

# A Qualitative Study of Nursing Practitioners' Experiences on Dying Alone Due to COVID-19 in Greece

Polychronis Voultsos (✉ [pvoultsos@auth.gr](mailto:pvoultsos@auth.gr))

Aristotle University of Thessaloniki

Anna Tsompanian

Democritus University of Thrace

Maria Deligianni

Aristotle University of Thessaloniki

Alexandra K. Tsaroucha

Democritus University of Thrace

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## Research Article

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# Abstract

## Background

Dying in isolation and without saying a goodbye before, during and after death causes patients, families and health providers to suffer greatly. In Greece, there is still limited knowledge about dying in isolation as perceived by frontline nursing practitioners working in a COVID-19 ward or ICU. Nursing practitioners spend a lot of time near their patients. Greece is most vulnerable country to the international problem of dying in isolation during the COVID-19 pandemic.

## Methods

A prospective qualitative study using in-depth interviews with fifteen frontline nursing practitioners working in a COVID-19 ward or ICU was conducted from July 2021 through December 2021. We performed a thematic analysis of the data.

## Results

Dying in isolation without saying a goodbye before, during or after death emerged as an extremely inhuman experience that critically ill covid patients and their loved ones had to go through. Fear of spreading COVID-19 infection, fear of liability, and fear of hindering the performance of nursing duties were emerged as main reasons behind strict visitation restrictions. Patients and family members were reported to have expressed very strong desire to communicate and interact with each other. Most participants were shown to be with high levels of empathy, willingness to provide holistic care. Furthermore, most participants were shown to be with high levels of psychological and moral distress. All participants held that visitations should be allowed on an individual basis, and remote communication technology should be available to any covid patient. Importantly, it was identified in this study that physicians' and nursing practitioners' discretion and goodwill can significantly mitigate the problem of dying alone. In some COVID-19 health care settings visitations were allowed at physicians' discretion. These "clandestine" visitations were mentioned as practices that existed in reality, even though they were not officially recognized by the Greek rules. Furthermore, the quality of nursing care seemed to have shifted towards a broader definition. Political neglect was a factor that emerged as a major factor that enlarges the problem of dying in isolation. Finally, and most importantly, a shift towards a less patient-centered model of care was emerged from the data analysis.

## Conclusion

The results reinforce the existing literature on many fronts. However, we identified some nuances that are of great importance in planning tailored interventions to mitigate the problems related to dying in isolation from COVID-19, and most importantly, hold down the commonly accepted patient-centered model of care. On the account of the patient-centered model of care and the modern (broad, positive-holistic) concept of health, providing holistic care for critically ill covid patients is both an institutional duty and a moral obligation.

## Background

The COVID-19 pandemic radically altered the end-of-life care. Limitations on in-person interaction between patients and family members undermines the quality of end-of-life care. In-person contact is a hallmark of high-quality end-of life care [1]. Of the many unprecedented adverse outcomes of the COVID-19 disease one “stands out as particularly vile, the experience of dying alone” [2]. Lonely deaths from COVID-19 due to strict “no-visitor rules” is a recurring topic in the COVID-19-related literature. Putting visitor restriction policies in place across most health care settings negatively affects the chances of dying with someone present. COVID-19 patients are hospitalized in isolation and family members are prohibited from meeting them and say a last goodbye to their loved ones. Many COVID-19 patients isolation rules aim to prevent virus from spreading. Difficult situations involving patients with severe COVID-19 who are hospitalized and left alone in a room where “spaceship-dressed” health professionals visit them are daily occurrences during the COVID-19 pandemic. Since early 2020 many people have died in isolation because of the COVID-19 pandemic across the world. COVID-19 patients are dying “alone, surrounded by machines and strangers wearing heavy protective gear” [2], namely, a death that Callahan calls “wild death” [3]. Patients are dying without being surrounded by and communicating with family members. Sometimes compassionate nursing practitioners help connect the dying patient with family via smartphone or virtual means. Indeed, remote communication strategies can promote effective face-to-face communication between dying patients and family, which is very important to family members [4]. Nevertheless, it is argued that even if this connection did take place, family members felt like they did not get to say final goodbye “properly” to their loved ones [5]. Such situations occur frequently during the period of the COVID-19 pandemic and may have serious (unknown at present time) psychological consequences for family members and healthcare providers, such as feelings of helplessness, frustration, guilt, moral distress and prolonged complicated grief [6]. At any rate, relatives should not be left in the dark about the health status of their loved ones [6]. Besides, the pandemic has changed funerals and significantly increased the risks of complicated grief [7, 8]. In addition, the circumstances surrounding many covid deaths may negatively affect people’s natural coping skills [8]. Jordan et al. recommended a three-level public health approach to manage a surge of complicated grief [8]. At any rate, it should be highlighted that the circumstances surrounding the hospital stay of patients in COVID-19 wards or ICUs involve conditions such as “contemporary” dying in isolation for which we are unprepared as society [9].

Providing care for patients hospitalized in COVID-19 wards is a demanding nursing, requiring continual contact with patients who are suffering as well as frequent communication and provision of support to family members who are experiencing intense negative emotions. A systematic review and meta-analysis conducted by Pappa et al. highlighted high prevalence rates of depression, anxiety and insomnia among healthcare professionals who stand in the frontline during COVID-19 pandemic [10]. COVID-19 pandemic has the potential to negatively affect health providers’ mental health [10]. More precisely, given the nature of their work, nursing practitioners cannot detach themselves from patients. Because of the overwhelming number of lonely deaths, nursing practitioners routinely face stressful situations that cause them to experience both psychological and moral distress, and especially compassion fatigue. Note, moreover, that nursing practitioners may experience positive emotions which “interweave and

coexist” with their negative emotions and can play an important role in nursing practitioners’ mental health recovery [11]. It is argued that physical and social rewards and support are crucial to maintaining nursing practitioners’ mental health [11]. Furthermore, it should be kept in mind that dying lonely covid death may lead to post traumatic stress and cause long term negative consequences for the grieving relatives [12].

Most importantly, in light of the COVID-19 pandemic there has been a noticeable shift from the well-established patient-centered (autonomy-driven, focusing on individual patient’s needs) medical ethics towards a tough new (public health-driven, paternalistic) medical ethics. This shift shakes the foundations of the autonomy-driven and empathy-based medical ethics that is commonly accepted over the last decades. In other words, this shift shakes the foundations of the well-established medical ethics for the sake of a new medical ethics model in light of the humanitarian crisis circumstances due to the COVID-19 pandemic. Given that an inherent part of nursing is to respect human values and rights, this shift represents a shocking transition for nursing practitioners and other healthcare workers that goes against their basic training and core values and beliefs [13].

Currently, organizational variables such as adequacy of healthcare staffing, adequacy of hospital resources, and number of critically ill or even intubated covid patients admitted and hospitalized in non-ICU wards due to shortage of ICU beds, changed for the worse in Greece over the past months. Of course, short supply for health workforce and beds for patients is not a Greek phenomenon, especially in the humanitarian crisis of the COVID-19 pandemic and in view of the need to handle the huge influx of covid patients. For years, the health workforce and hospital supplies for staff and beds for patients were perceived to be in short supply in most developed and developing countries (for instance, across the US) [14, 15]. However, there are additional reasons why workforce shortages in healthcare are happening in Greece in the current epidemiological context. This was mainly due to policies such as: a) Spending cuts. The Greek financial crisis has taken a heavy toll on public sector health care spendings over the last decade. b) The fact that all the unvaccinated healthcare professionals were given mandatory unpaid leave from work. They were put out of the job by law. c) Lack of training courses dedicated to the management of patients with severe respiratory impairment related to the COVID-19 disease, in order to make a maximum number of physicians and other healthcare professionals operational. This is presumably due to the considerable emphasis that policy placed on vaccination campaign rather than on substantially strengthening the healthcare services against the increasing influx and particular needs of covid patients. Furthermore, d) Lytras and Tsiodras in their recently published study regarding the period between September 2020 and May 2021 found that equity and quality of care under increasing influx of covid patients has received less attention in Greece [16]. In addition, it should be kept in mind that in Greece there are further escalation factors affecting the humanitarian problem of dying in isolation due to COVID-19, such as the following: e) The vast majority of the population in Greece consists of faithful Orthodox Christians who have firm and sincerely held religious beliefs. f) The bonds between the members in a Greek family are still very strong. g) In Greece, patients’ trust in their health care providers in general is declining. The same holds for patient’s family.

We were interested in exploring the nursing practitioners' experiences on dying alone due to COVID-19 in Greece because there is still limited knowledge about dying in isolation as perceived by frontline nursing practitioners working in a COVID-19 ward or ICU. Little research has evaluated nursing practitioners' perceptions about the stressful situations they routinely face because of the overwhelming number of lonely COVID-19 deaths in hospitals with strict no-visitor rules in place. This study aimed to provide a comprehensive and in-depth exploration of nursing practitioners' lived experience of dying or nearing a lonely death from COVID-19, through a phenomenological approach using semi-structured interviews and thematic analysis of interview data.

## **Methodological Aspects**

### **Objective**

The present work was formatted as a prospective qualitative research study centred on exploring how nursing practitioners experienced while caring for covid patients who were dying or nearing death due to the current circumstances of COVID-19 pandemic. We became interested in the research topic because it is cruel and inhuman to die a lonely death while suffering agony borne by both body and mind. In addition, over the past recent years Greece adopted extreme austerity measures (due to financial crisis) that led authorities to cutting spending on the public healthcare sector, among other sectors. This resulted in a lack of optimal infrastructure and human resources in the public health care sector, which are further barriers to providing optimum care (including end-of-life care) under the COVID-19 pandemic conditions.

As nursing practitioners spend significant time at patient bedside, we decided to explore dying of COVID-19 in isolation experiences through the lens of frontline nursing practitioners. Furthermore, we hypothesized that nursing practitioners experience a great deal of psychological distress during care of dying COVID-19 patients, and that even when operating under the COVID-19 pandemic conditions nursing practitioners can facilitate a good death for their patients. To gain insights into the experiences of nursing practitioners data were collected through semi-structured in-depth interviews conducted with 15 experienced nursing practitioners' between July 2021 and December 2021.

### **Research questions**

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

What are nursing practitioners' lived experiences of caring for covid patients who are dying alone or nearing death in isolation during the COVID-19 pandemic in Greece?

The secondary research question was as follows:

When nursing under the COVID-19 pandemic conditions, what factors remain critical for fostering a culture of "good death" in terms of mitigating the problem of dying in isolation?

### **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 also has a master's degree in extracorporeal circulation, and at the time of the study, she was pursuing a postgraduate degree in ICUs (expecting to graduate) and a postgraduate degree in bioethics. AKT is a professor of experimental surgery.

## **Study design**

## **Theoretical framework**

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

## **Inclusion criteria**

Nursing practitioners must have met all of the following inclusion criteria to be eligible for participants in this study: a) Being working as frontline nursing practitioner in a COVID-19 ward or intensive care unit (ICU), b) caring for critically ill covid patients, c) since the beginning of the pandemic.

## **Participant selection**

Purposive sampling was used to identify nursing practitioners who had professional lived experiences with critically ill COVID-19 patients. Potential participants were approached via an invitation letter which was sent by email using the interviewer's (AT) personal acquaintances. AT is a nursing practitioner. A few days later, potential participants were contacted by phone or by email to ask if they wanted to participate and arrange an interview. Finally, 15 frontline nursing practitioners were selected from COVID-19 wards and ICUs in different tertiary Greek hospitals. Participants were asked to share their experiences with critically ill covid patients and their relatives. None of the participants dropped out of the study. A snowball sampling technique was used to maximize heterogeneity. Recruitment continued from July 2021 through December 2021 and ultimately reached a total of fifteen participants. After first contact, all the individuals were told that the purpose of the study was to better understand how do nursing practitioners experience caring for covid patients who are dying alone or nearing a lonely death in light of the current circumstances due to the COVID-19 pandemic, 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 policies regarding anonymity, voluntary participation and confidentiality of the study (see below, Ethics approval and consent to participate subsection in the Ethics declarations section).

## **Setting**

All interviews were held in neutral and quiet places with a comfortable environment of the participant's choice. No one aside from the participant and interviewer was present at the interviews.

As phenomenological researchers, we aimed to remain neutral (normal, unreflective and effortless) on issues that were discussed with the participants. Therefore, the interviewer had explored beforehand her

own perspective and was emotionally prepared in order to be able to control her possible influence on the interview.

The interviewer placed great weight on establishing beforehand a rapport between herself and the informants. During the interviews the interviewer did her utmost to not speak too much and allow enough time for the informants.

## **Description of the sample**

The participants included in the study (N = 15) were nursing practitioners who met the aforementioned inclusion criteria and were working in the capital region of Attica. All but one of the participants had great professional experience as nursing practitioners. The participants represented a wide range of great previous work experience in nursing. Most participants were women of varying ages with only 2 out of a total of 15 participants being men. As to their educational background, all the participants had graduated from higher education nursing schools. Nine out of the 15 participants in this study possessed a master's degree. The years of previous work experience ranged from 17 to 30 years, with only 2 participants having 2 and 14 years of previous work experience, respectively. The mean (SD) previous work experience of 14 participants was 23.5 (SD = 5) years, with only one participant having 2 years of previous work experience. All participants were working in tertiary referral hospitals. Most participants (N = 13) resided and were working in the capital region of Attica (Athens and suburbs). Fifteen participants were working in Attica. Two participants were working in Thessaloniki (the Greece's second city) and in (the university hospital of) Alexandroupolis, respectively. The participant characteristics are presented in Table 1.

Table 1  
Participant characteristics

Participant	Work experience	Gender
P1	19	Female
P2	23	Female
P3	22	Female
P4	30	Female
P5	26	Female
P6	26	Female
P7	27	Female
P8	28	Male
P9	28	Female
P10	21	Female
P11	17	Female
P12	19	Female
P13	14	Female
P14	30	Male
P15	2	Female

## Data collection

Thirteen interviews were conducted in person (face-to-face) in line with the governmental COVID-19 safety guidelines. Two interviews were conducted via video calling. As a first step, two pilot interviews were conducted. Each interview was conducted by two researchers with great experience in interviewing (AT and PV). Based on the pilot interviews and a review of the relevant literature, the interview guide was developed and pilot tested. Based on the initial results, the interview guide questions were slightly refined to be more understandable. Moreover, we developed a list of questions that the interviewer could optionally ask to gain better insight into participants' experiences.

The interview guide covered a number of topics that aimed to capture a wide range of the participants' lived experiences. These topics were related to a) the situation of dying in isolation itself, b) the factors that can mitigate the problem of dying in isolation, c) the reasons behind restricting interactions between patients and their loved ones, and d) the consequences of providing care for patients who are dying or nearing a lonely death. 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 “During the COVID-19 pandemic, many hospitalized covid patients are dying or nearing a lonely death while suffering agony. Can you please describe in detail what does this situation mean to you?” (*a grand tour question to make the participant comfortable*), “What is it like to be a nursing practitioner caring for a patient who is dying a lonely death or nearing death in isolation?”, “How does caring for a patient who is dying alone or nearing death in isolation affect your professional or private life?” “In your view, what are the reasons behind the strict visiting rules imposed by hospital covid settings, which leave patients isolated”, “In your opinion, under what circumstances should be adopted exceptions (if any) to the general no-visitor rules?”, “How might you facilitate continuing bonds between grieving persons and your patient when the policies do not allow them to visit with their beloved ones before, during or after death?” and “What challenges were faced by you in dealing with patient’s close relatives who were not allowed to get in contact with their dying or critically ill loved ones, or when their loved ones’ unclothed deceased body was delivered to them in plastic unopenable bags?”. Additional questions were asked to elicit more detailed explanations and identify the essential themes of nursing practitioners’ perceptions of the topic of interest.

The interviews were audio-recorded and transcribed verbatim. Field notes were made during and after the interview to record nonverbal cues from participants or procedural aspects of interview process that seemed to be factors to consider when conducting data analysis. The interviews took place between July 2021 and December 2021 and lasted from 28–47 min each (mean 38 min). We discontinued data collection when we believed that further data collection would be unnecessary, namely, the essential (though problematic) methodological element of data saturation was satisfied. Before interview transcripts were formally coded and analyzed they were not sent back to the participants for checking and verifying the accuracy of them. Participants were not asked to check the consistency between their intentions and the results of the researchers. Trustworthiness in terms of credibility was maintained by discussing the content of the study through continuous communications between the researchers and the supervisor (PV).

## **Data analysis**

Thematic content analysis was chosen to analyse the qualitative interview data [17]. We placed considerable emphasis on demonstrating qualitative reliability [18]. All authors independently carefully reviewed and repeatedly read the transcripts to familiarize themselves with the narrative interview data and gain a better understanding and sense of them [17]. The interview data were thematically categorized. To identify quotations related to our research questions PV created the initial codes from the interview data and in the next step he suggested initial overarching themes. Both inductive and deductive coding methods were used. To further secure the analysis, the whole process of coding was aided and organized by using a Computer Assisted Qualitative Data Analysis Software (CAQDAS) (NVIVO, 2015). All researchers constantly compared the data to ensure that the codes were used consistently [19]. Initial codes were classified into more abstract categories and eventually core-categories using a constant comparative approach. The data analysis helped us to generate a number of themes and sub-themes. In

a next step the transcripts were reread and constantly compared with the list of themes and subthemes to make sure that our themes were representative of the data set. Each researcher engaged with all the other researchers to limit research bias and achieve effective communication and coordination. PV selected and drafted the initial illustrative quotes. All the other authors revised and suggested additional quotes. Reflexive thinking was used throughout the research process to limit unintentional personal bias.

## Results

Ten themes and a number of subthemes have emerged from the data analysis of the participants' narratives. Most findings were recurring. However, our data analysis attempted to shed light on the nuances of the participants' perceptions. Dying in isolation emerged as an extremely inhuman experience that critically ill covid patients and their loved ones had to go through. Burying your loved one unclothed without saying a goodbye emerged as an unprecedented inhuman situation. Patients and family members were reported to have expressed very strong desire to communicate and interact with each other. Five reasons of strict visitation restrictions were identified in this research, related to epidemiology, fear of liability, fear of hindering the performance of nursing duties, fear of visitor collapsing because of wearing the protective clothing, and the fact that protective clothing is intended to be used by healthcare staff only. All participants held that visitations should be allowed on an individual basis, and remote communication technology should be available to any covid patient. It is to be noted that physicians' and nursing practitioners' discretion and goodwill can significantly mitigate the problem of dying alone. This was a most striking finding. Importantly, many participants suggested that in some COVID-19 health care settings visitations were allowed at physicians' *de facto* discretion. These "clandestine" visitations were mentioned as practices that existed in reality, even though they were not officially recognized by the Greek rules. Furthermore, the quality of nursing care shifts towards a broader definition. Nursing practitioners have shown high levels of empathy (towards both patients and their loved ones) and strong willingness to provide holistic (bio-psycho-social) nursing care to their patients. In that regard, they were experiencing very high levels of moral and psychological distress mainly due to secondary posttraumatic stress. Besides, participants reported having feelings of inferiority. It is to be highlighted that some factors related to political neglect were mentioned as major factors that enlarge the problem of dying alone due to COVID-19 in Greece. As such, lack of workforce, further compounded by the fact that many skilled but unvaccinated healthcare providers were put out of the job by law, against a background of overwhelming workload due to increasing influx of covid patients, were mentioned as major factors that make the problem of dying in isolation from COVID-19 in Greece bigger compared to other countries. Finally, and most importantly, shift towards a less patient-centered model of care was emerged from the data analysis.

The findings reinforce the existing literature on many fronts. However, we identified some nuances that are of great importance in planning tailored interventions to mitigate the patients, family or health providers problems related to dying in isolation from COVID-19, and most importantly, hold down the commonly accepted patient-centered model of care. The findings of this study might inform strategies to promote organizational support in order to enhance nursing practitioners' personal resilience and ability

to meet the emotional needs of their covid patients within a stressful environment without experiencing moral distress, psychological distress and compassion fatigue.

More precisely, from the thematic data analysis emerged a number of themes and subthemes presented below.

## **Dying in isolation was an extremely inhuman experience that patients and their loved ones had to go through**

### **The agony of being critically ill with COVID-19**

All participants emphasized that dying or nearing death in isolation due to the particular conditions of the COVID-19 pandemic is an unprecedented inhuman, unbearable and devastating experience. It is far from being consistent with what is called "good death". However, they regarded this situation as fully expected under the particular circumstances in which COVID-19 patients are hospitalized. The participant P14 highlighted repeatedly that dying alone, with family members not being allowed to say a goodbye before, during and after death, is an "*extremely undignified situation*". Participants said repeatedly it is "*extremely inhuman*" (i.e. P7) or the "*absolute horror*" (P1, P5). The participant P9 said, "COVID-19 disease is the disease of loneliness...".

The participant P11 declared that nursing practitioners encounter great difficulty (due to psychological distress) in taking care of covid patients who are dying in isolation. The following quotation from her interview is indicative of the situation:

*It was the hardest part of caring for patients [with COVID-19] nearing the end of life. Letting a human being die alone, under these conditions...Neither work, nor fatigue, or danger, or anything else is so hard to deal with...*

In a similar vein, the Participant P5 said,

*...[caring for COVID-19 patients dying alone] is the most difficult [painful] part of caring for COVID-19 patients...it is worse than the [COVID-10] disease itself!!....*

Besides, the participant P11 said that dying or nearing death in isolation is a soul-destroying situation and the most difficult part of caring for covid patients.

The following quotations are indicative of what terrible experience does a hospitalized covid patient who is dying or nearing death in isolation go through:

*...it's very soul-destroying for patients... it is like to be going to be executed by a firing squad...*

(Participant P2).

*...they have experienced so much loneliness!... I wonder how they did manage to avoid going crazy...*  
(Participant P14).

*I think you can go crazy there [in a covid ward or ICU] due to loneliness, anxiety and solitary confinement. You literally can lose your mind...* (Participant P3).

Patients were reported as experiencing psychological distress, which was characterized by strong fear of death and loneliness. Patients who are staying in a COVID-19 ward are in an unknown (P7), and repulsive environment (P1) with monotonous sounds [beeping of monitors] (P1), where patients are constantly looking at the sky. Patients are coping with the terrible feelings of being isolated from others and being totally dependent on others (P7), at the same time. They were having infrequent and short interactions with “space-dressed” health providers in a quasi-depersonalized environment (P9). Besides, they were experiencing intense physical distress at the same time (i.e. feeling of dyspnea).

Participants stressed that every covid patient room should be equipped with TV in order to animate covid patients (P3, P4, P5, P15), given that family members are currently not allowed to rent a TV for their loved ones because of the particular circumstances of the COVID-19 pandemic (P4).

Participants stressed that when they were providing routine nursing care they observed that patients’ eyes offered a most powerful expression of strong fear of death. Two participants (P4, P5) observed that COVID-19 patients’ fear of death was heightened before they were intubated. Participants said that covid patients (P4, P5) and family members (P6) were informed by TV channels that intubation is often a last effort to stave off death and it is most likely to cause death for the patient.

Ultimately, participants’ opinions were divided on the association between patient’s age and fear of death. The greater number of participants were of the opinion that younger patients express greater fear of death. The participants took the view that while younger patients were afraid of leaving many things behind, older patients felt that their life cycle was going to be closed (i.e. P3, P6, P11). Many participants said that there was no association between patient age and fear of death (P2, P7, P8, P12, P13, P14), with some participants considering that older patients were expressing greater fear of death than younger patients who “*feel invincible*” (i.e. P5, P9).

### **Covid patients’ and family’s strong desire to see each other and get together**

This was a main and recurring theme that emerged the data analysis. The participant P14 described in a representative manner this desire. The following long quotation is indicative of the situation and deserves to be mentioned:

*[The patients] were feeling helpless, so lonely and anxious... There were patients struggling to get up from the unit bed in order to jump through the hospital window and meet their loved ones. Outside [the covid ward], a patient’s son was crying his heart out, and said, “I’m losing my mother.” He was begging us to see her, just to tell her a two-word phrase never said before: “I love you”. The mother was pleading with us but*

*we had to say no... That's how we did end up here... Outside [the covid ward], souls were torn to pieces... however, inside, we could keep performing our duties.*

### Patients' desire

All participants said that critically ill covid patients had a great need for seeing their loved ones in person. The following quotation is representative to illustrate this point:

*The [covid] patients' desire to talk to a loved one was so strong that...what can I say? ...they have experienced so much loneliness!... I wonder how they did manage to avoid going crazy... (Participant P14).*

Participants said that immediately after extubation patients felt the strong urge to see and interact with their loved ones (P7). It was mentioned that a message from their loved ones was enough to make patients open their eyes and have bright eyes (P3).

Importantly, one participant (P13) emphasized that the need for in-person interaction between COVID-19 patients and family members is generally strongest in Greece due to the fact that there are still very strong family bonds in the Greek society.

Finally, and most importantly, the participant P5 highlighted a lack of peoples' trust in their loved ones' health care providers in Greece. This makes the family members' desire to be near their hospitalized loved ones much stronger. The participant put it best in saying,

*In Greece we are used to want our relatives in the hospital... it is not ordinary in our culture to handover our patient to physicians and nurses... they do not trust us as we do not trust them...*

### Relatives' and friends' desire

This recurring finding emerged from participants' narratives. The patient's relatives were reported to experience strong negative emotions and especially to be distressed by the lack of contact and interaction with their loved ones. The following quotation describes terrible and unhuman scenes and is representative to illustrate this point:

*[... The relatives were experiencing it] ... as condemnation. They were mourning before death. They were feeling helpless. They were irritated...it is reasonable. To feel despair because you could not see a loved one and say a final goodbye. Patients leave alone. Patients spend their final moments alone, without their loved ones, with their children being a few meters away from the hospital. Indeed, condemnation! This will haunt them [the relatives] forever... (Participant P14).*

In a similar vein, the following quote is indicative of the situation and deserves to be mentioned. The participant P7 described a terrible and unhuman scene. She said,

*[A patient's daughter said,] I plead with you...I want to go in [the patient room] to see my mother, I want to say her goodbye...and she was crying...crying... she said, "I will do a covid test", "I will get dressed up in the protective suit"... "I beg you to let me see her"... "only to see her" ...and then...when the patient died, she went crazy and he was absolutely right.*

Furthermore, the participants P4 and P8 said,

*The relatives want to see their loved ones, even from a distance, at least for a little bit of time...*

The relatives preferred to stay near their loved ones' patient rooms even though they knew that they had no chance of entering the patient rooms. Some of them were experiencing "silent pain" (P1). It depends on their character, they were shown to be understanding (P1):

*We also told them, it makes no sense staying here, physicians will inform you at some point, It would be better for you to go home and get some rest. However, they were in denial of reality...they were staying over here and this ... did not make any sense because they would never enter [patient rooms]...*

(Participant P7).

*Some relatives were begging to get into...however... but when they realized that they did not have a chance to enter, regardless of how much they had begged, then, they were simply experiencing their distress in silence... but... do you know how much powerful scream is that silence? These looks are unforgettable... (Participant P14).*

Guilt sensitivity seemed to cause patients' family members and friends to be vigilant and sensitive to ways in which inactions could potentially cause patients to feel abandoned. The following quotation is representative to illustrate this point.

*The relatives were crying and telling us that they could not provide much needed support and aid to their loved ones... They were asking us to do our utmost, to be substituting for them while they could not enter in patient rooms..... and we did as much as we could. we tried to be substituting for the [relatives]. They were asking us if they might do something to help their loved ones, even by bringing small things for them such as baby wipes... They were asking us to convey their regards and a message to their loved ones ... by saying that they [patients] are not abandoned... at any rate, the fact that they could not offer any help might make them feel guilty for the rest of their lives ... (Participant P4).*

Moreover, the strong religious sentiments of the Greek population might increase family members' risk of suffering negative emotions caused by the fact that their dying loved ones were barred from receiving communion because of being in isolation:

*In the past [before COVID-19] relatives often said, "we do not mind if he does not understand, we would like the priest to put at least one drop of Holly Communion in patient's mouth...it doesn't matter if he is intubated... (Participant P2).*

## **Burying your loved one unclothed without saying a goodbye is an unprecedented inhuman situation**

This recurring finding emerged from participants' narratives. The following long quotation describes heartbreaking situations and is representative to illustrate this point:

*Naked bodies, in a tragic condition, in big war bags. That was all it was? Is that the last salutation? Is there a right to have their dignity respected? Do we have some respect for the dead? This was all it was? This is leaving this world behind in a decent way...? Leaving behind a world in which he [the deceased] has been living and offering. The last greeting should be allowed to relieve the person who is left behind from dealing with psychological distress and suffering forever. We could dress them [the deceased bodies] up, cleanse them, groom their head, so as to leave with dignity. Yes, I know it. There is no time... but we have always had, and we should always have time for a deceased human body... what can I say... we need additional staff members so as to have enough time to provide holistic care to these [critically ill] patients I have been trying to protest about it [these circumstances] ... No answer! The only thing I hear all the time is "the virus is spreading fastest" ... (Participant P14).*

Proper and dignified management of the deceased body was reported as an effective facilitator of a humanitarian response to the death of a covid patient within the difficult COVID-19 pandemic circumstances.

*...we said, a human being is leaving. We were making the sign of Cross, we were putting clean sheets on him and then we were putting him in the bag...(Participant P7).*

*every human is unique, he has traced a path on the earth and the moment he leaves deserves dignity and respect (Participant P12)*

Participants said that not being allowed to say a goodbye after death is *extremely "cold"* (P3, P10), given that *"every single individual was a unique existence of this world in their earthly life that leaves behind..."* (P3).

Importantly, the participant P5 put it best in saying,

*"...burying the unclothed deceased body of our loved ones is not consistent with our culture".*

## **Reasons behind strict visitation restrictions**

Some significant reasons of prohibiting covid patient room visitations or family members from saying a goodbye to their loved ones' deceased bodies have emerged from participants' narratives. Among these reasons were included those related to: a) epidemiology (precautions to prevent spread of COVID-19) (P15), and b) liability fears (i.e. P2, P4):

*Some people were telling us "I've been sick with covid! ... Let me in". "But if your mother was the patient, then, what would you do?" ... However, if you come in and get infected you will demand accountability of me... (Participant P4).*

*A family member says you, "I would like to be sure that inside the plastic bag is my mother" ... however...if you have contracted covid, who will protect me from being accused of having harmed you? (Participant P2).*

In addition, a third reason emerged from our data analysis was c) preventing hindering the performance of nursing duties. Two participants argued that the presence of family members in patient rooms and wards might hinder the daily performance of their nursing duties. (P13, P15). Note, however, that at the same time the participants P13 and P15 underscored the positive consequences of family presence at the bedside. The participant P13 said that family members near the patient's bed can lighten the nursing practitioners' workload and prevent them from bearing in their mind tragic images related to "*inhuman*" scenes with relatives grieving and begging for a brief hospital visit. In a similar vein, the participant P15 said that family members near the patient's bed could relieve nursing practitioners of their duties to provide holistic care for their critically ill covid patients.

Furthermore, the following emerged as one more reason of preventing patients' relatives from visiting their loved ones. d) The participant P2 expressed concerns as to whether some visitors should be allowed to enter the patient rooms for fear of fainting because of wearing the protective clothing. Moreover, the following has emerged as one more reason of prohibiting visitations: e) Participants argued that allowing one family member to enter the patient room would press healthcare providers to give more family members the permission to visit their hospitalized loved one (P2, P4, P5, P6). Importantly, this reason of strict visitation restrictions has been highlighted by a number of nursing practitioners who know well the context of practicing nursing in Greece. Moreover, e) one participant (P4) said that the protective equipment such as protective clothing is intended to be used by healthcare staff only. This was regarded as one more reason behind enforcing strict no-visitor rules.

The background of overwhelming workload due to increasing influx of covid patients and lack of workforce, further compounded by the fact that many skilled but unvaccinated healthcare providers were put out of the job by law, made the aforementioned reasons more significant. This finding has emerged from our qualitative data analysis. Many participants were of the opinion that better organizational strategies should be developed to address the aforementioned reasons even in light of the current circumstances due to the COVID-19 pandemic.

### **Visitations should be allowed on an individual basis**

Many participants expressed the opinion that hospitals should have the discretion to allow visitations on an individual basis. This came up as a recurring finding. Most participants clearly asserted that enforcing strict and unexceptional visitation restrictions is the cause of inhuman conditions and is completely unacceptable. Dying alone without saying goodbye (before, during and after death) was referred to as unprecedented inhuman situation for both patients and family. Participants emphasized that dying with someone present would be consistent with the principles of "*patient-centered care*".

Most participants wondered why in extreme and existential situations family members could not enter patient rooms under the necessary protective measures just like the hospital staff does. The following quotations are representative to illustrate this point:

*In the beginning I was so angry... I was stressed out! I was trying to understand why this was happening...I was trying to change it...The intensive care unit is a place where you can easily exercise surveillance... we [healthcare providers] do not live in isolation...however, we enter patient rooms ...We take precautions when we enter... Maybe it will be the same case with visitors...After all .... Depression! ... I relinquished trying...because feelings are lacking...goodwill and benevolence are lacking.... (Participant P14).*

*Why do we can get dressed up and enter? Do we live in isolation?... [Relatives] could dressed up and enter in... but with proper guidance on how to get dressed up and how to get undressed... (Participant P1).*

*I find it totally unacceptable that we do not allow close relatives in for two minutes, at least when the patient is intubated; most of them end up dying (Participant P12).*

*...it is distressing and sorrowful the fact that family members cannot say a goodbye before the patient get intubated (Participant P9).*

Notwithstanding, participants (P4, P6, P12) stressed that in some cases the encounter can be extremely harmful to a critically ill patient with low oxygen saturation, because of the strong emotional reaction that can it cause to the patient.

The following quotation is indicative of the situation for particular patient groups.

*One patient, after a loved one has had visited him, was crying a lot... all night (Participant P4).*

Moreover, it is to be highlighted that getting dressed in protective clothing upon entry covid patient rooms is a difficult skill for family members to learn and requires the assistance of specially trained nursing staff. Such a staffing shortage means visitors cannot be allowed entry. This was mentioned in the interviews as a reason why family members cannot be allowed in covid patient rooms, in addition to the previously mentioned reasons (P4).

Ultimately, it is noteworthy that all participants agreed on the urgent need for additional staff and improved organization to facilitate the in-person encounters or remote interactions between covid patients and relatives.

### **Remote communication technology should be available to any covid patient**

All participants underscored the value of effective patient-family remote communication. They said loudly and clearly that the health care system should guarantee that the patient will have an opportunity to effectively communicate with their loved ones at least right before the patient is intubated (P12). The following quotation is representative to illustrate this point:

*Technology is very important for achieving effective remote communication... it s a consolation for the relatives to see their loved ones opening and closing their eyes, to show signs of being alive... (Participant P2).*

The quotation “*The relatives want to see their loved ones, even from a distance, at least for a little bit of time...*” (Participant P4 in line with the Participant P8) highlights the importance of the use of effective remote communication technology.

Ideal remote communication between patients and their loved ones requires both technical equipment and available trained personnel. For instance, hospitals should have enough tablets and/or iPads to go around. Or at least a landline fix or wireless telephone should be accessible to all patients hospitalized in a shared room. However, participants appeared to realize that it is true that it is not easy to find a sponsor for adequate remote communication equipment in the hospitals throughout the country. Given that the number of hospital beds in the covid patient rooms has been increased and the covid patients suffer from severe disability and muscle weakness, the number of the already existing fixed telephones in the hospital rooms cannot address the remote communication needs of covid patients (P12, P15). Moreover, they emphasized the need for healthcare settings to be adequately staffed by frontline nursing practitioners to secure ideal remote communication between patients and family (P10). Nevertheless, it is necessary to be highlighted that almost all participants placed much greater emphasis on the need for in-person contact between patients and family before death (at least right before the patient is intubated), during the dying process and after death.

### **Physicians’ and nursing practitioners’ discretion and benevolent goodwill can mitigate the problem of dying alone**

#### **“Clandestine” visitations were allowed at physicians’ discretion**

Participants mentioned that in some COVID-19 wards physicians had a definitive *underhand* say on permitting or prohibiting visitations. Physicians’ *de facto* discretion to allow visitations on an individual basis was a recurring finding that emerged from participants’ narratives. These visitations were mentioned as practices that existed in reality, even though they were not officially recognized by the Greek rules. Importantly, the participant P14 said that higher-social-status individuals or individuals being in relationships with people who occupy high places and status in society were often given a clear opportunity to pay a casual visit to their loved ones. In the same vein, the participant P13 suggested that patients might be frequently visited by their loved ones at the physician’s discretion. Family members could drop by their hospitalized loved ones at physicians’ discretion. At the same time, participants were obliged (with a broken heart) to prohibit “*children of a lesser God*” (P14) from entering the patient rooms for a few minutes despite the fact that their loved ones were dying! Nevertheless, physicians that permit relatives to pay casual visits to their loved ones might be motivated by compassion and goodwill (benevolent interest).

The following quotations are representative to illustrate this point:

*Ok...in special cases, relatives might have been given special permission to visit their critically ill loved one (Participant P1).*

In a similar vein, the Participant P13 implied that family members were allowed to drop by their hospitalized loved ones. The participant repeatedly said that physicians were managing to fix the problem and highlighted that in her workplace the patients' relatives were gentle, tolerant and condescending.

*If someone was in great need [to see the hospitalized loved one], the issue was handled by physicians... such events were occurring frequently... relatives were allowed to drop by their critically ill loved ones (Participant P13),*

Other participants said,

*I think that sometimes physicians (who were the deciders on such issues) are more tolerant of letting someone [see their loved one who is hospitalized] if he or she was constantly and intensely begging for visiting the patient (Participant P4).*

*Σε κάποιες τραγικές περιπτώσεις όπου είναι για να φύγει ο ασθενής, αφήνουν να τον δει [ο πολύ στενός συγγενής] και να τον αποχαιρετίσει (Participant P15).*

*Some doctors allowed relatives enter covid patient rooms in secret; this is forbidden... and if something went wrong while or due to the particular visit physicians might be in trouble. Nevertheless, some physicians allow patients' close relatives to enter in our covid ward (Participant P12).*

*In some tragic cases where the patient was about to die, they [the physicians] were allowing very close relatives to see the patient and say a final goodbye (Participant P15).*

### **Mitigating the problem of dying in isolation was at physicians' discretion**

Physicians' discretion and benevolent goodwill emerged as factors playing a pivotal role in mitigating some of the effects of strict visitation restriction. It was emerged from our data analysis that in addition to the physicians' *de facto* discretion to allow family members to enter covid patient hospital rooms (on an individual basis), it was up to their discretion as an act of benevolent goodwill a) to offer more or less support to those covid patients who are unable to make the best use of remote communication technology, and b) to spend more or less time with their patients (in the patient rooms) or spend more or less time on informing family members of their loved one's condition, thereby contributing to lessen the negative effects of strict no-visitor rules on both patients and family members. The effective use of remote communication technology was at the discretion of the health care settings (P4), nursing practitioners (P9, P13, P14) and physicians (P1, P7). The following quotations are representative of the aforementioned findings:

*It was up to physicians' discretion and generosity... (Participant P4).*

*Each hospital had its own guidelines. I told you what we were doing with tablets but in other hospitals this was not happening... [in our ward] the physicians were entering in [in the patients' wards] frequently, they transferred information from relatives to patients.... [And] they were helping them [the patients] to make use of remote communication technology... (Participant P2)*

*The physicians were constantly dressed up, 24 hours a day... (Participant P11).*

*We were fighting in there - and you know, the respiratory patients are difficult – alone, without any physician in patient rooms.... They were staying in [patient rooms] no more than an hour a day... (Participant P7).*

As mentioned below, a fear of being contaminated or contracting COVID-19, or even of transmission of the disease to the family members or colleagues was deeply embedded in some participants (P4,P5,P7). Given the truth of the assumption that the same holds true for physicians, this fear might cause them to be unwilling to spend a lot of time in the covid patient rooms.

Providing adequate information to patient's relatives can serve as a distress relief and put them at ease (P4, P9). However, participants said that providing information was far from being an easy task in light of the current circumstances due to the COVID-19 pandemic. Physicians may have no time to inform relatives because of overwhelming workload. Besides, physicians may be reluctant to provide adequate information about patient's condition because of the fact that a covid patient may get worse very quickly in an unforeseen way:

*Ο γιατρός καιγόταν δεν μπορούσε να τους ενημερώσει και θα τους ενημέρωνε τηλεφωνικά κάποια στιγμή της μέρα. (Participant P7).*

*The physicians were so busy that they could not inform them [the relatives]... they could do it via phone, at a particular time of a day. (Participant P7).*

*When physicians are on shift work and has to deal with a lot of people, they are dressed up, they cannot provide information to relatives ... besides, physicians are reluctant to provide adequate information because of the fact that the patient's condition can change quickly [for the worse] and the relatives [who do not see their loved one] cannot understand it... (Participant P10).*

Other participants said that relatives might be given information about their loved one's current health status at physicians' discretion as an act of benevolent goodwill:

*This [providing information] is at the discretion of each physician and in his sensitivity, and the time he wants to spend on this piece. (Participant P1).*

*... [In our department] the physicians were providing full information [to relatives] (Participant P2).*

*...we were providing information [to relatives] 24 hours a day (Participant P13).*

## Mitigating the problem of dying alone is at nursing practitioners' discretion

Nursing practitioners' discretion and benevolent goodwill emerged as factors playing a pivotal role in mitigating some of the effects of strict visitation restriction. In this perspective, nursing practitioners could facilitate the use of remote communication technology. All participants highlighted the role of remote communication technology in reducing loneliness in hospitalized covid patients and psychological distress in family members. Participants said that they were facilitating the use of remote communication technology at their discretion (voluntarily, as a gesture of goodwill), especially for the sake of patients who are unable to make use of it, to mitigate the negative consequences of the strict no-visit rules. The effective use of remote communication technology was at the discretion of the health care settings (P4), nursing practitioners (P9, P13.P14) and physicians (P1, P7).

At any rate, while all participants were willing to help patients use remote communication technology, nursing practitioners' discretion and benevolent goodwill was of key importance for providing more or less substantial support. For instance, while the participant P11 said she often put a phone to the patient's ear, she never brought her own phone into a covid patient room. In contrary, the participant P12 said she brought her own phone in a patient room, enveloped with celluloid. The following comments indicated that the use of remote communication technology could be carried out at nursing practitioners' discretion as an act of benevolent goodwill.

*We were entering patient room for the sole purpose of helping them [patients] to make use of their mobile phones...perhaps smartphones... in order to communicate with their relatives...sometimes it was necessary to call from our own mobile phone... (Participant P13).*

*... there was so great need [for patients] to talk to their loved ones... so great ... What more can I say? ...They had experienced high levels of psychological distress due to loneliness ... I do not know... I do not know how they managed to deal with loneliness...how they managed to not go crazy...Yes, of course, it [providing assistance and support to patients make use of remote communication technology] should always happen... however, whether it happens or not is at our [health professionals'] discretion and benevolent willingness ... I hope you do understand... (Participant P14).*

Note, however, that the participant P10 mentioned that a nursing practitioner in her workplace had been said,

*... I'm dressed up [in the special protective suit] for a long time [and that makes me feel uncomfortable], I'm sweating...[so]...I have no time to open the camera*

Furthermore, the following quotation of the participant P13 was representative to indicate that nursing practitioners were making every effort to find alternative options to help patients and relatives. The participant said,

*We are trying different things to alleviate their pain [relatives' and patients' due to the ban on family visits to covid patients]...*

Participants said that in addition to using remote communication tools they were trying (at their discretion) various strategies to mitigate the negative consequences of the strict no-visit rules, such as a) hospitalizing more patients (especially patient that are relatives or around the same age) in shared hospital rooms to enjoy the company and mitigate the isolation (P9, P13), taking measures to protect their privacy and dignity, b) being more hours near the patients, c) serving as mediators between patients and their family members, or even d) letting family members off the hook when they take a sneak peek at their hospitalized loved ones, especially when the hospital's spatial setup makes it easy.

Patients were in great need for successful human interaction with health providers. Most participants were willing (as a gesture of benevolent goodwill) to offer holistic support to critically ill COVID-19 patients (as presented below). Note, however, that they had every right to say that they felt constrained in spending time to provide holistic care, mainly because of overwhelming workload and staff shortages. At any rate, it should be kept in mind that a fear of being contaminated or contracting COVID-19 as well as a fear of transmission of the disease to the family members or colleagues was deeply embedded in some participants, a fear that was also expressed explicitly (Participants P1, P4, P5 and P7). This fear might cause nursing practitioners to be unwilling to spend a lot of time in the covid patient rooms.

Moreover, some nursing practitioners confessed that they made use of their *de facto* discretionary power to perform a proper and dignified management of the deceased body. The participant P10 admitted that she acted in more respectful for the deceased body way.

*I decided to dress them up... for that purpose, I was asking for an orderly's help... I did not want them to go naked in a bag... I didn't want...*

In a similar vein, the participant P11 admitted,

*It has happened to delay the process of deceased body management up to have the covid test results [namely, to be tested negative for covid], so that the funeral can take place without special prohibitions.*

These practices were mentioned as practices that existed in reality, even though they were not officially recognized by the Greek rules.

### **The quality of nursing care shifts towards a broader definition**

During the COVID-19 pandemic there has been a shift towards a broader definition of hospital nursing care (i.e. P4). This emerged from our data analysis. Many participants highlighted the importance of involving themselves in providing holistic (multidimensional / bio-psycho-social) nursing care, aiming to address the needs of dying patients and families for psychological and spiritual support. They were willing to spend as much time as possible with patients. They intended to hold patient's hand, have a proper verbal and nonverbal communication with them, provide psychological support and play the role of the relative or even the confessor.

Many participants said that empathy-driven provision of holistic nursing care might negatively affect their routine work (basic nursing) because of spending time on a time-consuming task, which however they could not afford to do, given the shortage of nursing personnel. The participant P12 complained that she had no time to cleanse the patient's body. The participants P7 and P9 said that they tried many times to spend time in the patient room holding the patients' hands. As a consequence, however, the other patients were left without being provided with timely and proper nursing care. Note, however, that the participant P2 said,

*I want to provide psychological support... but I cannot...I'm forced to set priorities...I do my best so that the patient can survive, as well as the patient next to him ...once he gets out of the hospital alive, after discharge from the hospital he can undergo psychotherapy...*

More particularly, many participants made great (empathy-driven) efforts, on a basis of benevolent goodwill, to stay more time near the patients in order to make the use of remote communication technology easier for them (sometimes using their own iPads) or provide to covid patients holistic (bio-psych-social) support. Furthermore, many participants said that they were playing the role of a psychologist (P5, P6, P9, P10, P11, P15) or the role of a confessor who provides spiritual support (P5). They felt obliged to facilitate conversations about patients' needs and wishes. At any rate, they attempted to play the role of family members (P5, P7, P15). Note, however, that nursing practitioners can feel the patient, but not to the extent of feeling like a family member (P8, P15).

The following are typical comments that reflect recurring findings indicative of participants' strong desire to provide holistic and personalized care for critically ill covid patients.

*Nursing responsibilities include, but are not limited to, performing basic nursing care... and then go home... this would be inhuman... you [a nursing practitioner] have to go deeper into patient's inner world to meet his needs as much as you can... Humans are not only body, but they are also soul and mind... You have to play the role of a relative or a confessor...at the same time you want to take off the protective suit that makes you feel uncomfortable, and get out of the patient room because you are afraid of the virus .. However, you stay there because your services are so humanitarian...At any rate, however, it is so difficult that you are gradually building up a warm relationship with your patient! ... " (Participant P5).*

*It is not enough to say two words...you must do psychological support, but there is no time (Participant P15).*

*Nursing practitioners want to help, to give consolation, but the time is too short... the workload is overwhelming...the length of stay in hospital has been considerably increased...besides, there is a striking lack of healthcare workforce...(Participant P2).*

*Even in case of emergency, we cannot get into the patient's ward quickly, we must get dressed up following a strict dress procedure... besides, we cannot stay long inside [the ward]... we need staff... (Participant P4).*

*Now[under pandemic circumstances] you [a nursing practitioner] can only do the things necessary to provide basic nursing care, nothing else. This is due to the lack of staff, not the psychological state* (Participant P12).

*You [a nursing practitioner] cannot provide holistic care... cannot spend more time speaking with a patient ... there is no time... importantly, there is no staff! ... I do not know if anyone cares about this ...* (Participant P14).

The participant P6 highlighted the value of achieving effective nonverbal communication in providing holistic and personalized care and said,

*...While performing routine nursing care, body language plays a crucial role in the interaction between patient and nursing practitioner. The way you [a nursing practitioner] enters a patient room...talk to the patient...look at him...touch him... Everything has a role to play [in providing holistic nursing care] ...*

Many participants insisted loudly and clearly that a psychologist should regularly visit and provide support to COVID-19 patients (P5, P9, P11).

### **Nursing practitioners experience very high levels of moral and psychological distress**

This was a recurring theme that emerged from participants' narratives. It is noteworthy that most participants felt that their empathy-driven psychological distress did not affect their routine work because of resilience and coping mechanisms they have had developed many months after the COVID-19 pandemic began. However, participants said that these mechanisms could not protect themselves from developing empathy-driven psychological distress. Their traumatic lived experiences at workplace negatively affected their psycho-physical state and familial life rather than their work performance.

#### Secondary posttraumatic stress

Providing nursing care for critically ill COVID-19 patients was reported as a traumatic experience which caused nursing practitioners to feel high levels of psychological distress. The following quotation is representative to illustrate this recurring theme that emerged from participants' narratives. Witnessing the process of saying goodbye via remote communication technology before the patient get intubated was referred to as a highly stressful event:

*This [saying goodbye via remote communication technology] was the most important thing for patients with infaust prognosis who were in need of being intubated in order to be on a ventilator, they were saying goodbye to their loved ones via a video call...in such situations, we were in patient rooms and have been witnessing that event...these were the most tough and sorrowful situations we had to deal with... Of course, these patients were most likely to not survive...(Participant P9).*

It was reported as a factor profoundly negatively affecting the nursing practitioners' mental state and wellbeing (subjective and relational). As they had heightened levels of empathy (see below), participants

described strong emotional responses to traumatic situations or events they witnessed as workplace due to the inhuman process of dying in isolation. Participants' interviews suggested that work-related traumatic scenes which they had been experienced or witnessed at workplace were internalized. The affective color of these internalized situations was extremely unpleasant and caused them to feel mentally and physically sluggish or unhealthy. They described dramatic symptoms such as insomnia, anxiety, depression, anger and nervousness, negatively affecting their well-being:

*Whatever you want to or not, it [the stressful event] enters your inner world...I was feeling like I'd lost my smile... I was not in the good mood to do anything...I was feeling like I was a "going to work and coming home from work" machine...I had abandoned everything in search of being able to remain strong enough in my job-related activities. What can I say?... I was feeling down, very down...like I was in a constant state of sadness... (Participant P3).*

*...irritability, anger, anxiety, psychological pressure, stress, a lot of stress...(Participant P7).*

Not surprisingly, they could not leave it all behind at the end of their shift. Traumatic events that occurred in workplace had serious implications for nursing practitioners' private life (daily living). They confessed that the trauma stayed with them long after the stressful event:

*I did not make it to not take it [these traumatic experiences] home after my shift was finished (Participant P15).*

Participants' constant exposure to significant levels of traumatic stress made it tougher for them to hold down their regular daily living activities. They could not get rid of thoughts, imaginations, auditory hallucinations and other posttraumatic symptoms, even while they were sleeping:

*I try to leave it all behind... however ..., while I was relaxing...I kept hearing in my dreams beeping of patient monitors and asystole alarm sounds waking me up in the middle of the night..." (Participant P 12).*

*Thought and images were causing me to wake up in the middle of the night...absolute horror...This is such a terrible nightmare...I never felt something so terrible in my entire professional life ... thirty years in the ICUs...but... Who cares for my psyche? (Participant P14).*

The resources of nursing practitioners' psychological distress that emerged from the data analysis can be classified in three categories: a) traumatic experiences due to enforcing strict no-visitor rules, b) lack of time so that nursing practitioners cannot provide adequate holistic care, c) feelings of frustration after exhaustion, c) the fact of dying alone itself, and d) the fact of putting unclothed deceased bodies into military plastic bags, namely, the specific treatment of a deceased body during the coronavirus pandemic. It is to be noted that participants said that inhuman, hard and traumatic situations where grieving patients' relatives were begging for a brief hospital visit were extremely difficult situations to deal with (P4, P14). Furthermore, one participant's comment emphasized the value of being successful after having put a great effort. The comment clearly indicated that nursing practitioners feel frustration when they realize that all their efforts were in vain.

*When your patient dies after having put great effort into providing psychological support, having been staying for many hours in patient room, you wonder what was the meaning of your effort? ... You can't get over it... (Participant P9).*

The participant P9 said that too much self-reflection was needed to maintain her own emotional stability and ability to continue providing high-quality care for covid patients. In a similar vein, the Participant P7 said,

*Look...I was not even in a position to encourage myself...at some point my mind went blank... We have experienced very traumatic events under tragic circumstances...which...will leave an indelible impression in our inner world...*

### Moral distress I

In addition to psychological distress, participants reported going through experiences that demonstrated moral distress (in the strict sense of the term). All participants felt almost prevented from acting on what they considered that might remedy or mitigate the problem of dying alone. In other words, they felt almost prevented from spending time with patients to provide holistic care or facilitate remote communication between patients and family members, or spending time with family members to support them. Besides, they felt prevented from providing care for deceased bodies.

Lack of time and overwhelming workload, further compounded by a lack of workforce (P2,P3,P4,P5,P6,P7,P9,P12,P10,P14,P15), were sapping their energy needed to provide holistic support for their COVID-19 patients who were dying or nearing death alone. Moreover, the following factors are included among the common causes of participants' moral distress: inadequate staffing, inadequate remote communication equipment, challenging hierarchies within interprofessional relationships, and duty conflicting with COVID-19 health and safety protocols. These factors are further mentioned elsewhere in this Results section.

### Feeling of inferiority

Participants reported feeling required by the 'inhuman' health care system to carry out the assigned nursing tasks working like a robot, namely, like a machine-like human.

*...providing care just to provide care, because we had to, just to get it over with it... (Participant P7).*

They reported feeling treated like an inferior part of the patient's care team because of hierarchies within interprofessional relationships. The unprecedented circumstances of nursing during the COVID-19 pandemic makes more striking the power imbalance between physicians and nursing practitioners and call for the upgrade of nursing practitioners' voice as equal members of the therapeutic team. They highlighted the difficulty in shifting the balance of power in favor of the nursing practitioners within a health care system which most clearly shifts the balance of power in favor of the physicians. Note,

however, that these are perceptions that can only be partly attributed to nursing practitioners' inferiority complex. Two objective reasons for these perceptions were emerged from data analysis.

First, physicians mentioned that physicians spend much less time in covid patient rooms.

The participant P7 said,

*The physicians were practicing "telemedicine" from outside the patient rooms ... "telemedicine", you understand? However, we [the nursing practitioners] have been there, in patient rooms, for so many hours a day...the physicians have been in patient rooms for only an hour... however, they wanted everything to be done in just an hour...*

Second, they reported feeling prevented from providing holistic nursing care while at the same time their voice was not heard by physicians or other professionals of higher rank.

Furthermore, the participant P7 complaint that nursing practitioners are not treated as equal members of a hospital care team. The participant said they are seen as the operatives of the care team. She was repeatedly emphasizing that the existing health care system seems to cause nursing practitioners to become drones, task-processing, handling, mechanical, with low motivation levels and a lack of humanity. This affects negatively the healthcare service quality provided to patients, support provided to family members and tribute paid to the deceased body. Nursing practitioners are led to consider only numbers. The participants P5 and P11 complained that healthcare policy makers are making decisions without taking into account nursing professional opinions, despite the fact that that nursing practitioners spend a lot of time near the patient and can better than anyone else to contribute to developing health-promoting spatial planning in new opened COVID-19 healthcare wards on ICUs. The participant P11 complained that those with administrative tasks in the public healthcare sector are only interested in numbers [implying that they are technocrats]. They are not taking account of nursing practitioners' opinions when they are deciding what to do.

The participant P14 said,

*We are...What can I tell you? ... We are nothing to them...Since physicians do not take us into account, could we expect that they [policymakers and regulators] would be more than willing to do so?*

The participant P11 said,

*After all, we [nursing practitioners] are just another number...Quite so, just a number...This is very awful...*

Despite the strict visitation restrictions imposed by the law, participants described physicians acting as a facilitator of in-person contact between patients and family in extremely exceptional cases. However, participants themselves and their colleagues could not do something like that. This made them feel inferior to physicians.

## **Nursing practitioners' high levels of empathy towards patients and family**

All participants said they have had a strong sense of professional responsibility and high levels of empathy towards both covid patients and their loved ones. The circumstances of the COVID-19 pandemic enhanced nursing practitioners' empathy and strengthened their sense of responsibility and duty. All participants admitted (more or less intensely) that they showed humanity to their patients and relatives. The following quotation is representative to illustrate this point:

*OK...we build resilience over time...however, we make every effort to approach our work from a humanitarian standpoint. We do the best, not only for patients, but also for the sake of our soul...of course....* (Participant P1).

Participants showed empathetic attitude and willingness to provide holistic care for critically ill COVID-19 patients (included psychological support) attempting to substitute roles which traditionally were performed by family members in order to address their absence.

As patients' relatives were constantly expressing a strong and heartbreaking desire to see their hospitalized loved ones, many participants (i.e. P1, P4, P7, P12, P15) expressed strong sympathy for what patients' relatives were going through:

*How can [someone, namely, a relative] process such a negative experience?...It may give rise to frustration and leave mental scar...* (Participant P4).

*We often put ourselves in relatives' shoes... therefore, we often justify relatives' behavior. For instance, relatives may get angry because we did not give food to the patient because of overwhelming workload* (Participant P15).

*The relative is right to say I took him to hospital on foot and now I take him back in a plastic bag... [the relative] cannot see the course of the patient's treatment, whose body image can change very quickly as his medical condition worsens...* (Participant P12).

In addition, they showed empathy-based willingness to help patient's loved ones who - according to most participants - had every right to call to obtain up-to-date information about the health status of their loved ones, beg for obtaining whatever contact or communication with their loved ones or even just take a look at them. According to most participants family members had every right to have intense negative emotions and reactions (such as anger, intense anxiety and intense grief) that might cause them to behave in forceful and annoying manner that seems to be extraordinary. Family members' intense psychological distress, nervousness and grief before death (P14) were due to the lack of their adequate communication and in-person contact with their loved ones before, during or after death. Therefore, all participants were of the opinion that family members were most likely to experience severe and prolonged psychological distress with unknown long-term consequences. Importantly, all participants placed great emphasis on the fact that according to protocols the *unclothed* deceased body was put in an hermetically sealed military plastic bag which then was put in an hermetically sealed coffin. This process of putting a deceased body in a plastic bag unclothed was regarded by participants as extremely cruel, inhuman,

undignified and disrespectful for both the grieving family members and the deceased body. A participant confessed she had a conscientious objection and put a dead body in the bag dressed up. Almost all participants said that as COVID-19 patients' symptoms can quickly turn serious whereas family members had no opportunity to follow the course of the disease, their dramatic reactions were completely reasonable. Some participants emphasized their willingness to show respect for a deceased body for reasons of dignity and respect for an individual who came a long way on the earth before dying. Lack of time and workforce were mentioned as the main reasons for being prevented from providing holistic care for the patient before, during and after death, and for family members as well. Participants felt that they and their colleagues were doing the best they could in light of the particular and unprecedented circumstances due to the COVID-19 pandemic.

Participants clearly suggested that the unprecedented current pandemic circumstances caused them to put themselves in patients' shoes. Most participants instantly envisioned themselves and family members in the patient's place:

*We are afraid of a loved one being in the situation and circumstances of the patient...*(Participant P1).

*...we keep imagining our loved ones being in their [patients'] place* (Participant P7).

*We [nursing practitioners] have been sick [with COVID-19], too....we have also been in patient's place, some of our family members have been sick [with COVID-19], we have lost loved ones...I lost my mother...* (Participant P6).

*I am afraid of me being...I am afraid of dying alone...without my loved ones being present with me...* (Participant P4).

### **Political neglect was reported as a major factor that makes the problem of dying in isolation bigger**

Political neglect has been mentioned as an important reason behind the problem of dying in isolation during COVID-19 pandemic in Greece. More specifically, participants repeatedly highlighted the lack of trained healthcare workforce. They said that the pre-existing lack of healthcare workforce due to the recent financial crisis has been enlarged by the fact that many skilled but unvaccinated healthcare providers were put out of the job by law. Participants said that politicians passed the buck for crisis decisions to the unvaccinated citizens and more particularly the unvaccinated healthcare professionals. Furthermore, within our interview data was repeatedly mentioned that the quality of care in the public and more particularly the primary health care sector under increasing influx of covid patients has received less attention in Greece

### **A shift towards a less patient-centered model of care**

Participants were of the opinion that strict and unexceptional visitation restrictions are not in consistency with the *patient-centered and empathetic medicine* which shows respect for humanity and fundamental human rights. Strict and unexceptional no-visitor rules are extremely inhuman. This was a recurring

finding. One participant said that the authorities and other decision-makers adopt a technocratic approach. They make decisions on the basis of “numbers” (namely, numerical data). That is to say they shift the focus away from human values and rights in the medicine.

The participant P7 pointed out that the policy that places considerable emphasis on vaccination campaign rather than strengthening the health care services against the COVID-19 pandemic indicates a shifting away from the patient-centered model of care.

*[...in the public health policy] there has been a recent shift from struggling to provide patient-oriented medicine towards passing the buck for crisis decisions to the unvaccinated citizens and more particularly the unvaccinated healthcare professionals, who have been put out of the job by law despite the (already in effect) lack of workforce in the healthcare sector. The authorities pass their responsibility of supporting the provision of patient-centered medicine onto the unvaccinated citizens... (Participant 7)*

This shift is indicated by most results of this study. That is to say that in light of the difficult circumstances due to the COVID-19 pandemic the health care system does not maintain a commitment to providing patient-centered care to the greatest extent possible throughout the country. Some participants were of the opinion that the Greek public health authorities have not provided adequately support to the public healthcare sector (P7, P15). Many participants highlighted the lack of workforce (P7,P9,P10,P12,P14, P15). Adopting the patient-centered model of care entails facilitating effective in-person (on an individual basis) or at least effective remote communication between COVID-19 patients and families. Furthermore, adopting the patient-centered model of care would promote the provision of effective psychological support to COVID-19 patients.

## Discussion

Dying alone without a last goodbye is very inhuman. It cannot be a “good death”. The testimonies collected in this study confirmed that dying alone is not socially regarded as a “good death”, and that core elements for a “good death” include facilitating patient dying surrounded by and communicating with family members. Scholars argue that there is no agreement in the literature regarding the concept “good death” [20, 21]. It is argued that it is unclear whether “good death” is related to dying alone or accompanied. A crucial point is the difference between the most prominent aspects of the lonely experience of dying, namely, existential loneliness and social (social) loneliness [22]. According to the British Geriatrics Society (Appendix In Ref. 25) among other aspects of a good death are comprised a) access to spiritual and emotional support, b) having “control over who is present and who shares the end”, and c) having time to say goodbye (namely, having the family present) [23]. At any rate, dying without someone present has considerable social and existential consequences for both patients and families [24]. It is noteworthy that a large number of scholars are of the belief that dying accompanied and having time to say goodbye (before, during and after death) is a core element of what constitutes “good death” [20, 24–26]. Dying alone is not justifiable [27]. Death is more than an individual experience. It is a phenomenon that belongs to the community [26]. Although putting covid patients in isolation is a

radical precautionary measure to help prevent the spread of coronavirus (COVID-19) in people, the impact of this measure on the course of the pandemic remains questionable [27]. Dying accompanied by family is said to be beneficial for the critically ill patients, family and health professionals [27]. The inability to say a goodbye cause family and friends to feel complicated grief and express frustration. This may occur when a staff nurse is unavailable to facilitate an effective remote communication between family members and patients who are unable to make use of remote communication tools on their own [1]. Moreover, in-person interaction among patient, family and healthcare professionals is necessary for high-quality death and better bereavement outcomes for relatives. Initiating and holding end-of-life discussions with dying patient's relatives are negatively affected by the COVID-19 pandemic [24]. These discussions along with provision of holistic approach are associated with high quality of death and better bereavement for relatives [6, 28]. Bio-psycho-social support should be provided not only before death but also afterwards to address family member's bereavement and grief [6, 28]. Ongoing and consistent communication between healthcare professionals and family is of paramount importance for providing a patient-family centered care in light of the unprecedented circumstances due to the COVID-19 pandemic [6]. Furthermore, it should be noted that authorities or hospitals should consider to facilitate contact between patient and family members before starting the process of dying. Once the process of dying starts, the contact may be no more meaningful due to the mental status of the patient. The testimonies collected in this study confirmed that dying in isolation with family members being restricted from saying goodbye to their loved ones who are dying of coronavirus, before, during or after death, is too inhuman to continue to be tolerated. It is too painful for both patients and family. Moreover, all participants highlighted that remote communication technology has a crucial role to play in putting family and friends in touch with their hospitalized loved ones. Efforts need to be made to promote the use of remote communication technology in covid patient rooms. While it is argued that meaningful communication can occur through ideal use of remote communication technology [1, 29], the findings of this study give us the opportunity to make the assumption that in the COVID-19 healthcare context remote communication cannot be considered to be equivalent to open communication (in-person contact) in general. The testimonies collected in this study suggested this assumption. Importantly, Selman et al. (2021a) conducted a qualitative content analysis of English-language tweets and found that technology was "often presented as an inadequate substitute" [30].

As it is cruel and inhuman to die a lonely death, which however, has become the "new normal" in the context of COVID-19 pandemic, "administrative decisions regarding visitation policies must be critically examined and evaluated" [2]. Strict visitation policies have been strongly criticized by scholars. It has been argued that "such policies 'prioritize, above all else, containment of the coronavirus', without considering other public goods, such as compassionate, family-centered care, reduction of fear, and improved health outcomes" [2]. Therefore, hospital visitation policies should become more permissive on an individual basis. Relaxation of the general strict no-visitor rules should be decided on a case-by-case basis. In Spain dying alone during the COVID-19 pandemic results from prevention measures imposed by protocols enacted by authorities [26]. Selman et al. (2021a) have conducted a qualitative content analysis of views and experiences of Twitter social media users (exploring English-language tweets) and

found that infection control restrictions vary across regions and institutions [30]. In the US, despite the fact that strict no-visitor rules have been considered “unavoidable reality’, necessary in service of the ‘greater good’” [31, 32], the hospitals and other institutions caring for COVID-19 patients were considered the best decision-makers given that they had the knowledge and expertise to assess the particular situation [2]. Many health care settings enforced and explicitly stated in their policies a *strict* no-visitation rule during the COVID-19 pandemic. They did not permitted visitations to covid patients even during end-of-life circumstances. Nevertheless, there was observed a relaxation of visitation policies. Other health care settings were enforcing *vague* policies by enforcing general no-visitation rule (without clearly stating their guidelines regarding visitation rights of hospitalized COVID-19 patients) included a list of explicit or discretionary exceptions (decided on a case-by-case basis). Furthermore, other health settings were enforcing a *lenient* visitation policy that allowed restricted and monitored visitation to COVID-19 patients [2]. Sudai advocates “for redistributing hospitals’ discretion so that it is shared among additional stakeholders” in the USA [2].

As argued in the literature, in case of a patient dying in isolation, family members’ and friends’ negative emotions may partly due to the fact that they have a “sense of guilt at failing to fill a social or personally desired role” [9]. They are likely to feel a sense of helplessness, frustration and guilt due to the fact that they were not allowed to provide care and support for their loved ones when their loved ones needed them the most [6]. Selman et al. (2021a) have conducted a qualitative content analysis of English-language tweets and found that “Twitter users who posted about a friend or family member dying of COVID-19 without a familiar person present expressed sadness, despair, hopelessness and anger about their experience and loss” [30]. Family members may “reflect genuine concern that the beloved relative or friend may feel terror or fear in dying alone” [9]. Recent British studies underscore the family members’ need of visiting dying patients despite strict no-visitor rules [33, 34, 35]. The findings that emerged from our data analysis reinforce the previous literature. Importantly, the reasons behind strict visitation restrictions in Greece that emerged from the data analysis might be addressed even within the COVID-19 pandemic circumstances. This point emerged from our participants’ narratives. Putting great effort to achieve in-person contact between dying covid patients and family is worth fighting for, for the sake of a fundamental human right: to die a dignified death.

Epidemiology-related factors, liability-related factors and fears of hindering the performance of nursing duties against a background of lacking trained workforce were mentioned as main reasons behind enforcing visitation restrictions. In the existing literature, among the kinds of reasons mentioned in the literature are included epidemiology-related reasons and liability-related reasons, which are facilitated by a cultural background where death in isolation is already a long established normality [2]. As to epidemiology, there is not enough evidence to support the assumption that strict visitation policies prevent the virus transmission inside the hospital walls [2]. Moreover, it is argued that “rigorous infection control measures” can control the risk of virus transmission inside the hospital walls [2]. As to liability, “yet, it is not clear that strict visitation policies do reduce liability exposure” [2]. The gradual medicalization of death and the expulsion of death from the community have produced a new normality

of dying. This reality is a cultural background against which strict visitation restrictions are easily accepted [2].

Participants in this study were of the opinion that *vague* policy should be enforced in Greece by enforcing a general no-visitation rule, which however, allows visitations on an individual basis. However, it should be highlighted that it is not easy to state clear guidelines regarding visitation rights of hospitalized COVID-19 patients. For instance, Selman et al. (2021b) found that “online UK newspapers focused on how COVID-19 disrupted ‘saying goodbye’ (prior to death, at the moment of death and after death) and conflicted with cultural understandings of a ‘good death’ and ‘good grief’, despite efforts undertaken to mitigate the effects of restrictions.” However, “articles focused on what was forbidden rather than permitted and offered little practical guidance for the public” [36]. Furthermore, a key theme that emerged from our data analysis was that physicians’ and nursing practitioners’ discretion and benevolent goodwill played a crucial role in mitigating the problem of dying a lonely death within the COVID-19 pandemic circumstances. In some COVID-19 health care settings, visitations were allowed at physicians’ *de facto* discretion although they were not officially recognized by the Greek rules. Note, however, that such sporadic instances could not completely address the problem. These sporadic instances could give rise to multiple kinds of inequities. But at any rate, we found relaxation of the strict no-visitor rules at physicians’ discretion. As the participants in our study were working in different hospitals (fifteen participants in the capital region of Attica, two participants elsewhere in the country), it is most likely that this was a scenario playing out in many hospitals across the country. It probably means that it is imperative that relaxation of the general and strict no-visitor rules should be enforced.

Compassionate care for dying patients and family includes facilitating high-quality communication between them by allowing visitations on an individual basis to the greatest extent possible and making use of communication technologies for the sake of patients who are disabled due to their medical condition or unable to make use of technology on their own. All participants in our study highlighted the need for making use of remote communication technology as a substitute for in-person contact between patients and family or friends. High-quality communication between end-of-life patients and family is “ethically important” not only to dying patients, but also to family members in the context of the COVID-19 pandemic [4]. Therefore, nursing practitioners’ caring for covid patients dying alone often involves some form of caring for caregivers or family members who are suffering.

Clinicians, nursing practitioners and funeral officiants should try to mitigate the impact of infection control measures, for example, using video-technology to improve connectedness.

Participants in this study reported themselves to be so empathetic towards critically ill covid patients who were dying or nearing a lonely death. While it is not easy for someone to understand the experience of someone else, participants in this study seemed to be able to understand the covid patients’ experiences very well. This emerged from participants’ descriptive interview quotes. Note that stepping in patient’s skin is a heartbreaking stressful habit, which may lead to chronic wearing and compassion fatigue. However, in light of the current circumstances due to the COVID-19 pandemic it matters a lot to patients in

the clinical context. While emotional engagement is essential for showing clinical empathy, emotional labor is vital to perform such a task successfully [37].

Not surprisingly, some participants expressed disappointment when their efforts were not adequately “rewarded” in terms of patient survival. Many participants reported themselves as trying to provide holistic (biopsychosocial) care for dying or nearing death covid patients and substitute their family members to the maximum extent possible. They put great effort into building transparent communication and providing compassionate and bio-psycho-social (and spiritual) care for covid patients who were dying or nearing a lonely death. Indeed, to provide optimum care, a nursing intervention should be based on the holistic personalized model of care. In this regard, it has to be noted that the British Secretary of State for Health and Social Care highlights the need to support greater personalization of end-of-life care and address the dying people’s spiritual needs [38].

Importantly, as argued in the literature, health professionals cannot substitute for the offer of a family member or a beloved one even though the involved health professionals do their utmost to accompany the dying patient and thus dignify the death [26]. The same holds true for participants in our study. Galbadage et al. outlined “an integrative approach to address the unique and holistic needs of critically ill patients dying with COVID-19” [39]. The authors propose a biopsychosocial model for addressing the biopsychosocial and spiritual needs of patients dying with COVID-19. Note, however, that empathetic communication between health professionals and critically ill patients is not easily attainable given that health professionals cannot spend adequate time with the patients mainly due to overwhelming workload, and the fact that they were “spaceship-dressed”, could only speak behind their shields and kept their own social distancing with the patients [27]. Although it is a difficult task, providing compassionate care for dying patients and family is a fundamental human right [40]. In the USA and Europe, a right ‘not to die alone’ has been officially outlined by the Declaration on the Promotion of Patients’ Rights in Europe, (“Patients have the right to humane terminal care and to die in dignity”) [41], the Dying Person’s Bill of Rights (“I have the right to not die alone”) [42], and the British Secretary of State for Health [38]. The book “The rights of the dying patient” written by Agius encompasses many types of rights related to the process of dying. The “Right to support” is included among them. In the Appendix 2 (p.147) it is stated that “Dying should not be an event suffered in isolation...support for the dying patient should come from family members and other people close to the patient” [43]. The state should protect patients’ and family members’ rights in the event that a health care unit does not enforce visitation rules that are overly restricted. The guidelines, whatever they may be, should be adapted to the particular circumstances and applied by health providers as broadly as necessary.

Furthermore, nursing practitioners’ intense responses to difficult situations involving covid patients who are dying alone, emerged from our data analysis as a recurring finding. Given that in light of the coronavirus pandemic such situations were a daily occurrence, nursing professionals’ strong (empathy-based) responses to these situations were a daily occurrence, too. It is true that nursing practitioners have unique experiences of working in a COVID-19 ward and have to overcome extreme, totally new and unpredictable situations which they experience as challenging and uncertain [44]. These experiences

make it more likely nursing practitioners will suffer posttraumatic stress symptoms and have profound negative impact on their psychological health [45]. Besides, most participants in our study felt intensely they must provide care in a way that is contrary to what they believed to be the appropriate care plan. That is to say that they had high levels of moral distress [46]. Given that nursing practitioners' mental wellbeing is critically important when caring for patients affected by COVID-19, organizational strategies should be developed to enhance nursing practitioners' personal resilience and reduce their dysfunctional levels of anxiety related to caring for end-of-life COVID-19 patients [47].

Surprisingly, participants in our study made explicit reference to the shift towards a less patient-oriented model of care. Their high levels of nursing education and their great experience working as nursing practitioners might presumably provide an explanation for these comments. They felt that within the COVID-19 pandemic circumstances the health care system prevented them from providing patient-centered and personalized end-of-life care. While patient-centered clinical bioethics requires that an individual's needs are met, population-based bioethics requires that the needs of a whole population are met [48]. Note, however, that in the current epidemiological context, this is an international phenomenon. Given that providing palliative care in humanitarian crises interacts with factors such as discrimination (i.e. ageism) and power imbalance, decisions and judgements should be made in light of humanitarian ethics, showing a greater and honest respect for it [48]. We resist accepting as morally right the consideration that "we must understand that in our culture of choice, the death we experience is not always the death we would choose" [9].

Drawing on a thematic analysis of the interviews with nursing practitioners, we have drawn conclusions that have implications for Greece and other national contexts. While this study is situated in the Greek healthcare context, the findings of this study may have important implications for other national contexts in which there is a similar shift from the patient-centered care model towards a population-centered care model. The patient-centered care model and to that effect the intended patient-driven healthcare model have gained widespread acceptance and plays a leading role in modern medical ethics. In our opinion, in Greece as well as in many other national contexts the commitment of the healthcare system to the principles of the patient-centered model of medicine was not as strong as we thought over the last decades. It was not strong enough to be self-consistent and context-independent. Internationally, the COVID-19 pandemic did not make medical ethics. The COVID-19 pandemic only revealed medical ethics to scholars and society, and paved the way for the medical ethics of the future. In the new scenario, the major role will be played by the population-oriented healthcare management, which in the current sanitary crisis is carried out on the basis of horizontal rules which apply across all health care settings. Besides, in the new scenario the hierarchy of principles inspiring care provided to hospitalized individual patients has been completely redefined. The humanitarian crisis in the COVID-19 pandemic violates fundamental human rights for the sake of public health and safety.

Ultimately, political neglect (resulting in lack of trained healthcare workforce among other things) was repeatedly mentioned or suggested as a major reason for making the problem of dying alone due to COVID-19 in Greece bigger. Indeed, given that the COVID-19 pandemic was here to stay for a long period

of time and was expected to cast a long shadow into the foreseeable future, organizing training courses dedicated to the management of patients with severe respiratory impairment related to the COVID-19 disease seemed to be absolutely necessary. However, this was not a Greece-specific finding. Selman et al. conducted a qualitative content analysis of English-language tweets and found that “a sense of political neglect or mistreatment was frequently expressed” [30]. Note, however, that Lytras and Tsiodras in their recently published study “anonymized surveillance data were analyzed from all intubated COVID-19 patients in Greece between 1 September 2020 and 6 May 2021”. The authors found that equity and quality of care under increasing influx of covid patients has received less attention in Greece [16]. In-hospital mortality of severely ill COVID-19 patients has been adversely affected by regional disparities [16]. Furthermore, Lytras and Tsiodras noticed that there were patients unable to get an ICU bed who died outside the ICU. The authors found that being intubated outside an ICU was strongly associated with significantly increased mortality. Besides, the authors were of the opinion that “some of them might have been deemed “too ill to benefit” from the ICU” [16]. Given the surge of COVID-19 cases that causes hospitals to be on the verge of collapse in parts of the country, the findings of the aforementioned study might be predisposing factors for low quality of dying, which made the pre-existing problem of dying in isolation bigger.

At any rate, dying in isolation during the COVID-19 pandemic is a humanitarian crisis problem that needs to be addressed immediately. Future efforts to promote a collaborative and inclusive approach to end-of-life care planning may foster a more balanced decision making on allowing more visitations on an individual basis, thus improving patient-centered outcomes. In this perspective, additional staff members are needed urgently. On the account of the patient-centered model of care and the modern (broad, positive-holistic) concept of health, it is fair to say that providing holistic care for covid patients is the essence of our responsibility for justice in medicine in the current epidemiological context. It is an institutional duty on the part of the government and a moral obligation on the part of health care workers.

### **Implications for practice and policy**

As mentioned above, drawing on a thematic analysis of the interviews with nursing practitioners we have drawn conclusions that have implications for Greece and other national contexts in which there is a similar shift from the patient-centered care model towards a population-centered care model. As emerged from data analysis *vague* policy should be enforced in Greece by entering into force a general no-visit rule, which however allows visitations on an individual basis. We advocate for the transfer of discretionary power from the State to hospitals. Policymakers should respond to the phenomenon of dying alone in light of the covid humanitarian crisis and allow hospitals the greatest degree of discretion on how to allow family visits to dying covid patients. Moreover, broader use of remote communication technology should be offered to promote effective communication between dying patients and family members. In an ideal solution, technology might be connected to a camera installed inside each patient room so that patients in the ICU don't need to touch any screen or keyboard. Since COVID-19 precautions (to protect patients and hospital staff, and prevent the spread of the virus) may need to remain in place for the unforeseeable future, hospitals should have the authority to consider how best to balance safety

precautions with maintaining in-person contact between critically ill covid patients and family, as well as how best to facilitate ongoing and constant communication between healthcare providers and patient's family. We wish that the hospitals' discretion would be "shared among additional stakeholders" and especially healthcare workers. Evidence based guidelines on not allowing covid patients to die a lonely death should be available to enable a "good death" for patients and families.

Schloesser et al. put it best in saying "Staying connected with seriously ill and dying patients must be facilitated, allowing face-to-face, (shared) contact whenever possible, and allowing decisions to be made on an individual basis. It should always be possible to visit dying persons" [40]. The same holds true for Greece in the current epidemiological context. The findings of this study can inform tailored interventions under pandemic conditions that facilitate in-person (on an individual basis) or at least remote interaction among patients, family and healthcare professionals, and enhance resilience and mitigate vulnerability of healthcare workers.

## **Limitations**

First, our sample size was not too large. However, we used randomization to avoid selection bias. Second, as this study involved mostly nursing practitioners working in Athens, results can readily be generalized to all the health care settings throughout the country. Indeed, given the truth of the results of the recent study conducted by Lytras and Tsiodras in Greece, dying alone while being hospitalized in regions of Greece away from the capital region of Attica can make things much worse [16]. However, the results are suggested to be applicable to larger number of nursing practitioners in many other health care settings in the country. Third, the participants were not asked to check the consistency between their intentions and the results of the researchers. This limits the trustworthiness of the study in terms of confirmability.

## **Conclusions**

Dying in isolation without saying a goodbye before, during or after death emerged as an extremely inhuman experience that critically ill covid patients and their loved ones had to go through. Fear of spreading COVID-19 infection, fear of liability, and fear of hindering the performance of nursing duties were emerged as main reasons behind strict visitation restrictions. Patients and family members were reported to have expressed very strong desire to communicate and interact with each other. Most participants were shown to be with high levels of empathy, willingness to provide holistic care. Furthermore, most participants were shown to be with high levels of psychological and moral distress. All participants held that visitations should be allowed on an individual basis, and remote communication technology should be available to any covid patient. Importantly, it was identified in this study that physicians' and nursing practitioners' discretion and goodwill can significantly mitigate the problem of dying alone. In some COVID-19 health care settings visitations were allowed at physicians' discretion. These "clandestine" visitations were mentioned as practices that existed in reality, even though they were not officially recognized by the Greek rules. Furthermore, the quality of nursing care appeared to have shifted towards a broader definition. Political neglect was a factor that emerged as a major factor that

enlarges the problem of dying alone due to COVID-19 in Greece. As main factors related to political neglect was mentioned the lack of workforce, further compounded by the fact that many skilled but unvaccinated healthcare providers were put out of the job by law, against a background of overwhelming workload due to increasing influx of covid patients. Finally, and most importantly, a shift towards a less patient-centered model of care was emerged from the data analysis. Our findings reinforce the existing literature on many fronts. However, we identified some nuances that are of great importance in planning tailored interventions to mitigate the patients, family or health providers problems related to dying in isolation from COVID-19, and most importantly, hold down the commonly accepted patient-centered model of care. Developing strategies and taking actions in the face of the COVID-19 pandemic should be guided by an ethical model based on the patient-centered model of care.

## **Abbreviations**

ICU = Intensive Care Unit

## **Declarations**

### **Availability of data and materials**

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

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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. MD and AKT assisted in the data analysis and revisions of the paper. All authors have read and approved the final manuscript.

### **Authors' information**

Polychronis Voultsos is an Associate Professor of Medical Ethics. Anna Tsompanian is a lawyer; graduate from a university nursing school; Msc in extracorporeal circulation; Master's in ICU student (expecting to graduate); Master's in Bioethics student. Maria Deligianni is a pediatrician and a PhD candidate. Alexandra K. Tsaroucha is a Professor of Experimental Surgery, director of the Postgraduate Program on Bioethics.

## **Ethics 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. We adhered to the ethical principles of anonymity, voluntary participation and confidentiality. The participants' confidentiality was protected 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. 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: 9.482/22-6-2021). 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.

## **Competing interests**

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

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