

# The Medical Futility Experience of Nursing Professionals in Greece

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## Research Article

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## Abstract

## Background

Providing futile medical care is an ever timely ethical problem in clinical practice. While nursing personnel are very closely involved in providing direct care to patients nearing the end of life, their role in end-of-life decision making remains unclear.

## Methods

This is a prospective qualitative study conducted with experienced nursing professionals from December 2020 through May 2021. Individual in-depth qualitative interviews were conducted with sixteen participants. We performed a thematic analysis of the data.

## Results

Importantly, many participants were half-hearted in their attitude towards accepting or defining futile medical care. Furthermore, interestingly, emerged a list of well-described circumstances, under which the dying process is most likely to be a “bad and undignified” process. These circumstances reflected situations revolving around: a) pain and suffering, b) treating patients with respect, c) the appearance and image of the patient body, and d) the interaction between patients and their relatives. Fear of legal action, lack of regulatory framework, physicians pressured from (mostly uninformed) family members and physicians’ personal motives were reported as important reasons behind providing futile medical care. It is highlighted the nursing professional’s role as participant in decisions on futile care and as mediator between physicians and patients (and family members). Furthermore, it is prioritized the patient’s role in decisions on futile care. It is highlighted the impact of patient’s effort to keep themselves alive on nursing professionals’ willingness to provide care. Providing futile care is a major factor that negatively affects the nursing professionals’ inner attitude towards performing their duties. Finally, the psychological benefits of providing a futile medical care are highlighted, and the importance of the lack of adequately developed end-of-life care facilities in Greece is emphasized.

## Conclusions

These findings enforce our opinion that futile medical care should be conceptualized in the strict sense of the term, namely, as caring for a brain-dead individual or a patient in a medical condition whose continuation would most likely go against the patient’s presumed preference (strictly understood). For a great part, our findings were consistent with prior literature. However, we identified some issues that are of clinical importance.

# Background

Medical futility is a long-held concept. It was introduced in the 80's as a distinct concept of bioethics, which however, is not a well-defined concept. It is extremely difficult (if not unattainable) to precisely define medical futility. The American Medical Association Council on Ethical and Judicial Affairs was of the opinion that medical futility is "inherently a value-laden determination" and stated: "a fully objective and concrete definition of futility is unattainable" [1]. It is arguably stated that medical futility is "an elusive concept" [2] like other terms such as love and art [1]. While medical futility was initially strictly conceptualized as based on evidence-based medical judgments, over the last decade it was turned out to be broadly conceptualized as based on not only medical but also value judgments [3]. Katz recently and in consistency with previous literature [1] states that "futility in medicine has been defined as excessive medical intervention with very little prospect of altering the clinical outcome in a positive manner" [4]. Katz attempted to provide a broad definition and states "If treatments fail to release our patients from the preoccupation with the illness and do not allow them to pursue their life goals, then perhaps that treatment is futile" [4].

White et al. put it best in saying "futile treatment has been commonly understood in two senses: firstly, the likelihood that treatment will confer patient benefit is unacceptably low (quantitative futility); secondly, the quality of the resulting patient benefit is unacceptably low (qualitative futility)" [5]. Note, however, that it has been argued that the concept of medical futility (broadly understood) comprises four aspects: a) The chance of success, namely, achieving the desirable goals is extremely low. b) There is consent of patients or their surrogates. c) The patient's quality of life is poor. d) The consumption of medical resources is not proportional to the expected benefits. Every single health professional may make a different judgment with regard to these aspects when considering the situation of a particular patient [1].

Nursing professionals are frequently confronted with situations where they believe providing further treatment is no more beneficial to the patient while imposing extra suffering to them. By profession, nursing professionals are very closely involved in providing direct care to patients who may be in the final stage of life and especially near death. They may be in prolonged, continuous, and intense contact with these patients. Nursing professional's role is related to (both physical and narrative) proximity, namely, nearness to the patient's body while understanding his or her story [6]. At least in many developed countries, the majority of deaths occur in hospital settings against patients' wishes. As nursing personnel spend the most time with the patient and the role of nursing professionals in end-of-life decision making remains unclear [7], further investigation is needed to find out more about their perceptions on "futile treatment".

Medical futility still remains a key priority research topic for clinical ethics. In Greece, few research has been conducted on this topic. This study aims to contribute to filling this knowledge gap. We conducted a qualitative research involving in-depth interviews, focused on investigating the medical futility experiences of nurses with long history of caring for severely ill or terminally ill patients.

# Methodological Aspects

## Objective

The present work is a prospective qualitative research study centered on exploring the descriptions of nursing professionals' lived experiences and attitudes towards futile medical care. Data were collected through semi-structured in-depth interviews conducted in person (face-to-face) with 16 experienced nursing professionals between December 2020 and May 2021.

## Research questions

The primary research question that defined the focus of this study was as follows:

What are the experienced nursing professionals' lived experiences of medical futility in Greece?

The secondary research question was as follows:

What are the factors (if any) that can cause experienced nursing professionals to consider a medical intervention as futile?

## Research team

PV is an Associate Professor of Medical Ethics. AT conducted the interviews. She has a degree in Nursing and a degree in Law. She has a master's degree in extracorporeal circulation and was pursuing a Postgraduate degree on ICUs (expecting to graduate), and a Postgraduate degree on Bioethics at the time of the study. AKT is a Professor of Experimental Surgery.

## Study design

## Theoretical framework

Thematic analysis was selected as the methodological orientation to underpin the study.

## Participant selection

Purposive sampling was used to identify experienced nursing professionals who potentially had professional lived experiences of medical care considered as futile. The participants represented a wide range of ages and previous work experience in nursing. All the participants had graduated from university nursing schools. Thirteen out of the 16 participants in this study possessed a Master degree, with one participant being in possession of a doctorate degree. Initially, we approached nursing professionals who might meet our inclusion criteria using the interviewer's (AT) personal contacts. Potential participants were approached in person, by phone or by email and then contacted by phone to schedule an interview. None of the potential participants refused to participate or dropped out. Recruitment continued from December 2020 through May 2021, reaching a total of sixteen participants. After first contact, all the individuals were told that the purpose of the study was to better understand the medical futility

experience of nursing professionals in Greece and that the interview was expected to take between 30 and 60 min to complete. After agreeing to participate, the participants received a brief explanation of the objectives and the policies regarding anonymity, voluntary participation and confidentiality of the study.

## **Setting**

The interviews were conducted in neutral places of the participant's choice. All interviews were held in quiet places with a comfortable environment. As phenomenological researchers, we were interested in describing the participants' experiences while maintaining a natural (normal, unreflective and effortless) attitude. No one aside from the participant and interviewer was present at the interviews.

## **Description of the sample**

The inclusion criteria for participation in the study were (1) being working in Greece as a nursing professional for at least ten years, and (2) being experienced in providing care for severely or critically ill patients for at least ten years. Furthermore, participants should be (3) graduates of university nursing school. We thought that nursing professionals who had graduated from university schools could get an in-depth understanding of futile care and better express their experiences and perceptions on it. The selected study participants (N = 16) were experienced nursing professionals with considerable work experience in caring for severely or critically ill patients. None of them had worked in settings where severely or critically ill patients were not included. Participants were diverse in terms of age, gender identity, work experience and educational background. The age of the participants ranged from 30 to 52 years, with the majority being between 39 and 52, The mean (standard deviation, SD) age of the participants was 41 (SD = 6) years. The years of previous work experience ranged from 10 to 29, with the majority being between 14 and 29 years. The mean (SD) previous work experience of the participants was 17.5 (SD = 6) years. All participants resided in Athens. The participant characteristics are presented in Table 1.

Table 1  
Participant characteristics

Participant	Work experience	Age	Gender
P1	20	48	Male
P2	29	52	Female
P3	18	43	Female
P4	22	41	Female
P5	25	45	Female
P6	20	47	Male
P7	10	36	Female
P8	10	39	Male
P9	12	36	Female
P10	10	33	Female
P11	14	37	Female
P12	23	41	Female
P13	16	40	Female
P14	18	41	Female
P15	24	50	Female
P16	10	32	Female

## Data collection

The interviews were conducted face-to-face. The development of the interview guide was based on review of the relevant literature. As a first step, the interview guide was pilot-tested. The guide was slightly refined based on the initial results from a few interviews to allow the participants to better understand the specific issues being asked in the questions. Then, we developed an informal grouping of topics and questions that the interviewer could ask in different ways for different participants. The interview guide covered a number of topics to capture a wide range of the participants' lived experiences. These topics were related to a) the factors that can cause nursing professionals to deem an intervention as futile care, b) the reasons behind providing futile medical care, and c) the consequences of providing futile medical care. The participants were encouraged to expand upon the examined topics. They were asked broad questions and encouraged to respond in a conversational way to express themselves. The interviews were semi-structured and started with questions such as "What does futile medical care mean to you?" (*a grand tour question to make the participant comfortable*), "What would motivate or did motivate you or other healthcare professionals to deem a medical treatment as futile?", "What factors would contribute to

your patient experiencing a 'good death' or a 'dignified death'?", "What was it like to be a nursing professional caring for a patient receiving futile medical care?", "Can you please describe in detail what were your responses to providing futile medical care?", "How do you think others perceive providing futile care?", "What does dying a 'good and dignified death' mean to you?" and "What do you know about other health professionals experiences or attitudes towards providing futile care?". Additional questions were asked to elicit more detailed explanations and identify the essential themes of nursing professionals' perceptions on futile medical care.

The interviewer audio-recorded the interviews to collect the data. In addition, field notes were made after the interview to record nonverbal behavior patterns, as well as procedural and contextual aspects of the interviews, which enabled deeper and contextual critical reflection on the data collected. The interviews lasted from 38 min to 55 min each (mean 44 min). We stopped data collection when we believed data saturation was reached, namely, when no additional information was obtained from further interviews. The interview transcripts were not returned to the participants for their comments and/or corrections.

## **Data analysis**

Qualitative data were analyzed using thematic content analysis [8]. Verbatim transcription of the audio-recorded narratives was performed. We followed Gibbs' advice on demonstrating qualitative reliability [9]. Using this perspective, we carefully examined, verified and repeatedly read the transcripts to obtain a good sense of the participants' narratives [8]. We constantly compared the data (as described by Patton [10]) to ensure that the codes were used consistently. The data obtained from the interviewees were thematically categorized and analyzed. Open coding was used to identify quotations related to our research questions. Three data coders coded the data. We did not provide a description of the coding tree. After summarizing these quotations in notes, we grouped phrases reflecting the same context to form categories and subcategories that might represent starting points for the results of the study. Then, the transcripts were reread and were constantly compared with the list of categories and subcategories to identify further phrases in transcripts that might help address the research questions. Therefore, we strived to capture and investigate in depth all aspects of the participants' narratives related to the research goal. Moreover, we coordinated communication and shared analyses.

A data management software program (NVIVO, 2015) was used to secure and further refine the systematic character of the analysis. The participants did not provide feedback on the findings. Participant quotations are presented to illustrate the themes and findings. Reflexive thinking was used throughout the research process to reduce unintentional personal bias. Each of us engaged with the other researchers to limit research bias.

## **Ethical Considerations**

The interviews were conducted in neutral places of the participant's choice, thereby ensuring privacy and confidentiality and minimizing environmental impact. We adhered to the ethical principles of anonymity,

voluntary participation and confidentiality. The participants' anonymity and confidentiality were maintained throughout the study: to preserve their anonymity, pseudonyms were used to describe participants in this study, and the interviews were registered and stored in a strictly confidential fashion.

## Results

Participants' perceptions of futile care varies depending on the patient's condition and the personal perspective of patient's condition. The perceptions of the participants in our study on medical futility are related to moral values to respect patient wishes, ease suffering, maintain truthfulness and distribute scarce healthcare resources appropriately.

### 1. The concept "futile medical care"

While participants might each have a familiar sense of what we would mean by invoking the term "futile medical care", the term was not explicitly defined. Several participants in this study have shown cautious attitude towards labelling a medical treatment as futile. Our data analysis suggests that this is because participants not only realized the difficulty of providing a clear definition of the entity "futile treatment", but also were hesitant as to whether they could view a life sustaining medical treatment as futile. However, participants view the concept "futile treatment" as familiar. They appeared to have a sense of the term "futile medical care". Some participants viewed the concept "futile medical care" as quantitative futility, some other participants viewed it as qualitative futility, with some participants attempting a mixed approach.

More precisely, 7 out of the 16 participants in this study (P4, P7, P9, P11, P13, P15 και P16) felt that providing medical care to patients with no life expectancy is providing futile care. However, they did not attempt further to define the term "life expectancy". Please note that most important things can be said or experienced in the last hours of the patient. Two out of the 16 participants (P8 and P12) felt that a medical care that cannot improve patient's quality of life is futile, without however attempting further to define the term "quality of life" in the context of end-of-life care. Three participants (P3, P5 and P6) said that futile care is an ineffective care without attempting further to define what is meant by the term "ineffective". Participant P14 viewed as futile the treatment that proves harmful to the patient in the sense that it imposes extra pain or suffering.

Interestingly, several participants (P1, P2, P10 and P14) expressed explicitly their concerns about labelling a medical care as futile. Participant P2 said that had difficulties in defining the concept "futile medical care". More precisely, participant P2 said, "*it is difficult for someone to determine situations that could cause health professionals to consider a medical intervention as futile*". She said that she learned from her professional experience that many elderly people are discharged alive from the intensive care units. Furthermore, she attempted to provide a definition based on survival rates and quality of life. In a similar vein was participant P1. In addition, the following interview quotes are indicative of the difficulty of providing (or reluctance to provide) a clear definition of the concept "futile medical care". Participant P1

suggests that “*the concept ‘futile medical care’ needs to be discussed by an international scientific community*”. Participant P6 suggests that “*the determination of medical futility can only be made within the context of clinical situations, which however, should be clearly outlined*”. Participant P13 said, “*there is[the concept] ‘futile medical care’ but...I don’t know [if it is morally right to accept it] ...*”. Participant P10 said, “*...a medical intervention...perhaps...must never be labelled as futile...*”. Participants P1 and P14 declared, “*I do not like the term futile medical care*” and “*the concept futile medical care is a hard concept*”, respectively.

## **2. Patient’s reliance on machines – Technological dependency**

Participants P5 and P6 believed that mechanical support should only be provided in patients who have chance of recovery from being dependent on them. Interestingly, however, some participants expressed strong reservations on this view. Participant P10 emphasized that “*technology by itself cannot make it futile to further provide medical treatment*”. She said that a medical treatment can by no means be considered as futile if there is verbal or non-verbal communication (i.e., through eye contact) of the patient. Participant P11 clearly declared that providing further medical care to a brain-dead patient should be considered as futile. “*However*”, she said, “*I do not know if the provision of a life-sustaining treatment to a patient in persistent vegetative situation might be thought of as futile*”.

## **3. Reasons behind providing futile medical care**

Fear of legal action, lack of regulatory framework, physicians pressured from (mostly uninformed) family members and physicians’ personal motives were reported as important reasons behind providing futile medical care.

Fear of legal action was a factor that emerged from our data analysis as significant reason behind providing futile medical care. This was a recurrent finding throughout the narratives of the vast majority of participants (14 out of the 16 participants in our study). Only two participants (P2 and P7) believed (even though not wholeheartedly, using the expression “*rather not*”) that the fear of legal action was not a significant reason behind providing futile medical care. Furthermore, physicians pressured from family members into providing futile medical care (P3, P4, P14, P15, P16) and the lack of a clear regulatory framework for futile medical care in the country (P1, P4, P14) were reported as driving forces for the provision of futile medical care through intensifying the health professionals’ feeling of fear of legal action. Participants (P5 and P8) reported that in some hospitals where there have been developed documents (according to protocols, regarding the provision of futile medical care) which are to be signed by the patients or their representatives (i.e., family members), the fears of lawsuits are limited.

Moreover, some participants were of the view that the physicians were drivers of futile medical care. Participant P2 said that the physicians were drivers of futile medical care because of their emotions or their personal motives such as the egoistic motive for “*carrying it off*”, namely, coming out on top. She said that physicians are not afraid of lawsuits. Participant P7 said that “*psychological and emotional*

*factors are more significant reasons behind providing futile medical care than the fear over encountering legal problems*". At any rate, it should be highlighted that many participants were of the opinion that physicians often provide futile medical care to their patients.

Participant P3, who had long previous work experience in intensive care units, wonders why many futile treatments are provided in ICUs where the probability of taking any legal action against the health professionals is very low. ICUs are closed facilities.

Interestingly, three participants argued in favor of providing futile medical care, at least under particular circumstances. They reported their lived experiences during their long career history (more than twenty years) as nursing professionals. Participant P2 reported a case of a patient in a critical situation. There were pressures from nursing personnel on physicians to consider the medical care as futile and "*let him leave*". However, the physician's persistence in providing futile medical care resulted in the patient being discharged from the intensive care unit in a "*good level of conscience*". The experienced nursing professional P1 said that "*while a patient was expected to live for a very short period of time, finally, he lived much longer*". Participant P5 reported that had witnessed the case of a child in end-of-life phase. The medical team had decided to consider the provided care as futile and to interrupt it. The child died during seizures. Participant who witnessed that scene was emotionally charged for the rest of her life.

Interestingly, participant P2 emphasized the lack of facilities providing end-of-life care. She said that while many patients who have been treated in intensive care units are ranked as severely disable at discharge, further treatment of these patients may be erroneously labelled as futile despite the fact that it might be beneficial and valuable to them (might improve their quality of life) if provided in a palliative facility or at patients' own home. Patients in such situations cannot be treated sufficiently in an understaffed classic open hospital ward.

### **3.1. Consumption of considerable resources**

Furthermore, wastage of money and consumption of considerable resources is a reason behind labelling a medical care as futile. The vast majority of participants declared that spending money and consumption of resources should be factored in when considering the provision of a medical treatment that can be labelled as futile, especially in the time of the Greek financial crisis, namely, over the last decade, when the available resources were limited (P9 and P14). Note, however, that most participants appeared to not wholeheartedly support this consideration. The expression "*even though it seems unfair*" was recurrent in the interview data (P3, P4, P8, P14), especially because the patients had paid their health insurance contributions (P6 and P11). Participants P2 and P3 said that we are obliged to take into account the costs, especially when it comes to providing medical care in intensive care units where the consumption of resources is considerable. Two participants (P11 and P12) expressed some clear reluctance to accept the role of costs in end-of-life decision making. Participant P1 expressed his clear negative attitude towards the suggestion that costs should be taken into account when making end-of-life decisions. In contrary, participants P2 and P16 provided wholehearted support to this consideration, without reservations.

The high costs of futile medical care delays accessibility to healthcare resources for patients who have life expectancy (P9, P10, P12 and P14). Participant P15 clearly determined the term “life expectancy” when considering the role of costs in labelling a medical care as futile. She said, “*if a patient has a chance to survive the costs should not be taken into account*” implying that even a very low survival rate may be important. Participant P7 said that we should not take into account the costs when it comes to facilitating a dignified death. She said, “*ensuring a dignified death is the only meaningful thing we can offer to these people [patients nearing the end of life]*”. Indicative of the participants’ half-hearted attitudes towards accepting the role of costs in deciding about a futile medical care was the speech of participant P10 who was of the opinion that the money saved by avoiding or stopping futile medical care could be better spent on creating for him the most advantageous conditions possible, such as “*providing better psychological support or palliative care...improving the atmosphere in the patient room, i.e., by painting the walls...making the patient laugh...*” However, the participant found this suggestion impracticable.

Participants P13 and P15 declared that physicians often do not consider the costs. This is true, despite (healthcare administrator’s) recommendations on the contrary (P13).

## **4. Who is the decider? - The nursing professionals’ role in deciding on the futility of a certain treatment**

In this study, it is highlighted the nursing professional’s role as participant in decisions on futile care and as mediator between physicians and patients (and family members). Furthermore, it is prioritized the patient’s role in decisions on futile care.

Almost half of the participants suggested that end-of-life medical decision process should incorporate the patient (prioritizing their preferences) and the attending physician (P2, P4, P5, P7, P8, P9, P14). Participant P3 was of the view that physicians should make unilateral end-of-life decisions, after having listened to the nursing personnel. However, almost half of the participants suggested that end-of-life medical decision process should always incorporate all key stakeholders, including nursing professionals and family members (P6, P7, P10, P12, P15, P16). Participant P4 was right in saying that a person who is in long-term proximity relationship with the patient (“*the closest person to the patient*”) should be considered as close family member.

Participants recognize that nursing professionals are frequently not involved in the end-of-life decision making process (P7), and therefore, they feel abandoned and powerless (P14). Participants wanted to be more involved in end-of-life decisions (P3, P10, P11, P13) for the very reason that nursing professionals spend much more time with the patient than physicians. Participant P13 said: “*nursing professionals and patients are rubbing together*” and considered that nursing professionals should play a leading role in end-of-life decision-making. Importantly, P14 said that nursing professionals understand the patients’ values and preferences, and hence, they are ideally positioned to act as mediators between physicians and patients (and family members). Participant P7 said, “*nursing professionals are included in end-of-life*

*decisions, though to a limited extent*" and emphasized the need for good communication between health professionals in order for nursing professionals to be consistently included in end-of-life decision making processes. Some participants considered inappropriate for family members to be included in end-of-life decision making processes due to the fact that pressures from them is often a driving force for the provision of medically futile care (P2, P8, P14).

## **4.1. Provision of information to family members**

From our data analysis it has emerged that patient family members often keep (false) hopes alive due to a lack of information and knowledge. It is so difficult for them to accept that the death of a loved one is inevitable, and they believe in a miracle. For instance, participant P4 (who had 22 years of previous work experience) said, *"Nobody is wired to accept that death happens..."*. Family members may become quarrelsome and imply that in case of negative development they might take legal recourse against the attending physicians (P4). It was emphasized that the bonds between family members are particularly strong in Greece (P7). Participants highlight that in the Greek clinical context patients and family members lack information about end-of-life issues (P1, P4, P7 and P14). It has been stated that well-informed family members (especially when the information provided is accompanied by psychological support) are expected to put less pressure on physicians trying to cause them to provide futile medical care (P10). Participant P8 suggested that public education should focus on the specific and limited role of the intensive care units as well as the option of palliative care to prevent the general public from having unrealistic expectations. Interestingly, two participants (P1 and P10) highlighted the psychological benefits of providing a futile medical care mainly due to offering (false) hopes. Participant P1 (who had 20 years of previous work experience) said, *"Let's see it in a holistic way...providing a futile medical care may be psychologically beneficial, even if it may not be biologically beneficial...Nobody knows how much grief and death cost in our inner world."*

## **5. Participants' personal responses to situations where futile care is provided**

It was emerged from our data analysis that providing futile care is a major factor that negatively affects the nursing professionals' inner attitude towards performing their duties. While participants developed resilience promoting strategies to deal with providing futile medical care, they emphasized the negative impact of providing futile care on their inner world. A tension between their inner world and outer world was emerged from our data analysis.

Interestingly, participants normalized their negative experiences of providing futile care, stating that they were performing their duties to the best of their ability and with respect for their professional standards. However, in apparent contradiction to these assertions, they expressed concerns about their inner attitude towards caring for patients receiving futile medical treatment and emphasized the emotional nature of their duties. The open-ended questions permitted nurses to specify situations of futile care, which they regarded as morally distressing.

Six out of the 16 participants in this study (P2, P5, P6, P7, P11, P12) declared that providing futile medical care does not affect their behavior towards their patients and family members. Interestingly, participant P6 said that he takes care not to change his behavior towards his patients because *"patients nearing the end of life understand"*. Participant P7 said that he takes care not to change his behavior towards his patients (nearing the end of life), because she *"must ensure good quality of life for her patients right to the end"*.

Notwithstanding, ten participants declared that the negative emotions they experienced because of providing futile medical care affected negatively their attitude and behavior towards their patients. Participant P13 said: *"when you know that a medical care is futile, you are not in the mood to 'run', to communicate with the patient...when you feel that your efforts are not 'paid off' [on an emotional level], you feel that you are doing drudgery"*. Participant P3 declared, *"I may not be on-task... I may omit to provide the complete treatment to the patient"*. Participant P10 said, *"if there is a sense of vanity in the air, nursing professional may not be in a good mood and become less communicative"*. However, Participant P10 said, *"if the patient does not express (by any means) a strong desire for struggling to save his or her own life, nursing professionals work in a dominant atmosphere of futility."* In the same vein was participant P14. Participant P8 declared that nursing professionals distance themselves from their patients.

Participants P2, P5, P6, P7 and P11 said that they are able to get their emotional reactions under control, i.e., participant P2 said, *"I am often emotionally affected but...I turn off the switch..."*.

As regards the emotional experiences of caring for patients who receive futile medical care, many participants declared that they often experience sadness and grief (P4, P7, P9 and P14). Interestingly, some participants reported that they often feel anger or become stubborn for various reasons. Importantly, it has been reported that they feel that providing futile care saps their energy.

Participant P12 said that in such situations she often becomes stubborn about ensuring patients and families experience a 'good' and dignified death. She said, *"when providing a futile care, you have to show greater respect for the patient's body."* Participant P9 felt that providing futile care sapped her energy. She said, it *"wastes my energy which is something needed by other patients."* In a similar vein was participant P14 who declared that providing futile care is "soul-sucking." The participant said, *"I feel so angry with myself when I am forced to give false hopes to a sick person who looks at my eyes and say things that she would never say to her family."* Participant 4 had said almost exactly the same thing. Participant P16 said, *"We get angry because of the failure of our efforts to succeed...we are emotionally charged."* Importantly, participant P1 said, *"There are negative emotions in the inner world of nursing professionals, which will never be externalized..."*. Interestingly, participant P9 said, *"...I feel anger, because providing futile care wastes my energy...which is something other patients need..."*

## **6. The concept of "good or dignified death"**

All participants took a clear position on “good and dignified death”. Interestingly, from our interview data analysis emerged a list of criteria for assessing the patients’ quality of life and labelling the dying process as undignified, which, when identified in clinical situations involving medical treatment, the treatment might be perceived as futile.

A range of various and distinct features of “good and dignified death” were emerged from our data analysis. Some of them appeared as recurrent findings. These features can be roughly categorized into four categories. There was emerged features revolving around a) pain and suffering, b) treating patients with respect, c) the appearance and image of the patient body, and d) the interaction and interrelation between patients and their relatives.

Among the features of a good and dignified death have been cited 1) pain and suffering (P5, P6, P7, P10, P13, P14 and P16), 2) enforced continuation of patient’s (full of suffering) (P13 and P15), 3) treating the patient not as a person but as a medical event, (P14), 4) patient going to death without being prepared for his or her own death (P1), 5) the lack of respect for patient’s person and personality (P2, P3 and P14), 6) the patient’s inability to determine how he or she will die (P8), 7) the lack of cleanliness (P4, P7 and P14), 8) patient incapable of self-serving and completely dependent on others (P8, and P9), 8) patient’s feelings of humiliation and powerlessness (P14), 9) patient’s unmet actual (P14) or presumed preferences, i.e., not ensuring religious patients have the opportunity to take Holy Communion (P2), 10) patient feeling incapable of keeping pace with what is meant by the term “human being” or “human condition” (P3), and 11) patient feelings of imposing on others (P8).

Furthermore, many participants have recurrently placed considerable emphasis on two main aspects of “bad or undignified death” that deserve particular attention: the appearance and image of the patient body, and the interaction and interrelation between patients and their relatives. A number of situations have been reported by several participants (experienced nursing professionals) to be features of what is meant by the term “bad or undignified death”.

The appearance and image of the patient body regarding the patient’s appearance a) taken as it really is, b) as it is perceived to be by the patient, or c) as it is seen through others’ eyes. The patient dies an undignified death if a) his or her body is “melting” (P11), b) are getting bed sore (especially if the bed sores are neglected) (P7 and P13), c) the patient body changed and lost its shape (P11), the patient image degenerated into a decomposition image (P3), d) “150 sachets” are attached to the patient’s body (P4), e) a Levin feeding tube is inserted into the patient’s body (P4), f) the patient undergoes many painful venipunctures daily, while nearing his or her inevitable end of life (P12), g) the patient is not capable of self-serving (especially defecating or urinating) (P8), h) the patient arouses pity for him/ herself (P5 and P9), the patient begs to die (P5), i) the patient is not capable of speaking or communicating with others (P8), j) the patient is getting naked often (P4), h) if the patient could look at him/ herself in the mirror, he/she would feel sad (P5).

The interaction and interrelation between patients and their relatives is a factor which has been reported to be an important aspect of the “bad and undignified death”. It was said that dying a death in isolation,

in a “cold” hospital environment, is not dying a “good and dignified death”. Dying at home environment facilitates the patient to die a “good death” (P4 and P9). Dying a dignified death means dying surrounded by family and loved ones, communicating and being in contact with them, i.e., clutching the patient’s hand tightly or caressing the patient’s head (P2 and P4), giving to the patient their love (P14), thus making patient not feel alone (P2, P4 and P7), “*patient and family (or other loved ones) get through hard times together*” (P7), the patient has people around him or her to share his or her fears (P4). Family members must create an optimistic environment (P10) where there is no mourning (P14). Participant P2 who had a lot of experience in the specific field of intensive care medicine said, “*patients in sedation need human contact*” and “*you never know what a patient in sedation can understand*”. Importantly, participant added, “*I had a habit of caressing the head of a child who was in sedation...when she waked up, she told me that she kept seeing me in her dreams caressing her head.*”

## Discussion

### 1. The concept “futile medical care”

Participants arguably have difficulties in defining medical futility in a clear way. In our opinion Lantos et al. were right in saying that medical futility is not an objective entity and “must be determined in the light of the subjective views and goals of patients” [2]. Furthermore, some participants perceived medical futility as rather quantitative futility, with some other perceiving it as rather qualitative futility.

Futile treatment has been commonly understood in two aspect: the qualitative aspect and the quantitative one [5]. Some experts explain futile care only in terms of patient survival, while others consider quality of life, in addition to patient survival [11]. In several previous studies, nursing professionals described futile medical care as an ineffective care [12], failing to improve patient’s survival rates, to regard the overall outcome benefit to the patient’s health [5] or to prolong suffering without providing a “reasonable hope” for a patient to recover to “a state of relative independence or be interactive with their environment” [13] while using “considerable resources [13]. It fails to improve the patient’s quality of life, while prolonging suffering [13]. Interestingly, while White et al. found that futility is a familiar term with which doctors readily engage, they noticed “a high degree of variability in how this definition was applied in the clinical setting, reflecting the qualitative nature of patient benefit” [5].

Factors cited in literature as factors that can cause nursing professionals to consider a medical intervention as futile treatment revolve around the following key themes: Ineffective treatment, prolonging or imposing extra suffering, and considerable wastage of resources that might really benefit other patients [12, 14, 15]. Note, however, that scholars fail to quantify or further specify how to determine these terms.

On the contrary, lack of healthcare structures in palliative medicine and hospice care may be important reasons behind labelling a medical care as futile [16]. Further treatment of some patients may be

erroneously labelled as futile despite the fact that it might be beneficial to them if provided in a palliative facility or at patients' own home.

## **2. Patient's reliance on machines - Technological dependency**

The participants' half-hearted attitude towards labelling the life-term reliance on machines as futile medical care is consistent with their general hesitant attitude towards considering a medical intervention as futile care (as presented in other parts of the Results section).

We feel that the experienced nursing professionals' attitude is intuitively and morally justified. We are of the opinion that opinion that futile medical care should be conceptualized in the strict sense of the term, namely, as caring for a brain-dead individual or a patient in a medical condition, whose continuation would most likely go against the patient's presumed preference (strictly understood).

## **3. The reasons behind providing futile care**

The most important reasons behind providing futile medical treatments which had been cited in the literature were: "Patients'/family members' request and persistence", "Healthcare professionals' personal emotions, beliefs, and attitudes", and "Organizational factors and fear over getting involved in medical litigation" [13, 15, 16]. It is argued in literature that family members (more particularly family caregivers) demonstrate stronger insistence for providing futile medical care than patients themselves [17]. Family members insist on providing futile care because they have unrealistically high expectations because they are not well informed by the physicians (who may be unwilling or unskilled in discussing end-of-life issues) about the underlying conditions [16, 18], have difficulty to accept the reality of an imminent death, and fear of "loneliness and being neglected" [16]. Communication between health professionals and patient or patient's family members is essential for making better end-of-life decisions and judgments about futile treatments [7]. It is stated that "open and honest communication with patients and their families about treatment efficacy, expectations regarding outcomes, and other related considerations may help limit some futile treatments" [1]. Moreover, it is argued that efforts to limit futile medical care should include public information about the role of intensive care units (ICUs) and palliative care [18].

At any rate, a lack of legal support has been cited as reason for complying to family members' insistence on providing futile care [13]. Surprisingly, it is suggested that physicians may be the drivers of futile medical care because of their personal motives such as "prognostic uncertainty or their perception of healing as the core purpose of medicine, and the so-called treatment imperative [16]. Note that Willmot et al. found that physicians believe that "a range of factors contribute to the provision of futile treatment" [19].

On the contrary, providing futile care may help family members to visit the patient and be with them during the last hours of their lives [16]. Furthermore, it is argued that "ethically and legally doctors are not obliged to provide futile treatment to patients, even if the patient or their proxies are prepared to pay for it. However, it may be justified where such treatment is harmless and has a placebo effect" [20].

## **4. Who is the decider? - The nursing professionals' role in deciding on the futility of a certain treatment**

The physician is often the primary decision-maker who makes end-of-life decisions unilaterally. Nursing personnel is expected to follow these decisions. In some studies, participants (nursing professionals) agree that the physician is the leader of the decision-making process [7]. In the same vein were some of the participants in our study. Note, however, that this is a completely paternalistic and morally unacceptable approach. End-of-life decision is a shared decision-making process where all the stakeholders (i.e., patient, relatives and health care team, ethicists, spiritual care counsellors) must be involved [13, 18, 21]. The end-of-life decision is a difficult decision influenced by many individual patient factors [7, 21].

Nursing professionals are the main caregivers who spend most time near the patient, being in close physical and narrative proximity to them, thereby encountering their particularities [6]. However, the literature reports under-representation of nursing professionals in end-of-life decisions [7, 22, 23].

Nursing professionals arguably are motivated by a rigid desire that attending physicians should listen to them [22]. More generally, nursing professionals highlight the need for better inter-professional relationships when it comes to end-of-life decisions [23]. Note, however, that it is argued that physicians often recognize the role of senior and experienced nursing professionals and include them in end-of-life decision making processes [24].

## **5. Nursing professionals' responses to situations where futile care is provided**

Among the most important factors that cause to nursing professionals' moral distress are: a) Witnessing unnecessary suffering, and providing unwarranted and overly aggressive treatment [25, 26], b) Disregarding the patient's preferences [25], c) Shortage of resources and inappropriate resource allocation and utilization [25], d) Seeing the patient dying without having an opportunity to farewell their relatives and acquaintances [27]. All these factors are consistent with our findings. Furthermore, as nursing professionals are in close physical and narrative proximity to end-of-life patients, they may experience moral distress and desire 'to escape responsibility' [6].

As a means of defense (i.e., to minimize their own stress), nursing professionals experiencing moral distress may distance themselves from a patient and provide poor quality care [28]. However, most participants asserted that they managed to prevent negative effects of these situations on patient care. To appear professional, nurses may use mechanisms such as down-regulation of emotions [29]. In line with participant P9 in our study, a participant in a previous qualitative research study felt that providing futile care sips her energy [30].

## **6. The concept of "good and dignified" death**

As presented in the Results section, many participants specified various and distinct situations which, in their view, make dying process become an undignified process, and therefore, could cause them to view a medical treatment as futile. In our opinion, continuing these situations is most likely to be in conflict with the presumed preferences of the patient.

The concept of a good death is highly individual, where the patient's preferences should take precedence [23, 31, 32] and patient's integrity should be protected [32]. Dignity is perceived by nurses as a multidimensional entity [33]. Efstathiou and Ives put it best in saying "dignity is both inward and outward looking, concerned both about how the death is or would be experienced by the dying patient and also how it is perceived and experienced by others. This was illustrated through symptom control, physical cleanliness and removal of technical apparatus" [34]. The concept of "dignified death" or "good death" appears to be connected to maintaining dignity for the dying patient and achieving a less-medicalised death [34]. Maintaining dignity for the dying patient is an essential aspect of end-of-life healthcare. In that regard it is noteworthy that Parmryd et al. found that nursing professionals in critical care settings put every effort to protect patient's integrity [32]. However, "dignified death" is an abstract concept that is difficult to define. "Dignified death", within this study, was often talked about in connection with acts such as symptom control and relief from suffering, physical cleanliness and good appearance of the patient's body, removal of technical apparatus and providing patients with time to farewell their relatives and acquaintances. The relief from pain and suffering and the provision of physical care for the dying patient is essential for a dignified death [35]. Note, however, that "suffering" is a "rarely explicitly defined" concept, which is used to refer to a "negative, subjective experience that goes beyond the experience of pain" [36]. Physical presence of family members is regarded as essential during a good death [22]. Being surrounded by and communicating with family members is essential for dying a 'good death.'

Authors have argued that making the dying patient look clean and fresh reinforced dignity [35]. Bad appearance of the patient may result in separating the patient from the family, whereas good appearance may contribute to 'reconnect' the patient with their family, namely, promote a good death [37]. Note that in the literature it is argued that body image impacts on patient care and "influences a number of medical-related outcomes' [38]. Further investigation is necessary to explore how the deteriorating physical appearance of the patient (who already looks dead and their body appears to be a rotting body) factors into the futility determined by nurses [39].

## Limitations

First, although we put great effort into conducting a selection process free from biases, potential self-selection bias cannot be ruled out. Those who were particularly interested in the topic of research are more likely to have responded to our call for research participation. Second, our sample size was small. However, it was similar to that of other qualitative studies. Although saturation was reached, further research should explore these topics in more depth. Third, a limitation of this study is that only participants working as nursing professionals at hospitals in Athens were interviewed. However, the results of this study provide valuable insight into (experienced in caring patients nearing their end of life)

participants' perceptions on futile care. While many nursing professionals in the country are working under similar circumstances, we argue that the results are transferrable to similar contexts. Fourth, a limitation of this study is the fact that the data were only collected via face-to-face interviews and field notes. Other methods of data collection relying on some other methods, including focus groups, can enrich the findings of a similar qualitative work of research. Furthermore, recall bias may have occurred, at least with regard to certain findings. Finally, any qualitative interview study is prone to interviewer and researcher bias.

## Conclusions

From our data analysis, emerged a nursing professionals' half-hearted acceptance of futile medical care. This attitude was consistent with other findings of this study such those highlighting the positive aspects of a futile medical care and the participants' reluctance to label a medical care as futile for the sake of saving costs and resources. Interestingly, within this study emerged a number of clinical situations, which best describe in detail what is meant by the term "bad and undignified death". These findings enforce our opinion that futile medical care should be conceptualized in the strict sense of the term, namely, as caring for a brain-dead individual or a patient in a medical condition, whose continuation would most likely go against the patient's presumed preference (strictly understood). Further, for a great part, our findings were consistent with prior literature. However, we identified some nuances that are of clinical importance. Among these findings are included the following: It is highlighted the nursing professional's role as a mediator between physicians and patients (and family members), and the impact of patients' (nearing the end of life) expressed effort to live and desire for living on nursing professionals' willingness to provide care. Patients battling to keep themselves alive increase nursing professionals' motivation to continue providing care. In addition, the psychological benefits of providing a futile medical care are highlighted, and the importance of the lack of adequately developed palliative care or care at home for patients nearing the end of life in the country is emphasized.

## Abbreviations

ICU  
Intensive Care Unit

## Declarations

### Ethics approval and consent to participate

Prior to participating in this study, the participants were given adequate information on the aim, procedure, nature and confidentiality of the study, and their oral consent to participate was obtained. The study and consent procedure were approved by the ethics committee affiliated with Aristotle University of Thessaloniki, Faculty of Health Sciences, Department of Medicine (No: 3.392/22-12-2020). In addition, we confirm that **all methods were performed in accordance with the relevant guidelines and regulations.**

## **Consent for publication**

In this manuscript, personal details of participants are presented that compromise anonymity (Table 1). Written informed consent to publish this information was obtained from study participants.

## **Availability of data and materials**

The transcripts of the full interviews that were collected and qualitatively analyzed in the current study are not available due to the ease with which study participants could be identified. The redacted transcripts used and analyzed during the current study can be made available by the corresponding author on reasonable request.

## **Competing interests**

The authors declare that they do not have any conflicts of interest to disclose.

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## **Authors' Contributions**

PV was responsible for the study conception, data analyses, ethical analysis of the findings, writing of the paper and reporting of the study. AT interacted with the participants and performed the interviews, transcriptions, translations and initial analysis. AKT assisted in the data analysis and revisions of the paper. All authors have read and approved the final manuscript.

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