sustaining treatment and when possible, the variability of withholding of life-sustaining treatment (if any) among adults admitted into ICUs or terminal discharges.

Research Question

The framework used for the creation of this research question was PICO[9]. PICO is mainly used for quantitative research and allows comparison between interventions.

Table 1 - PICO framework

P	Population/Patient/Problem	Patient over 18 years old admitted into ICU OR with terminal discharged
I	Intervention	Withdraw of life-sustaining treatment
C	Comparison	Withdraw variability between studies
O	Outcome	The variability in withdrawal between physician, region, country, or continent.

The research question: Is there variability in withdrawal between physicians, regions, countries, and continents in patients over 18 years old?

Systematic review research design

The systematic review was carried out according to the preferred reporting items for systematic reviews and meta-analyses (PRISMA)[10].

Research pathway

The research was carried out using two main databases (PubMed and Cochrane Library). The research was limited from 1993 until 2019 hence avoiding COVID-19 pandemic studies. The justification for this is the stress caused to the intensive care units, therefore, modifying the pattern of actuation.

Only peer-reviewed articles in English, Portuguese, and Spanish language were used.

To Navigate PubMed and Cochrane Library it was used MeSH terms, applying Boolean search strategy combination “AND” & “OR”. The search criteria were not limited to the keywords, often using synonyms or variations of the word.

Table 2 - Term search for PubMed and Cochrane Library

Terms Match		Population		Intervention		Outcome
		Patient over 18 years old admitted into ICU or with terminal discharged		Withdraw of life-sustaining treatment		The variability in withdrawal between physician, region, country, or continent.
		OR		OR		OR
AND	1	Adults admitted in ICU	3	Abandon of care	6	Dignity in end of life
AND	2	Terminal Discharge from ICU	4	End of care in ICU	7	Variability in ICU
AND			5	Forsake of life-sustaining care	8	Unpredictability between ICUs
OR						
	9	Combine 1+3 with AND	10	Combine 2+6 with AND	11	Combine 3+7 with AND

Inclusion criteria

Table 3 - Studies inclusion and exclusion criteria

	Inclusion Criteria	Exclusion Criteria
P – Population	• Withdraw of life-sustaining treatment in ICU deaths or terminal discharges. • Withdraw of life-sustaining treatment with associated deaths.	• Under 18 years old.
I – Intervention	• Withdraw of life-sustaining treatment in all patients. • Withhold of life-sustaining treatment in all patients as a secondary result of the study.	• Under 18 years old.
C – Comparison	• When studying more than one ICU, the variability between them.	
O – Outcome	• Must include withdrawal variability. • A multicentre study must include the withdrawal variability of every centre or the mean of all.	• No clear data about the variability of withdrawal.
Study design	• Retrospective or prospective • Observational, interventional, or observational before and after a policy or legislation implementation.	• Grey literature • Non-peer-reviewed articles

Study selection

After the main search, all articles that met the inclusion criteria were subjected to full title and abstract revision for further coherence with the inclusion criteria. Those who were selected underwent a full analysis according to the inclusion and exclusion criteria. Articles with titles indicating adult and pediatric age were submitted to abstract review and, if possible, integrated using the adult part of the study. Articles without abstract or unclear abstract were excluded from the study. The approved articles were imported to Mendeley Desktop Software[11]. Prisma 2020 flow diagram for new systematic revision (figure 1) run through the steps for articles selection stages and the main characteristics of the excluded articles.

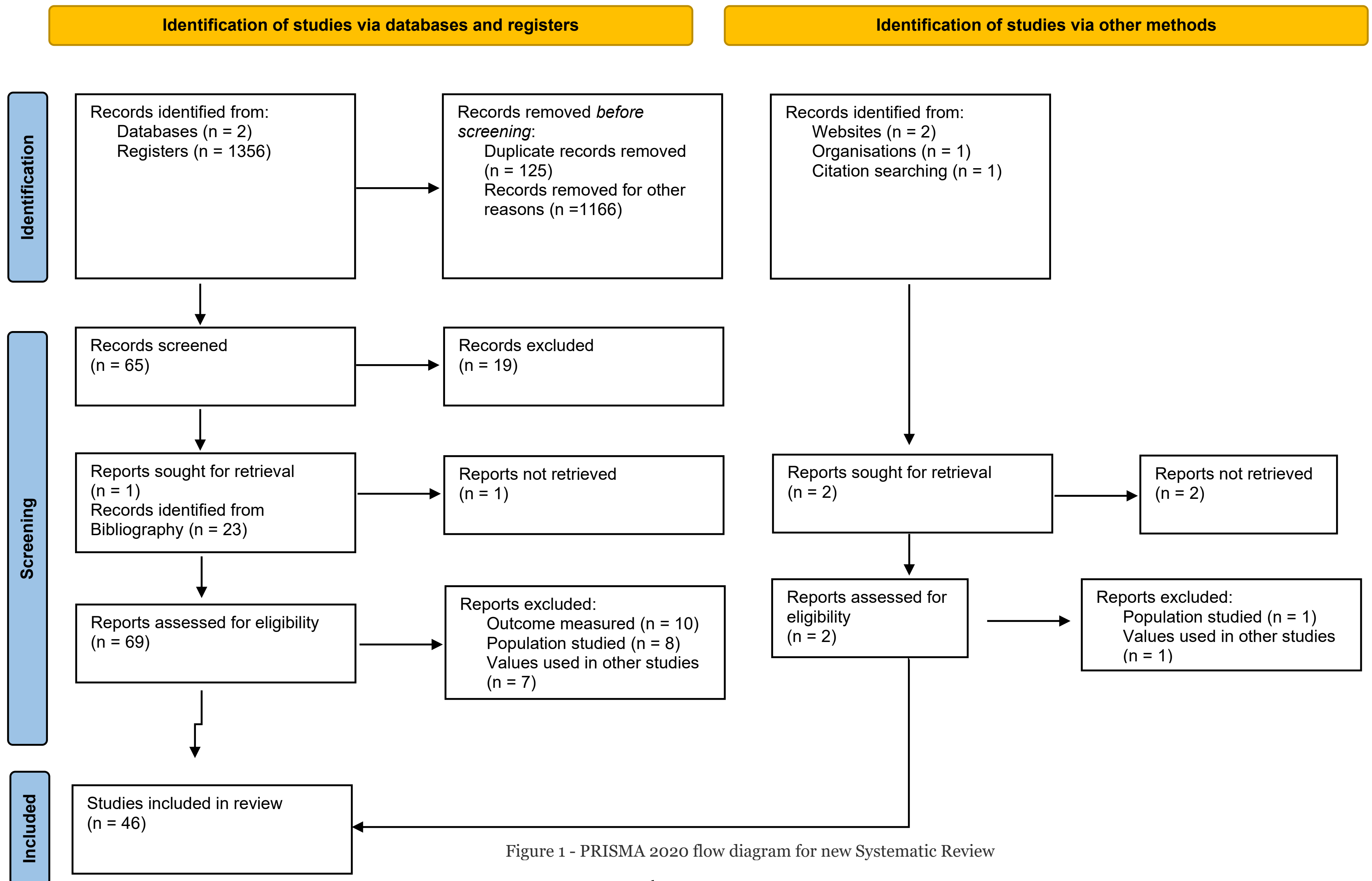

Figure 1 - PRISMA 2020 flow diagram for new Systematic Review

Data extraction

A systematic data extraction method was developed, this included the title of the articles, the region where the studies were performed, the design of the study, the population description, the outcome of the study, the number of deaths, the variability in withdrawal of life-sustaining treatment and the numbers of ICU used on the study.

Risk of Bias

To minimize the risk of bias assessment, attrition, or confusing bias a tool named "A revised tool to assess risk of bias in randomized trials"[(2)] was used. All articles underwent a double-check rating them at "High", uncertain/unclear", or "Low" risk of bias (Table 4). Only studies with a "low" rate in every field have been used, however in a few cases, studies with "High" risk rate in one of the fields were considered due to the usefulness of the study.

Table 4 - Risk of bias assessment

Study reference	Study design		Weight	D1	D2	D3	D4	D5	Overall
1	Observational	Prospective	1	+	+	+	+	+	+
2	Observational	Prospective	1	+	+	+	!	+	+
3	Observational	Prospective	1	+	+	+	+	!	+
4	Observational	Prospective	1	+	+	+	+	+	+
5	Observational	Prospective	1	+	+	+	+	!	+
6	Observational	Prospective & retrospective	1	!	+	+	+	+	+
7	Observational	Prospective	1	+	+	+	+	+	+
8	Observational	Prospective & retrospective	1	+	+	+	+	+	+
9	Observational	Prospective	1	+	+	+	+	+	+
10	Observational	Prospective	1	+	+	+	+	+	+
11	Observational	Prospective	1	+	+	+	+	+	+
12	Observational	Retrospective	1	-	+	+	!	+	+
13	Observational	Retrospective	1	!	+	+	+	+	+
14	Observational	Prospective	1	+	+	+	+	+	+
15	Observational	Prospective	1	+	+	+	+	+	+
16	Observational	Retrospective	1	+	+	+	+	+	!
17	Observational	Retrospective	1	+	+	+	+	+	+
18	Observational	Prospective	1	+	+	+	+	+	-
19	Observational	Prospective	1	+	+	+	+	+	-
20	Observational	Prospective	1	+	+	+	+	+	+
21	Interventional	Prospective	1	+	+	+	+	+	+
22	Observational	Retrospective	1	+	+	+	+	+	+
23	Observational	Prospective	1	+	+	+	+	+	!
24	Observational	Prospective	1	+	+	+	+	+	+
25	Interventional	Prospective	1	+	+	+	+	+	+
26	Observational	Retrospective	1	+	+	+	+	+	+
27	Observational*	Prospective	1	+	+	+	+	+	+
28	Observational	Prospective	1	+	+	+	+	+	-
29	Observational	Prospective	1	+	+	+	+	+	-
30	Observational	Retrospective	1	+	+	+	+	+	+
31	Observational	Retrospective	1	+	+	+	+	+	+
32	Observational	Retrospective	1	+	+	+	+	+	+
33	Observational	Prospective	1	+	+	+	+	+	+
34	Observational	Prospective	1	+	+	+	+	+	+
35	Observational*	Retrospective	1	+	+	+	+	+	+
36	Observational	Prospective	1	+	+	+	+	+	+
37	Observational	Prospective	1	+	+	+	+	+	+

Legend
+ Low risk
! Some concerns
- High risk

38	Observational	Prospective	1	+	+	+	+	+	+
39	Observational	Prospective	1	+	+	+	+	+	+
40	Observational	Prospective	1	+	+	+	+	+	+
41	Observational	Prospective	1	+	+	+	+	+	-
42	Observational	Retrospective	1	+	+	+	+	+	+
43	Observational*	Prospective	1	+	+	+	+	+	+
44	Observational	Retrospective	1	+	+	+	+	+	+
45	Observational	Retrospective	1	+	+	+	+	+	+
46	Observational	Retrospective	1	+	+	+	+	+	+
47	Observational	Prospective	1	+	+	+	+	+	+
48	Observational	Prospective	1	+	+	+	+	+	+
49	Observational	Retrospective	1	+	+	+	+	+	+
50	Observational	Retrospective	1	+	+	+	+	+	-
51	Observational	Retrospective	1	+	+	+	+	+	+
52	Observational	Prospective	1	+	+	+	+	+	+

Observational* - This study was designed as observational after policies or legislation changes. Weight – Every study was given the same weight no matter the number of regions or ICU studied. D1 – Randomization process, D2 – Deviations from the intended interventions, D3 – Missing outcome data, D4 – measurement of the outcome, D5 – selection of the reported result.

Chapter 3

Results

The search was able to identify 1360 studies with full access. The titles and abstracts were analysed reducing the number of studies to 67 that underwent full analyses. All 67 articles were submitted to a revised tool to assess the risk of bias in randomized trials[2] and checked against the inclusion and exclusion criteria and 27 were excluded. The remaining 46 articles were imported to Mendeley Desktop Software[11], The justification for the exclusion of those 27 articles can be found in figure 1.

Studies design

From the 46 studies included for this revision (Table 7), 27 were prospective and 19 retrospectives. From these 46 studies, only 2 were interventional trials and 3 observational before and after policy or legislative changes, the bulk (41 studies) were purely observational. Although purely observational, the studies (12–14) were designed to be performed after hospital or legislation changes concerning end-of-life care.

The country coverage of the study is large, reaching 27 countries, some of the studies have covered more than one continent. The distribution of studies can be found in table 5, the total amount of ICU providing data about WLST studied was 858 across the globe (figure 2).

Figure 2 - Countries covered by the study (red).

Table 5 - ICU and studies distribution by regions of study

Distribution by region	N. of studies	N. of ICU
Europe	18	427
North America	18	129
Africa	3	10
Asia	2	5
Australia	2	3
Middle East	2	2
South America	1	282

By analysing the 46 studies, the prevalence of withdrawal of life-sustaining treatment varied from 0% to 93%, the mean 42,70%, and Std. deviation of 24.98% (table 6 and figure 3).

Table 6 - Frequency analysis

WLST %		
N.	Valid	46
	Missing	0
Mean		42.6974%
Median		45.3500%
Std. Deviation		24.9762%
Minimum		.00%
Maximum		93.00%

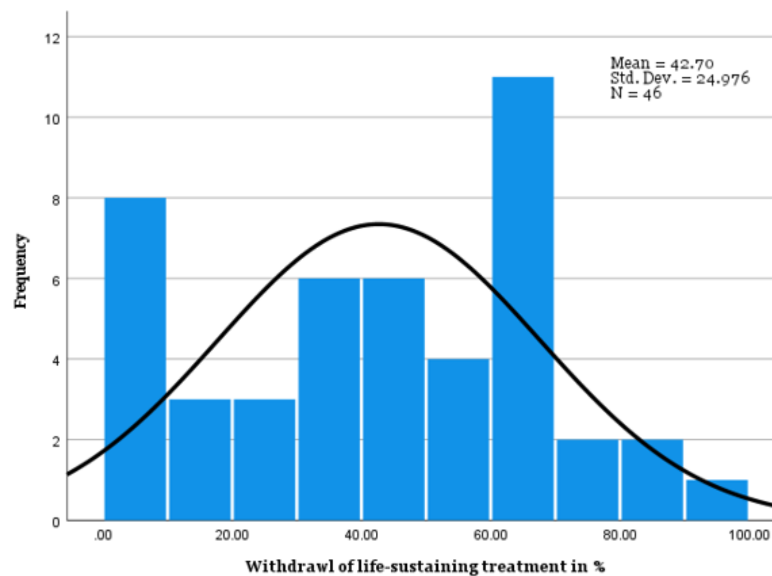

Figure 3 - Frequency analysis, study distribution

The studies were divided by the following regions: Europe(12,15–32); North America(14,20,33–48); Africa(20,49,50); Asia(51,52); Australia(53,54); Middle East(13,55) and South America(31). The WLST for every region was calculated as shown on figure 4, demonstrating a variability within and between regions.

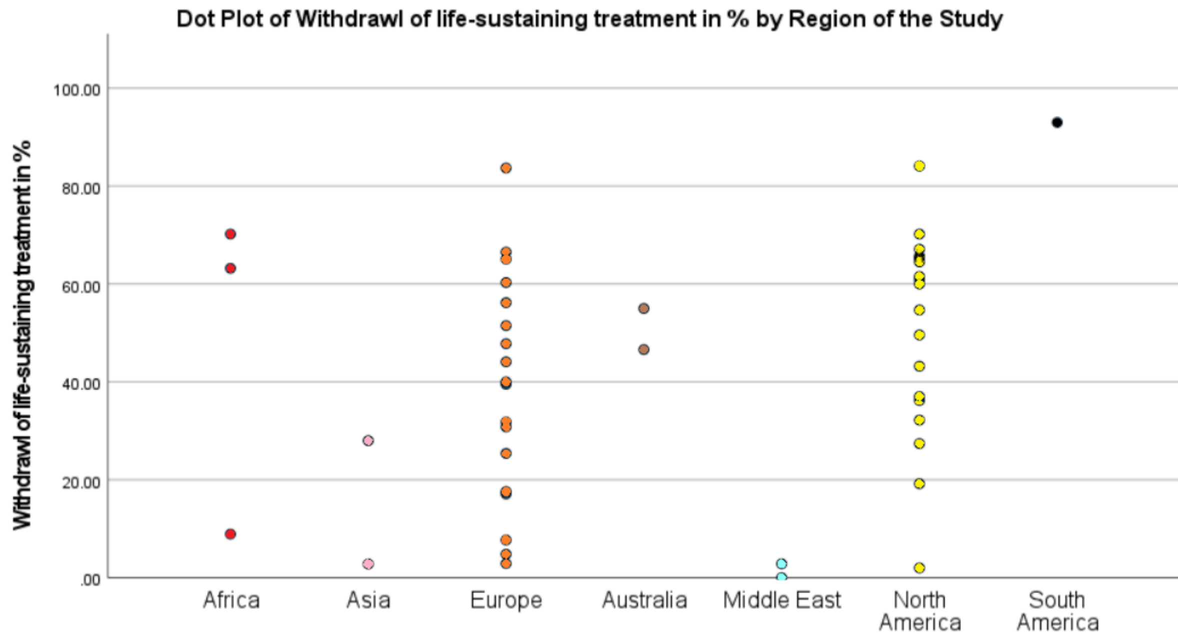

Figure 4 - WLST per region of study.

The mean of WLST for Africa was 45.08% (n=3, Std. deviation 34.37%), 45.1% for Asia (n=2, Std deviation 25.6%), 41.68% for Europe (n=18, Std deviation 25.06%), 48.27% for Australia (n=2, Std. deviation 23.91%), 35.54% for Middle East (n=2, Std deviation 23.20%, 45.54% for North America (n=18, Std deviation 24.12%), and 93% for South America (n=1, Std deviation 24.34%). The mean values differ significantly amongst regions with a significance of $p < 0.0015$.

The prevalence of WLST demonstrated comparably high variability across regions(31,56), countries, and ICUs within a country(24,35,40), or even by physicians[57] within an ICU(17).

Table 7 - Data analyses from the 46 accepted studies

Article's reference	Region	Study Design		Population description	Outcome of the study	N. of deaths	WLST (%)	N. of ICU
1	Europe	P	O	All ICU patients	WLST in-hospital deaths	3728	39.5	37
2	Middle East	P	O	ICU patients with end-of-life decisions made	WLST deaths "during the study period"	176	2.84	1
3	Europe	P	O	All ICU patients	WLST in ICU deaths or terminal discharges	582	25.4	6
4	Asia	P	O	All ICU patients who died in the unit	WLST in ICU deaths	173	2.8	4
5	Africa	R	O	All ICU patients who died in the unit	WLST in ICU deaths or terminal discharges	326	8.9	2
6	North America	P	O	All ICU patients	WLST in ICU deaths	5910	36.2	38
7	North America	P	O	All ICU patients	WLST in ICU deaths or terminal discharges	175	65.7	2
8	Africa	R	O	Patients ventilated due to brain injury	WLST in-hospital deaths	228	70.2	6
9	Europe	R	O	Not clear	WLST in-hospital deaths	36397	31.8	127
10	North America	P	O	All ICU patients	WLST in ICU deaths	46	27.4	1
11	Europe	P	O	All ICU patients who died in the unit or terminal discharges	WLST in ICU deaths or terminal discharges	3168	17.1	84
12	Australia	R	O	All ICU patients who died in the unit	WLST in ICU deaths	283	46.6	2
13	North America	R	O	Cancer Patients that died in the ICU	WLST in ICU deaths	267	32.2	1
14	Europe	P	O	Ventilated patients with a prospective stay in ICU over 72 hours	WLST treatment in-hospital deaths	363	44.1	15
15	North America	P	O	All ICU patients with trauma	WLST in-hospital deaths	954	60.9	63
16	North America	R	O	Severe head injuries with ventilation	WLST with associated deaths	228	70.2	6
17	North America	R	O	Not suitable for ICU but ventilated patients	WLST in-hospital deaths	562	49.6	1
18	Europe	P	O	All ICU patients who died in the unit	WLST in ICU deaths	90	47.8	1
19	Middle East	P	IT	All ICU patients	WLST in hospital deaths	69	0	1
20	Europe	R	O	All ICU patients who died in the unit	WLST in ICU deaths	176	66.5	2
21	Europe	P	O	All ICU patients who died in the unit	WLST with associated deaths	306	2.9	8
22	Europe	P	O	All ICU patients	WLST in hospital deaths	1513	4.8	1
23	North America	P	IT	All ICU patients with trauma	WLST in-hospital deaths	42	37	1
24	North America	R	O	Patients who died in ICU victims of burn injuries	WLST in ICU deaths	128	84.1	1

25	Europe	P	O*	All ICU patients who died in the unit or terminal discharges	WLST in-hospital deaths	773	51.5	1
26	Europe	R	O	All ICU patients	WLST in ICU deaths	208	83.7	1
27	North America	R	O	Patients over 55 years with trauma who died in ICU	WLST in ICU deaths	64	54.7	1
28	North America	R	O	Ventilated patients	Withdraw of ventilator	(!)	19.2	1
29	North America	P	O	Patients without decision capability or surrogate	WLST in ICU deaths	13	61.54	1
30	North America	P	O	Patients without decision capability or surrogate	WLST in ICU deaths	25	60	7
31	North America	R	O*	All ICU patients who died in the unit	WLST in ICU deaths	141	65.2	1
32	North America	P	O	All ICU patients who died in the unit	WLST in ICU deaths or terminal discharges	110	64.5	1
33	Australia	P	O	All ICU patients who had had withdraw	WLST in ICU deaths	82	55	1
34	South America	P	O	All ICU patients who died in the unit	WLST in ICU deaths	3050	93	282
35	Asia	P	O	All ICU patients who died in the unit or had withdraw	WLST in ICU deaths or terminal discharges	490	28	1
36	Europe	P	O	All ICU patients	WLST in ICU deaths	471	40	113
37	Europe	R	O	Patients who died in ICU victims of burn injuries	WLST in-hospital deaths	63	60.3	1
38	Europe	P	O*	Patient with organ failure admitted in ICU	WLST in all patients	(!)	7.7	25
39	North America	R	O	All ICU patients	WLST in all patients	(!)	2	1
40	Europe	R	O	All ICU patients	WLST in hospital deaths	338	65.1	1
41	North America	R	O	All ICU patients who died in the unit or terminal discharges	WLST in-hospital deaths	74	43.2	1
42	Europe	P	O	All ICU patients	WLST in all patients	51	17.6	1
43	Europe	P	O	Ventilated patients with a prospective stay in ICU over 72 hours and without cardiac surgery	WLST in ICU deaths	78	30.8	1
44	Europe	R	O	All ICU patients who died in the unit or terminal discharges	WLST in ICU deaths	347	56.2	2
45	North America	R	O	All ICU patients with trauma over 65 years old	WLST in ICU deaths or terminal discharges	70	67.1	1
46	Africa	P	O	All ICU patients who died in the unit or had withdraw	WLST in ICU deaths	106	63.2	2

P – Prospective, R – Retrospective, O – Observational, O* - This study was designed as observational after policies or legislation changes, IT – Interventional trial. (!) – No available information

Chapter 4

Discussion

Concept of moral, ethics, deontology, and law.

To die is as certain as the necessity of a baby to breath, it is no question to interpretation, it is not open to discussion, it is only a matter of time… however… as said by Dame Cicely Saunders, how people die remains in the memory of those who live on. But before this, it is necessary to understand basic terms such as Moral, Ethics, Deontology, Law, Withdraw and Withhold.

Therefore, Moral is a collection of principles, norms, and value judgments in place at any given point within a society and, most importantly, accepted by the majority of that society. This creates a background for the expected behaviour for that group of people in a certain situation. Since moral is related to a specific thematic, it is influenced as shown in this review by the society where the topic is being discussed, the historical background from the individual and the group but not by geopolitical division, consequently moral is a universal concept that allows groups of people to related even when they did not have previous interaction.

Ethics has its roots in the Greek word "Ethos" and its main use is to refer to the reflection process of moral standards. Since moral shapes the norms for the groups, ethics is the adaptation of the general norms, behaviours, and action to the individual but never relieving responsibility from the person itself. Thereby humanity evokes ethics for the utmost controversial and complicated topics as an attempt to serve as a bridge or a motorway to the values of the community (these values can change over time, hence the importance of this toll), this process must be above all unbiased and free of preconceptions for the formation of an unbiased and preconceptions unrestricted outcome[58].

An ethical dilemma is formed when a doctor is faced with multiple options for treating a patient, and what is the best decision for that specific patient, having in mind, the expected outcome for his/her situation. In this study the continuation of treatment fulfilling the needs of the patient, or the withdrawal of life-sustaining

treatment is the fracturing matter, what is the best for the patient vs what the family expects vs the allocations of resources in one bed over time.

A way to try to overcome this was the creation of the code of ethics, in medicine (Portugal) the code of ethics defines the main action of the person exerting the profession[59].

To live in society, mankind had to create a set of rules that have effect in a certain geographic region (country or community) that recognized as a regulative way to the actions of its members and therefore create instruments to enforce by way of consequences [60]. Then what is the difference between law and morality? Although morality tends to confer predictability to the community behaviour, morals and law may have a divergent approach on the same community, so morals can prevent in goodwill a person from making an action even though they are required or allowed by law. The best example of that is conscientious objection related to abortion practice.

Withdraw of life-sustaining treatment is the action of taking back something that has been granted by law or the discontinuance of health care administration or medicine[61,62].

Withhold is the simple act of holding back action or refraining from granting, giving, or allowing the administration o heath care or medicine[63].

The implication of withdrawing or withholding life-sustaining treatment from a moral, ethical, or legal point of view is tremendous with several repercussions. The grey zone of this problem is so big that is one of the most pronounced problems of modern medicine.

Ethical principles of autonomy, beneficence, non-maleficence, and justice.

The four fundamental towers[64] of ethics are autonomy, beneficence, non-maleficence, and justice. These are the foundations of bioethics. All four towers have the same weight, and not one of them is more important than the other, they are defined as general rules to guide the process of decision making against ethical challenging problems. The ultimate goal is an unbiased and preconceptions-free outcome, which is easier said than done since is hard to respect the four-tower equally. However, these four principles are only orientational and facilitators of the

organizational process of analyses in real-life cases, they are not enough to construct a full comprehensive outcome.

Autonomy is the principle with more relevance when it comes to patients making decisions at end-of-life or life-supporting treatment. According to Oxford Dictionary, the word Autonomy origins from two Greek words, “autos” meaning Self plus “nomos” meaning law, therefore autonomous implies having its laws, this does not exclude a person from the moral and the laws of the society where the individual is included.

For an individual to be considered autonomous, all his decisions must be taken in free will, according to his beliefs and personal goals(65), This call must be intentional, must be taken from self-rule without coercion. This type of decision can only be made if the patient can understand, comprehend, deliberate, and be able to decide without strings accordingly to his beliefs and rationalization. Consequently, any patient unable of taking any of these steps (because of his condition – very often patients in end-of-life care are unable to make decisions autonomy according to their beliefs or wills becoming more vulnerable for third part decisions - or external influence) is considered stripped of his autonomy.

End-of-life decisions can be made in advance, all deliberations can be made using legal mechanisms(66), it is important to create health awareness and clarify every doubt about treatment, prognosis, risks involving every step of the way, pros, and cons for all decisions and consequences of them.

For an autonomous decision, the patient must have every bit of information available together with the ability to understand and react accordingly.

The second tower of ethics is the principle of beneficence, we can find it over in the Hippocratic oath (like the third tower, the principle of non-maleficence). The second and third towers are intrinsically connected. In the second tower, the physician must act in a positive way towards the patient, obeying the ethical and moral principles of that given community, the physician must act to reach the goal of ending the pain, relieving symptoms, restoring health, organic function, or delaying the progression of the disease. The utmost outcome of the second tower is to improve the quality of life of the patient.

The benefit from the second tower of ethics must never exclude the first tower and should not prevent the patient from having access to the full knowledge of this disease as well as of his options[67].

This takes us to the third tower, non-maleficence, a fundamental column of bioethics where the physician must not cause harm. This is considered the pillar stone of modern medicine and should be considered from the first access to the health service until the last one.

Without wavering the first and second tower, any treatment or procedure is beneficial for the patient if its actual benefit is higher than the harm it will cause (example: chemotherapy).

The final but not less important tower is Justice, this refers to the equality in the distribution of physical human resources, the main objective is to balance the access to the health system no matter the age, sex, origin, political, or minority group. This tower is the pillar stone of modern health systems ever since the population is getting older (table 8) thus increasing the difficulty and cost of treatment.

The finite capacity to fund health systems put a lot of strain on respecting the four towers, especially when considered chronic diseases making the tower of non-maleficence a point of this study avoiding futility treatment preventing a prolonged death, respecting the patient dignity.

Table 8 - INE, population evolution by age group in Portugal

1	**População residente (N.º) por Local de residência (NUTS - 2013), Sexo e Grupo etário; Anual (2)**												
	Sex												
	M, W												
	Age Group												
	Total	**0 - 4 anos**	**5 - 9 anos**	**10 - 14 anos**	**15 - 19 anos**	**20 - 24 anos**	**25 - 29 anos**	**30 - 34 anos**	**35 - 39 anos**	**40 - 44 anos**	**45 - 49 anos**	**50 - 54 anos**	**55 - 59 anos**
	N.º	**N.º**	**N.º**	**N.º**	**N.º**	**N.º**	**N.º**	**N.º**	**N.º**	**N.º**	**N.º**	**N.º**	**N.º**
2020	10.298.252	436.034	444.706	501.888	536.441	563.793	547.593	566.252	650.225	764.673	802.818	745.021	742.729
2019	10.295.909	436.202	455.843	504.940	545.322	550.444	547.680	566.594	672.422	784.224	789.733	745.178	740.141
2018	10.276.617	430.461	466.754	510.351	552.744	538.705	547.330	576.115	685.764	801.116	775.377	749.983	728.938
2017	10.291.027	425.562	482.612	515.722	555.911	537.290	549.467	591.800	704.918	812.053	767.109	753.649	722.561
2016	10.309.573	428.244	490.004	524.168	558.165	538.556	551.919	614.838	731.253	811.722	758.984	756.882	714.805
2015	10.341.330	436.365	494.705	529.762	560.363	545.132	557.449	640.029	761.670	807.089	754.807	757.561	703.719

	60 - 64 anos	**65 - 69 anos**	**70 - 74 anos**	**75 - 79 anos**	**80 - 84 anos**	**85 e mais anos**
	N.º	**N.º**	**N.º**	**N.º**	**N.º**	**N.º**
2020	686.431	627.841	556.272	443.945	348.068	333.522
2019	676.762	622.912	549.591	432.058	353.254	322.609
2018	668.754	618.173	538.440	426.156	351.182	310.274
2017	659.099	619.886	521.503	424.997	349.350	297.538
2016	653.393	606.795	510.244	426.680	347.305	285.616
2015	651.855	593.746	498.638	433.987	341.071	273.382

Designation: Population in Portugal, Sex e age group; Annual, Periodicity: annual; Source: INE, Estimativas anuais da população residente; 1st year available: 2011: Last year available: 2020; Age group: Age range, in years, in which the individual falls, according to the reference moment; Resident Population: Group of people who, regardless of whether they were present or absent in a particular accommodation at the time of observation, lived in their usual place of residence for a continuous period of at least 12 months before the time of observation, or who arrived at their place of habitual residence during the period corresponding to the 12 months before the moment of observation, intending to stay there for a minimum period of one year; Reference period: Time period to which the information refers and which can be a specific day or a time interval (month, fiscal year, calendar year, among others); Last update date: 14-Jun-2021.

Terminal patient

The intensive care units receive a wide variety of patients, from acute trauma to terminal patients. Terminal patients are nothing more than a patient (the person that receives medical treatment from a doctor or hospital) and terminal due to his/her disease or illness that will eventually cause death for its incurability[68].

The Portuguese Association for palliative care establishes that a terminal patient must have no more than 6 months to live, this analysis is made upon several objectifications for the prognostic. The terminal patient is therefore beyond the capability of modern medicine to regain physical health, the patient is more than flesh and blood and is important to relieve the pain and suffering of the patient and loved ones.

Patients in end-of-life just like the elders start to see the “end of the road” and begin to accept the inevitability of the act of dying, the notion that there may not be a tomorrow changes the perspective of the “I”, this doesn’t mean that he/she accepts death and it causes extreme pain and suffering.

The fear of death is real in almost all modern societies. Death became pornography and should be hidden, kept away, and looked under seven keys where we can’t see it or feel it. People don’t die near their loved ones but are full of drugs and surrounded by beeping impersonal machines, instrumentalizing and prolonging the natural process of death over the boundary of human life.

When medicine fails and cure is not an option for physical or mental problems and the extension of life by the medical way is provided, physicians need to make decisions based on the four towers of ethics, unfortunately, according to A3ES the majority of medical training courses in Portugal this is a very untrained area. As mentioned by Lima MT in 2008 on “Reflexão Ética sobre Decisões Médicas em Fim de Vida, Comunicação apresentada no V Encontro Luso-Brasileiro de Bioética” at Porto, Death is our inner life mate and accept it on other is to face her in our selves.

Indubitably the only utmost thing for the patient at the final stage of his/her terminal illness/disease is to relieve the pain even if that means stopping ongoing therapy. The individual will proceed to lose his/her autonomy, individuality, decision-making capability, deliberative capacity, control of the body dying alone and afraid. Is the physician's responsibility and duty to overcome this problem even if what is

possible to give is only the impression of autonomy. The patient's will is important and must always be taken into account.

Therapeutic futility.

To better understand this topic, we must understand what medical treatment is, according to Collins Dictionary medical treatment means examination and treatment by a legally qualified physician for a condition that first manifested itself, worsened or became acute, or had symptoms that would have prompted a reasonable person to seek diagnosis, care, or treatment. Having this definition of futility treatment in mind we can define futile treatment every therapy when it is incompatible with the towers of beneficence and non-maleficence. In assumption we can say that its application is dysthanasia and therefore not ethical, wrong deontologically since as stated by the medical code of ethics, medicine should help, restore, or prevent the worsening of a condition if this is a benefit for the individual.

This brings enormous challenges such as what and how can we identify futile therapies? What is the right moment to withdraw or withhold them giving the patient a dignifying death? Should be the doctor (the carrier of scientific knowledge and professionally trained) to decide what and what's not futile or should the patient have a voice to stop a life that he/she can no longer relate to, or even the family that is emotionally involved, when the patient can no longer express his will.

The autonomy of the patient should always be respected with the ethical principles of beneficence and non-maleficence in mind.

Ultimately, we can set three categories for withdrawal or withhold in terminal patients[69]:

- The patient or legal guardian does not want a treatment to be used, because they have an expectation for that treatment.
- The patient or legal guardian does want a treatment to be used because they have an expectation for that treatment even if not scientifically proved for the specific case.
- The evolution of the clinical condition of the patient turns a prior useful treatment into a futile one or even not appropriated.

From an ethical point of view, the withdrawal of treatment or the withholding of treatment can be different, being the second one a natural way of letting the die, and

the first one involves a direct and deliberate action of removing imposed therapy also leading to the death of the patient. Neither one of the previous options goes against ethical principles if the goal is the well-being of the patient as stated in article 59º of the medical code of ethics[59].

The withdrawal of futile treatment must never be mistaken with euthanasia, in euthanasia death is deliberately the end goal invoking compassion and mercy and must always be requested by the patient. The withdrawal of futile treatments acknowledged the inevitability of death and let the natural course of life take place, the end goal is always not to prolong life without purpose having the patient's best interest in mind.

Patient autonomy

In medicine, every decision made will have consequences for the patient and those near him. So, for the patient to decide in the most accurate way about what is best for itself, it is fundamental that he/she are in control of all relevant information about the clinical case, being the doctor's duty to provide them and advise them in the light of their knowledge, but always keeping in mind that doctors should never coerce or try to influence their decision according to doctors' own beliefs.

A strong and healthy doctor-patient relationship is crucial for the interaction but unfortunately, with the overload of health systems, this can't always be reached, very often a patient is thrown from doctor to doctor.

The doctor-patient is for sure important since the patronizing aspect of medicine must be forgotten but at the same time, doctors must know the patient expectation, hopes, beliefs, culture, social and professional background to assist in all decisions[70]. Whenever possible the doctor should integrate his clinical decisions with patient will and the family expectation thus fostering the interaction between doctor-patient-family. In some cases, individuals don't want to be part of the discussion and can empower the doctor to decide the best course for his/her clinical case[71].

The informed consent is then born as a contract where the physician "translates" the scientific knowledge for the patient and family, the patient as an active role in the treatment process being a win-win situation where the patient and family know what is happening and what to expect and the physician is protected (to some extent).

The doctor must of course ensure that the patient is capable physically and mentally to understand the information given for the clinical case [59] and that the decision is given in a freeway[3]. The consent must be given in written with clear and understandable language for the patient organized from the most important to the least important and, whenever possible there should be a length of time (time in which the patient can consult his family, friends, or himself without pressure) between the delivery of consent and decision-making. There are consents with the start of action immediately and others that are reserved for specific situations (living will)[66].

Before this the physician must obey the patient's will and respect even if that leads to the patient death, however, is also the physician's responsibility to identify if such treatment could be able to revert the patient's clinical situation thus carrying more benefits for the patient then the withdrawal or withholding of treatment if this is ignored it could be considered therapeutic abandonment of a friable patient where the ethical principle of autonomy was misused to justify the abandonment of treatment. The inverse is also true where the physician must not subject the patient to the requested treatments (by the patient) without scientific proof, here the autonomy principle must not crush with beneficence and non-maleficence.

In terminal patients, we must go to the basics of food and hydration. This thematic is old and we still don’t have an answer or consensus for hydration and nutrition in terminal patients. At the end-of-life process, the individual becomes ill or severely disabled, both physically and/or mentally, as a result of his condition, the interest in prolonging life is often shattered. Since the normal route is death, it may be wrong to force nutrition and hydration on these patients and if this is the patient's will, it must be respected. This should be taken care not to be considered as euthanasia since this is a totally different circumstance where the physician is not aiding the patient to die and just allowing life to take its course.

It is important to remember that doctors don’t have the right to prolong death painfully or is it lawful. Every capable patient has the right to refuse any medical treatment according to their beliefs or understanding of his situation(72).

Ultimately, the decision of withdrawing or withholding treatment the most important thing to be taken into consideration is the respect for the ethical principles of beneficence, non-maleficence, and autonomy of the patient. For this, the patient must be seen in all his perspectives (biological and sociological) having in mind the

therapeutic objective and benefits for each treatment and always avoiding the prolongation of the natural process of dying.

Decision-making for incapable patients.

This thematic is so complex and to complicate things even further we need to talk about end-of-life patients without the capacity to express their decisions and will, this takes things to another level regarding withdrawal or withholding of life-sustaining treatment.

Attempting to mitigate this problem an advance healthcare directive was implemented and according to the health regulatory entity (ERS), in Portugal it can be done by nationals, foreigners, and stateless persons residing in Portugal, who are of legal age (18 years old), who are not interdicted or disabled by a psychic anomaly and who can give their conscious, free, and informed consent.

The validity of these documents is 5 years and can be changed by the titleholder at any given time, it is also anonymous being only able to access its health workers (physician or nurse).

It is important to state that in emergencies the choice expressed in these documents may not be followed when consulting these documents resulting in a delay of life-sustaining treatment.

To the doctor is always reserved the right to conscientious objection, whenever no harm is brought to the patient(71).

The main goal of an advanced healthcare directive is to protect the patient preference and to avoid futility treatment in end-of-life.

We can identify two distinct heath anticipated directives:

- First as mentioned above in which the individual registers his free, serious, and enlightened will regarding the health care that he prefers in the future if, for whatever reason, he becomes unable to express it personally or in an autonomously way, or even through the designation of a health attorney, who will voluntarily and knowingly assume the role of exercising representative powers in the field of health care, expressing the personal and autonomous will of the person they represent if they become unable to express it for themselves.

- Secondly and added by CNECV[73] we have the "biographical narrative", which consists of the collection and analyses of the authentic values, interests, base chouses of the individual considering also the family and social context. Whenever possible this should be the go-to.

By respecting the ethical principle of autonomy, we are respecting the principle of beneficence and non-maleficence even though this may inevitably lead to the patient's death.

The time and circumstances between the creation of the documents and the patient's clinical situation must be considered and the physician must ensure that the patient will remain unchanged.

To create this document the following items are mandatory (71,74).

- Limitation to capable, competent, adults and not inhibited by a psychic anomaly.
- Delivery of adequate information and clarification by a physician, safeguarding the right to non-information if that is the patient's wish, cannot compromise the validity of its decision.
- Certification before a notary to guarantee authenticity and avoid undue influence in the sphere of personal decision.

It is also:

- Standard form to standardize procedures (Attachment 1).
- Possible to revoke or modify at any time and without any formality.
- Validity of 5 years.
- Can be accessed by health professionals through RENDAV.

However, the creation of these documents may not be 100% valid if:

The proper clinical information about the patient's condition has not been given properly, detailed, comprehensive, or understood by the patient.

the patient may not want to carry out the will described previously.

The psychological context and health situation at the time of the statement may not be the same as in the context experienced in illness, which may constitute a

difference between the wish previously expressed and the actual will at the time the statement is used/presented.

In the absence of a health advance directive, or whenever there is doubt about the facts to be considered when deciding, it should always be the criteria for the best interest of the patient. Thus, analysing the benefits and risks of the therapeutic according to the patient clinical state.

When the best interest of the patient cannot be determined, or there is a divergence between various parts (like physicians and family), we must resort to the ethics committee or even for extra-institutional bodies, such as the judiciary. The best medical practice must always be the avoidance of treatment futility and dysthanasia.

Chapter 5

Conclusions

Now that we understand better the concepts necessary to understand the old problem of life-sustaining treatment patients in modern medicine such as withdrawal, withhold and, futility is our responsibility to respect the ethical principles of autonomy, beneficence, non-maleficence, and justice inf terminally ill patient, protecting the vulnerable ones.

We as rational creatures understand life as all and we must unquestionably give life its value doing everything in range of medicine to maintain, as long as possible but dignifying the person itself, avoiding dysthanasia respecting the health advance directive when in place. This being said, we must respect the cycle of life, aiding a better death.

Thus, the care must be made free from social, political, ethnic, religious, or ideological discrimination towards the patient.

Now that we recognise better the concepts necessary to understand the old problem of life-sustaining treatment patients in modern medicine such as withdrawal, withhold and, futility is our responsibility to respect the ethical principles of autonomy, beneficence, non-maleficence, and justice inf terminally ill patient, protecting the vulnerable ones.

We as rational creatures understand life as a whole and we must unquestionably give life its value doing everything in range of medicine to maintain, as long as possible but dignifying the person itself, avoiding dysthanasia respecting the health advance directive when in place. This being said, we must respect the cycle of life, aiding a better death.

Thus, the care must be made free from social, political, ethnic, religious, or ideological discrimination towards the patient.

Not only end-of-life patients must be considered when thinking about futility treatment, but this must also be applied to every patient in every interaction by every heath worker ensuring the ethical principles of non-maleficence and beneficence. We

must always height the pros and cons of the treatment (from the prescription of lifestyles to invasive procedures) and when the benefits are unequivocally less than the damages the treatment must be stopped.

It is important to know that a treatment deem futile by the doctor may not be considered as such by the patient or the family and, if the treatment doesn't cause more damage, then benefit it may be continued even so(75).

The term euthanasia was never used in this dissertation on purpose since it could confuse with treatment futility. Since euthanasia is the goal of ending life (a shallow life without an objective) and the removal of futility treatment as the goal to ensure that the individual dies with the dignity he deserves and when medicine can no longer revert the clinical condition.

As stated by the national ethics council for the living sciences (CNECV) "A avaliação ética destas decisões leva a propor que os médicos recusem as primeiras – nenhum médico jamais matará o seu doente – e se empenhem ativamente nas segundas – nenhum médico será indiferente ao sofrimento de uma pessoa doente, até ao último instante da vida, para que a morte humana, inevitável, possa ser dignamente vivida por cada um"(76).

The physician must obey the regional law and the leges artis imposed in their region and at the same time he must respect the will and beliefs of the patient in accordance with the ethical principles, whenever this task proves to be impossible, to the physician is reserved the right of conscientious objection as stated in article 12 of the medical code of ethics(59).

When the patient is unconscious or unable to express his decision, in Portugal, the existence of an anticipated health directive must be scrutinized (without postponing life-saving treatment). This document must contain the will of the patient or a heath attorney to decide end-of-life or until the patient regains the capability to do such.

These documents must serve as guiding lines and not binding, the physician must understand when and why this document was made, and when possible, to understand if that is the present will of the patient.

This situation can escalate extremely fast when the physician's decision is different from the patient or family's wishes or expectations, a compromise between all

parts must be made to provide a better understanding of the patient's situation and the acceptance of death as a process.

Health workers in ICU must understand the implications of the withdrawal of life-sustaining treatment as well as withholding treatment for the patient and family. A guided resolution for these problems should be considered to minimize the diversity mean in withdrawal and withhold of life-sustaining treatment among ICUs.

The main solution is an open dialogue between all parts to improve the care of the patient in end-of-life, if possible, these decisions should be taken by the patient itself before the loss of capabilities with the physician's help and guidance but never inflicted by anyone. In this form, the patient should be always protected from bad practice, futile treatment, or dysthanasia.

At last, we must be required to rethink death and the way we face it, we must undoubtedly hinder medicine for the sake of “we can” regardless of the ethical aspect of it. Medicine is a powerful conscious weapon that developed stunning deeds such as ICUs, but the progress should not be blind and orthothanasia is to be encouraged when the clinical condition requires it.

Death must be respected as a whole, and the process of dying must be lived in full.

Chapter 6

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Chapter 7

Attachment 1

Anticipated health directive form, Portugal.

RENTEV
TESTAMENTO VITAL

Rubrica do Outorgante

DIRETIVA ANTECIPADA DE VONTADE (DAV)

Ao abrigo e para os efeitos previstos na Lei n.º 25/2012, de 16 de julho, o presente documento traduz a minha manifestação antecipada da vontade consciente, livre e esclarecida, no que concerne aos cuidados de saúde que desejo receber, ou que não desejo receber, no caso de, por qualquer razão, me encontrar incapaz de expressar a minha vontade pessoal e autonomamente.

Este documento, que subscrevo sendo maior de idade e capaz e não me encontrando interdito ou inabilitado por anomalia psíquica, é por mim unilateral e livremente revogável a qualquer momento.

IDENTIFICAÇÃO DO OUTORGANTE

Nome

Doc. Identificação Nº Val.

Nacionalidade / Naturalidade

Nº Utente Data de nascimento

Morada

C. Postal País Tel.

Correio eletrónico

☐ **Pretendo nomear meu Procurador de Cuidados de Saúde**

Nome

Doc. Identificação Nº Val.

Nacionalidade / Naturalidade

Nº Utente Data de nascimento

Morada

C. Postal País Tel.

Correio eletrónico

SPMS EPE Serviços Partilhados do Ministério da Saúde

GOVERNO DE PORTUGAL | MINISTÉRIO DA SAÚDE

RENTEU
TESTAMENTO VITAL

Rubrica do Outorgante

☐ **Pretendo nomear meu Procurador de Cuidados de Saúde suplente**

Nome

Doc. Identificação   Nº   Val.

Nacionalidade / Naturalidade

Nº Utente   Data de nascimento

Morada

C. Postal   País   Tel.

Correio eletrónico

SITUAÇÃO CLÍNICA EM QUE A DAV PRODUZ EFEITOS

Quando me encontrar incapaz para expressar a minha vontade autonomamente, em consequência do meu estado de saúde física e/ou mental, e se verificarem uma ou mais das seguintes hipóteses:

(assinalar com um X as hipóteses aplicáveis)

☐ Me ter sido diagnosticada doença incurável em fase terminal

☐ Não existirem expectativas de recuperação na avaliação clínica feita pelos membros da equipa médica responsável pelos cuidados, de acordo com o estado da arte

☐ Inconsciência por doença neurológica ou psiquiátrica irreversível, complicada por intercorrência respiratória, renal ou cardíaca

☐ Outras:

CUIDADOS DE SAÚDE A RECEBER/NÃO RECEBER

Assim, manifesto a minha vontade clara e inequívoca de:

(assinalar com um X as hipóteses aplicáveis)

☐ Não ser submetido a reanimação cardiorrespiratória

- [ ] Não ser submetido a meios invasivos de suporte artificial de funções vitais
- [ ] Não ser submetido a medidas de alimentação e hidratação artificiais que apenas visem retardar o processo natural de morte
- [ ] Participar em estudos de fase experimental, investigação científica ou ensaios clínicos
- [ ] Não ser submetido a tratamentos que se encontrem em fase experimental
- [ ] Recusar a participação em programas de investigação científica ou ensaios clínicos
- [ ] Interromper tratamentos que se encontrem em fase experimental ou a participação em programas de investigação científica ou ensaios clínicos, para os quais tenha dado prévio consentimento
- [ ] Não autorizar administração de sangue ou derivados
- [ ] Receber medidas paliativas, hidratação oral mínima ou subcutânea
- [ ] Serem administrados os fármacos necessários para controlar, com efetividade, dores e outros sintomas que possam causar-me padecimento, angústia ou malestar
- [ ] Receber assistência religiosa quando se decida interromper meios artificiais de vida (crença: ________________)
- [ ] Ter junto de mim, por tempo adequado e quando se decida interromper meios artificiais de vida, a pessoa que aqui designo: ___________________________(nome), _______________ (contacto).
- [ ] Outras:
- [ ] Outras considerações pessoais ou eventuais motivações das minhas decisões.

VALIDADE

1. Esta declaração é eficaz durante 5 anos a contar da data da sua assinatura, podendo ser renovada nos termos da Lei n.º 25/2012, de 16 de julho.
2. Caso seja solicitado o registo no RENTEV, o mesmo só produz efeitos após receção pelo outorgante da informação de conclusão do processo.

RENTEV
TESTAMENTO VITAL

Rubrica do Outorgante

OUTORGANTE

Local | Data | Hora h m

Assinatura conforme doc. de identificação civil

MÉDICO (opcional)

Declaro que prestei as explicações que me foram solicitadas pelo Outorgante relativas a este documento e ao seu estado de saúde.

Nome | Cédula

Assinatura conforme doc. de identificação civil

NOTÁRIO / FUNCIONÁRIO DO RENTEV

(perante o qual a DAV foi assinada)

Nome | Id. Civil

Assinatura conforme doc. de identificação civil

(é favor carimbar/selar)

NOTAS

1. Antes de subscrever este documento, recomenda-se que debata previamente o assunto com um profissional de saúde da sua confiança, ou com a equipa de saúde que o cuida.
2. Pode optar pela subscrição da Declaração Antecipada de Vontade, pela designação de um procurador de cuidados de saúde, ou por ambos.