

Social Representations of Intensive Care Unit as held by ICU Patients' Families

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This paper discusses the findings of a socio-psychological qualitative study that examined the social representation that families of Intensive Care Unit (ICU) patients share about the ICU and the underlying themata that constitute this representation. The sample consisted of thirteen people (eleven women and two men) whose family members had been hospitalized in ICUs and were in a recovery phase during the interviewing period. Semi-structured interviews were conducted focusing on individual and family experiences of the ICU. The transcribed interviews were thematically analysed. ICU representation was found to be structured and organized around four themes: safety, danger, proximity and distance. These themes are discussed as themata, consisting of dialogic interdependent antinomies, chiefly those of safety versus precariousness and proximity versus distance. The implications of this representation for the support of ICU patients' families and communication with the ICU patients and staff are discussed.

Keywords: intensive care unit, family, social representations

Intensive Care Units (ICU) have long attracted the interest of psychologists both as regards patients that are treated in these units as well as their families who are usually waiting outside the ICU trying to support their patient relatives. Especially during COVID-19 pandemic, ICUs

have attracted more attention since they constitute a crucial place regarding the treatment and recovery by COVID-19, and a lot of patients worldwide have been treated in them. Through an analysis of interviews with relatives of patients who were treated in ICUs, this article, based on social representation theory, explores the meanings ICU patients' relatives share about ICU to deal with it as an unfamiliar space.

Being admitted to an ICU, is often a sudden and unexpected experience signifying most of the time an immediate danger for the life of the patient but also for the psychological well-being of their families. As noted by Kosco and Warren (2000), patients enter the intensive care unit in a 'crisis situation', while their families enter the hospital with a 'psychological crisis'. Focusing on the families of ICU patients, Verhaeghe et al. (2005) suggest that this 'crisis' is prolonged when certain cognitive, emotional, social and practical needs of the family are not met. Patient relatives need precise and clear information (cognitive); they also need feelings of hope and reassurance (emotional), to be in touch and close to the patient (social). On a practical level, they need more flexible visiting hours and comfortable waiting areas (Burr, 1998; Khalaila, 2013).

Interaction with the medical staff is significant for the well-being of ICU patient families (Heyland et al., 2002). When communication between physicians and relatives is limited, it usually leads to dissatisfaction among relatives (McDonagh et al., 2004). Lack of clear and quick information can lead to inaccuracies and misinformation, resulting in intense anxiety for relatives (Agard & Harder, 2007). In contrast, timely, frequent, understandable and consistent information regarding the health of their relatives, both formal (e.g., defined meetings) and informal and spontaneous (e.g., discussions in the hallway or by telephone), seem to be of particular importance (Engström & Söderberg, 2004; Plakas et al., 2009; Rabow et al., 2004; Verhaeghe et al., 2005).

With regards to the emotions of family members, numerous studies highlight that ICU patient relatives experience a range of mostly negative emotions such as sadness and grief (Engström & Söderberg, 2004), anxiety and depression (Pochard et al. 2005; Paparrigopoulos et al., 2006) and uncertainty about the future (Corbin, 2003). Feelings of fear, surprise and shock are also reported, as relatives often see their loved one unconscious and in mechanical support (Eggenberger & Nelms, 2007; Sinuff et al., 2009), as well as anger for not being able to help them (Kleiber et al., 1994). However, when they become accustomed to mechanical support and to the images of the ICU, positive feelings of hope and optimism are also reported (Plakas et al., 2009; Sinuff et al., 2009).

Family dynamics are also affected when one member becomes an ICU patient. Changes occur in the roles and responsibilities of the family members, since apart from their usual habits and responsibilities, they also have to spend a lot of time in the hospital, and they become more dependent on the wider family to cope with these responsibilities. Children of the family are often given the emotional burden to ‘charge’ others with positive energy (Engström & Söderberg, 2004; Johnson et al., 1995; Koukouli et al., 2013). These experiences either unite the family with an unprecedented and strong bond, or else deeply divide them (Eggenberger & Nelms, 2007; Engström & Söderberg, 2004).

Environmental factors, such as number of patients in the ICU rooms (more than one) and the limited visiting hours, often lead to enhanced dissatisfaction and stress, not only for the patients but also for their families. On the contrary, single rooms and open visit policies, allowing families to visit the patient whenever they wish on a 24-hour basis, have a positive effect for the patients and their families and reduce their stress and anxiety (Jongerden et al., 2013; Whitton & Pittiglio, 2011). The presence of relatives in the unit can be positive and supportive for the patients, as this intensifies their feeling of ‘belonging’, confirming the patient's existence as an individual but also as part of the social reality outside ICU (Bergbom & Askwall, 2000).

Therefore, based on existing literature on families of ICU patients the present study aims to analyse the relatives’ social representations of the ICU. These representations are important mainly as they give prominence to the experienced difficulties in ICU contexts, and the resources they draw from to cope with these difficulties while their beloved ones are in ICU. Exploring these representations allows us to look closer into the way they understand the ICU setting and what they expect from it in order for the provided support to be more accurate, meeting their needs. Besides, social representations of ICU are identified, based on the idea that these representations are built upon a dialogical base in which certain themata underpin the scope of the representational field.

SOCIAL REPRESENTATIONS OF HEALTH AND DISEASE

The theory of social representations has been widely used as a theoretical framework for social psychology to explore and interpret issues of health (Chatzimpyros et al., 2020; Flick et al., 2002, 2003; Herzlich, 1973; Herzlich & Pierret, 1985; Jodelet, 1991; Moloney et al., 2015; Murray & Flick, 2002). As Marková (2000, p. 430) points out, social representations are ‘relational and dynamic organizations of common(-sense) knowledge and language’. Thus, people’s representations of their reality consist of patterns of thinking that are constructed

through social interaction (Wagner et al., 1996). Therefore, an object is not considered self-evidently social because of certain innate characteristics, but because of the way people relate to it. The views that members of a group seem to share about a social object, define the object, and at the same time the group is defined by the common representations that their members share (Wagner et al., 1999).

According to Marková (2000), social representations are structured around ‘themata’, i.e., common sense prototypes that are deeply rooted on value systems and beliefs of a cultural context and they become apparent in public discourse in specific historical and social contexts. Themata are oppositional and a source of debate since each phenomenon becomes an object of social thought along with its opposite, being mutually interdependent (Marková, 2000, 2003). For example, we understand the meaning of the ‘day’ as we understand the meaning of the ‘night’, and the meaning of the ‘small’ in contrast to the meaning of the ‘large’. Thus, thinking in oppositions or antinomies consists of an integral part of socialization into culture. These oppositional taxonomies attract the focus of attention and can become a source of tension and debate. In this way, themata contribute to the ‘interactive construction’ of the boundaries of the opposites, leading to the genesis of social representation of phenomena like health and disease, life and death, and so on. Themata in social representations are created and organized through communication and language being expressed with arguments, explanations and hypotheses. Thus, the social process of thematization takes place both collectively and individually and there are phases that themata arise, are developed, and can disappear when they are no longer relevant to public discourses (Marková, 2015).

Based on the theoretical framework offered by the theory of social representations, the present study aims to explore the social representations of ICU that relatives of the ICU patients share by looking for these ‘themata’, the oppositional classifications around which the social representations of the intensive care units are constructed. This way we hope to contribute to the better understanding and support of the families that escort their beloved ones to the ICU.

METHOD

With regards to the setting of the study, the interviews have been conducted with relatives of patients hospitalized in a central Greek hospital in the city of Thessaloniki. The ICU, in this hospital as in most hospitals in Greece, has a restricted visiting policy both in terms of time (10 minutes in the morning, 30 minutes in the evening) and in terms of the number of visitors (one at a time), not allowing family members to be present in the ICU most of the day. Information is provided only once per day on a person-to-person basis and only by the ICU doctors. Another

characteristic of the ICU ward is that patients in need of mechanical ventilation for a long time will remain to the ICU since there are no step-down units. ICU beds in Greece are governed by the National Centre of Emergency Care and any patient requiring ICU care will be admitted to any hospital with available ICU beds. Therefore, in any given Greek ICU there are patients who have been admitted due to various reasons.

The sample that took part in the research was an availability sample rather than a random sample (Heyland et al., 2002). Researchers used their own social networks to get in touch with people whose relatives had been hospitalized in ICUs, taking into consideration that this could possibly affect the way that interviewees respond during the interview. Since they agreed to participate in the study and agreed to the interview being conducted, an information sheet was given to them explaining the aim of the research and the contact information of the researchers. People who wished to participate, contacted the researchers, usually through phone, and an interview was arranged. In the beginning of the interview, the participants were thoroughly informed about the aims of the study, and they were asked to sign a consent form. Thirteen people ($n = 13$), eleven women and two men took part in the interviews. They were all first or second-degree relatives of patients who had been hospitalized in the ICU in the city of Thessaloniki. The patients were hospitalized in the ICU (for a period of 1 week to 1 month) and during the interview they were in a recovery phase being admitted in other hospital clinics for rehabilitation purposes. The interviews lasted from 29 to 70 minutes and most of the times they were conducted in canteens, waiting rooms of hospitals or at the researchers' office.

The semi-structured interview included open-ended questions that focused on (a) the personal experiences of the ICU (What does ICU mean to you?), (b) the family dynamics (Do you think your relative's ICU hospitalization has changed the roles each one of you have in the family? In what way?), (c) the ICU environment (Could you describe to me the environment of the ICU?), and (d) the decisions taken in the ICU (In case you encountered a critical event in the ICU, who decided how to react?). Interviews were recorded and transcribed, in order later to be analysed.

The method of analysis used in the research is thematic analysis (Braun & Clarke, 2006). This is a method for identifying, analysing, and reporting patterns (themes) within data. Themes are specific, recognizable units of meaning that interact systematically and not arbitrarily (Willig, 2008). Themes may contain either explicit, directly observable content or indirect, latent content. This method is characterized by theoretical flexibility, being independent of a theoretical framework and making sense when it is part of an epistemological field. According to Joffe (2012), thematic analysis is a method that can be used to explore social representations,

since it focuses on the content of individuals' thoughts and feelings about the phenomenon under study, rather than trying to reveal the "one and only truth" concerning this phenomenon. As Joffe (2012) suggested, focusing on the notion of 'themata' it helps us understand the tacit content that underpins the 'themes' in a thematic analysis. Thus, Joffe (2012) advocates for an association between thematic analysis, social representations and themata. Taking this into consideration, in the present study we used thematic analysis oriented towards discovering the main themes in relatives' discourse concerning ICU and at the same time identifying antinomies in their discourse, leading us to identify the main 'themata', as defined by Marková (2000, 2007). Thus, thematic analysis is used to explore and identify social representations along with their symbolic meanings in social subjects' narratives. In this context, the present study attempts to highlight the social representation of the ICU as a multidimensional and controversial phenomenon that is formed during the continuous interaction between individuals and their environment. Thematic analysis followed distinct stages, by transcribing and repeatedly reading the interviews, formulating initial codes, classifying these codes into higher order categories, and finally organizing these categories into themes. Once all these procedures have been performed, the final analysis follows, which is attempted to be done in such a way that the 'history' of the data is given comprehensively, coherently, logically and non-repetitively (Braun & Clarke, 2006).

ANALYSIS

During the interviews with family members of patients held in ICU, four main themes were identified. The first two themes represented ICU as a safe and as a dangerous place whereas the last two represented ICU as a space that can both bring people together and contribute to their separation and distance. Drawing from the concept of themata as antinomies that are mutually interdependent (Marková, 2000, 2003), these pairs of oppositional themes, safety versus precariousness and proximity versus distance, are treated and discussed as antinomic but mutually interlinked themata that underpin and organize the social representation of ICU.

ICU as a Safe and Dangerous Place for the Patient to Be

The first two themes that emerged through relatives' narrative represent ICU both as a safe and as a risky place for the patient to be hospitalized, creating an antinomic two-fold character of ICU. More specifically, this contradiction becomes evident when participants talk about mechanical support as triggering feelings of uncertainty among the family members but at the same time as a way of maintaining the patient alive. A similar contentious issue that

imbues family members with ambivalent feelings of uncertainty combined with hope, is the fact that the patient remains hospitalized in the ICU context. Moreover, the provision of sufficient or non-sufficient information regarding patient's condition is deemed as a crucial issue for family members' recognition of ICU as a safe or a dangerous place. All these topics tend to enhance the idea that the social representation of ICU is constructed by this dialogic pair of safety and precariousness.

Mechanical support

A contentious issue in ICU is the use of specialized high technology devices that they are supposed to effectively support the life of the patient:

I think the machines stigmatize you. Their sound sticks to your mind. I do not know if it is good that you can watch the values on them e.g., of oxygen and I watched his oxygen falling and I didn't know if this is good or not for him and this was really disturbing me. I do not know if it is good for the relative to see them or not to see them. But it adds to your anxiety to see how much oxygen there is, how much it is, how much it is. (Mary, spouse)

In the abstract included in the first theme of danger, it becomes evident that the ignorance regarding the operation modus of these devices, and the way the sounds and the indications on the machines work, enhance the anxiety and uncertainty due to family members' incompetence to comprehend them.

On the other hand, there are narratives in the theme of safety that point out the importance of all the equipment in the ICU for the survival of the patient claiming that they make the family feel hope and relief:

I feel that my relative is more secure in the ICU because if he wasn't here, he would not be living now. Fortunately, I am very happy that they brought him here. The doctors realized that he needed support from machines, because now he has full mechanical support, we felt better and of course we waited for something better to happen. (Eleni, niece)

In contrast to the previous extract, it is the lack of ICU and its technology that leads to feelings of insecurity and uncertainty. This reveals the important role that mechanical support plays in the representation of the safety provided by hospitals in general. Its absence is combined with evidence of hospitals' inadequacy and survival precariousness. On the contrary, the presence

of such technological equipment is an element that contributes to the representation of ICU as a safe place for patients' life.

Therefore, as it can be seen from the above passages, mechanical support seems to be an important element of ICUs that creates ambiguous feelings to the patients' family members. As pointed out by Sinuff et al. (2009), mechanical support as the dominant medical technology, becomes the symbol of both life and death, since the relative experiences a range of negative emotions such as shock and fear, when the patient initially is being transferred to the ICU and then gradually these emotions seem to turn into more positive ones such as the hope and security.

ICU environment

In the theme of danger, ICU is constructed by family members as a place that carries the risk of hospital acquired infections and the deterioration of the patient's health. Procedures that take place within the ICU, such as family visits, seem to be potentially dangerous to the patient, thus justifying limited contact and interaction with the patient. Limited visiting hours and limited number of visitors are presented as ICU rules that the family should comply with, for fear of transmitting any germs and death may occur for the patient.

"I understand why I should stay in the ICU only for 5 minutes because I understand how dangerous it can be for the patient. So, a short visit is OK. There are infections and I don't want to transmit them to him. To transmit any germs. (Eleni, niece)

"In ICU there are a lot of serious infections, that's why I don't want my partner to stay there, and the doctors agree." (Anna, spouse)

Something similar is pointed out in the research of Alexias (2000), since the relative can visit the patient only for a few minutes and at the same time any physical contact is prohibited for patient safety reasons. These facts also combined with the imposition of a certain way of dressing, lead to the exclusion of the sufferer from society in a symbolic level. Therefore, the condition of the patient's hospitalization in the ICU makes family members to feel insecure, as the risk of microbial infection is possible and for this reason it is deemed necessary to take restrictive measures.

However, in the safety theme, family members' narratives, construct ICU as a safer place for the patient compared to other hospital units. Quite often patients enter ICU when they do not respond to the doctors' efforts and while their health deteriorates. Thus, the transfer to

ICU seems to introduce the patient in a safer environment, being constantly and in-depth monitored. The fact that the patient is under 24-hour close supervision by specialized staff that controls and regulates his condition, works positively for the attendant in terms of his own emotional and mental state. Therefore, constant monitoring seems to be the main element to the representation of ICU as a life-saving space.

“After some days in ICU, you feel safe that your loved one is there, it’s like as I used to say the Stockholm syndrome. When it was the time to leave ICU, I started to feel awkward, and I was wondering how my relative will be discharged from ICU. Here, there is safety as the medical staff monitors the patient’s condition and can imminently intervene if something happens” (Konstantina, spouse)

As confirmed by the above passage, the regulations and the operating procedures that govern the Intensive Care Unit seem to be oriented towards the provision of intensive care services, a fact which is accepted with great satisfaction by the patient's family. As mentioned above, leaving the intensive care unit and being transferred to another hospital clinic causes ambivalent feelings of hope and insecurity and vulnerability (Chaboyer et al., 2005).

It becomes evident by the above passages that patient’s hospitalization in ICU context constitutes a complex process for the family members. As the ICU could be a place for possible acquired infections, along with the dominant medical consensus that visiting hours could be harmful for the patient because of infections transmitted by the visitor, the family members experience feelings of uncertainty and insecurity strongly connected with the fear of patient’s death. On the contrary, the very same fact of hospitalization in ICU, in which specialized and constant monitoring of patient’s condition takes place, could contribute to the representation of ICU as a safe and life-saving space.

Information by ICU staff

As Agard & Harder (2007) suggest, relatives in the Unit expect to get information that is clear, concise and responsive to their concerns, so that to feel relieved and safe as much as possible. Something similar seems to be confirmed in the danger theme, in which the participants, focusing on the information provided by the ICU personnel, pointed out the insecurity they felt when the information they were given was parsimonious, and as a result they often had to reach their own assumptions about the patient’s health.

“I used to look at the monitors, and then I was asking a relative of mine who is a doctor what the numbers I had watched meant and she would tell me that it is oxygen saturation levels and then I would ask again to find out the normal levels or I was looking for them on the internet. In general, I wanted to know, and doctors do not bother to tell you because they are so busy...” (Angela, spouse)

It becomes clear that insufficient information given by ICU staff causes additional stress on the attendants as it burdens them to ‘search’ alone for signs and findings that would give them an idea of the health condition of their suffering relative. This process can become exhausting for the attendant and at the same time create erroneous and distorted perceptions about the course of the patient's health.

On the contrary, in the safety theme when the attendant recognized that the information provided by the medical staff of the ICU was sufficient, they felt reassured.

"I liked the information they gave me in ICU, because now (in the neurosurgery clinic) I get no information and I was used to go to the ICU and get informed about everything by the girls (doctors and nurses), about the wound or about how he moves, what did he do or didn't do, about everything! They did not hide anything from us, either good or bad, they would inform us to be prepared for everything." (Anna, spouse)

The provision of continuous, understandable and consistent information to the patient's family of the ICU patient contributes to the adaptation of the attendant to the specific condition (Rabow et al., 2004; Söderström et al., 2006; Verhaeghe et al., 2005). Furthermore, most participants in this study understand and accept the precise and risk-focused information that the staff of ICU provides them, due to the protective function it performs for their emotional state. Even when the doctors talk about the risks to the patient's health, they do so to help the family to adapt to the ICU condition but also to prepare themselves and to process possible negative outcomes to the patient's health (Lautrette et al., 2006).

It should therefore be noted that the way of providing information followed in the ICU contributes equally to the representation of the latter as a precarious and safe framework. As the intensive care unit is a flowing social interaction, it seems that the relative holds two different and oppositional meanings and ideas regarding the mechanical support: the hospitalization of the patient in ICU and the sufficiency and clarity of the provided information

by medical personnel that are closely linked to the overarching dialogic pair of the ICU as a safe and as a precarious place.

ICU as a Place that Unites and Divides Individuals

The two last themes that were identified by the thematic analysis are the themes of proximity and distance. These represent the ICU as a place where relationships can be shaped and empowered and at the same time as a place where relations can be terminated. More specifically, the relative encounters feelings of intimacy and alienation with all the social actors that is interacting with in the Intensive Care Unit. The very same relationship among the family member and the patient is presented as turbulent, promoting feelings of alienation as well as close contact. Also, the relationships among family members can be changed or modified during the presence of the patient in the ICU, as they can be strengthened or weakened. Moreover, the relationship with the medical staff in ICU can be controversial, as feelings of distance and connectedness can be manifested towards them. Thus, it becomes apparent that the antinomy proximity/distance that has always been a crucial point with regards to the relational level of individuals, arises also in the specific context of ICU.

ICU patient

In the ‘distance’ theme family members seem to experience negative feelings, since they see their beloved one being intubated and in need of mechanical support struggling with their need to be present in ICU.

"I was going, I was looking at her and I was leaving in a hurry. Three or four times I did not go to the ICU because I could not stand to look at her like that. Because looking at her like that in the ICU I was becoming exhausted... It hurt me that the patient had no contact. I always liked to be in contact with people, to tell me what she wants, what problem she has and to solve it. The fact that she cannot talk there, with all these machines, I could not stand it at all, I felt it suffocated me." (Martha, daughter)

The fact that the patient is under mechanical support tends to create ambivalent feelings and crucial questions to the relative with regards to the ability of the patient to perceive what is happening during the process of intubation. Thus, the risk that the deformed body found in the ICU “has lost” the social and individual characteristics that s/he used to have before, is reinforced, making the relative unable to cope with this new reality.

The dependence on the medical equipment of the ICU in combination with the loss of communication for the patient due to the intubation, seem to have a catalytic effect on the way the relative experiences this new condition of non-conciliation and interaction with the beloved, resulting in a limited interaction among the two individuals (Engström & Söderberg, 2004).

At the same time, in the 'proximity' theme, the patient-relative interaction seems to be very important during visiting hours even though they last from 10 minutes to an hour in total, during the day. The relatives seem to spend most of their day in the hospital, waiting for the minutes that they will be allowed to contact with their ailing relative. In line with this, a new daily life of the relative adapted to the new condition of hospitalization of the relative is formulated.

"I was always there as a guard. I would come at 2 o'clock, I would go to the briefing, then I would leave and because I was staying with my cousins, because I don't live here, I come from another city, I was sitting in the canteen across the street until 6 o'clock to see him for at least half an hour, to talk to him, to make him respond to my voice, to make him understand that I was there and then I would leave. I never left him alone." (Anna, spouse)

As noted in the literature, the maintenance of the relationship between the relative and the patient and the desire for contact can be enhanced and become a critical component for the emotional security of family members (Burr, 1998; Khalaila, 2013; Verhaeghe et al., 2005). Furthermore, it becomes apparent by their discourses that the aim of their presence in ICU is to maintain communication among the family and the ICU patient, even if this is practically impossible. In addition, through the desire for contact and interaction with the patient, another need seems to be satisfied, that of feeling useful in the ICU context. The presence of relatives assists the patient to understand what happened when s/he was unconscious, and at the same time to feel that s/he constitutes an integral part of the family despite the absence from everyday life due to ICU hospitalization (Bergbom & Askwall, 2000; Olsen et al., 2009).

In conclusion, the relationship of the family members with the patients in ICU seems to be strongly affected. There are narratives supporting the notion that the bonds become more tightened, with contact remains intact and at the same time there are contradictory voices, advocating for alienation in the pre-existing relation among them. This can also be understood in the way that the dyadic opposition of proximity and distance organize and shape the social representation of ICU held by family members.

In relation with the rest of the family

In the theme of ‘distance’, having a member of the family in the ICU seems to have a catalytic effect on the roles and the responsibilities that the other members of the family are called to undertake. As characteristically stated in the study by Johnson et al. (2014), family members in the ICU may not be able to meet their regulatory standards, confuse their roles and consequently the family system malfunctions.

"We also have a problem with our youngest son who was sick, and I felt that I had neglected him and I wanted to be close to him and support him. There have been also other changes. Because the tasks that the patient used to do, need to be done by me at this point. The patient (man) used to pay, fix things and do such things. I used to deal with things of the house, of the family. Now his tasks are loaded on me." (Penelope, spouse)

The findings of the present study also reveal changes in the regulatory structure of the family roles that load the family members with further obligations, making the adjustment to the current situation quite difficult and problematic.

However, in the theme of ‘proximity’ a different perspective seems to be also expressed regarding the relationships within the family during the hospitalization of a relative in the ICU.

“First of all, my children supported me with saying ‘don’t worry it will be fine’, ‘we will go further’ ‘it takes patience’ and so on. And I was getting courage, of course. And the children even more. They never lost faith that their father would be well. Now how long it will take us is something else to answer.” (Anna, spouse)

It seems that the hospitalization in ICU strengthens the family support network in order to cope with this emotionally painful experience. The expression of comforting comments by family members helps the relative to feel strong and deal with the current situation, and in turn this support allows the relative to give back emotional support to others. Recognizing the family as a ‘whole’, traumatic experiences seem to strengthen bonds and unite family members in an unprecedented way (Eggenberger & Nelms, 2007). As Söderström et al. (2009) point out, in this process the relatives seek to find the way to feel comfort and to "rebuild" their life under the new conditions, through enhancing family cohesion and interaction.

Consequently, complex relationship dynamics are being developed within family members when a loved one is admitted to the ICU. Relatives may feel dissatisfied regarding

their new position and role in the family and the change in their regulatory roles or/and feel more supported and connected to their family as a supportive network for managing this painful condition. Thus, it becomes obvious that the oppositional taxonomies of proximity and distance, that are organizing and shaping the social representation of ICU, are revealed in the relationships among family members, when a relative is hospitalized in ICU.

In relation with the medical personnel

In the theme of ‘distance’, the absence of substantial communication and interaction between the medical staff and the family is presented in the current study, highlighting the relational gap that exists between them in the ICU context.

"I often get in their position, and I realize that what they do is very difficult. Sentimental reactions (towards the relatives) should not take place in ICU. They have so many people to take care of, so they cannot be emotional. I think that deeply inside they feel upset about their patient's conditions, but they just don't show it. And I think it's normal." (Marina, niece)

In particular, the speaker attempts to justify the doctors for being more distant and not emotional towards the family, to achieve for themselves more personal strength and self-discipline in order to provide the most accurate medical care for the patient as well.

On the contrary, in the theme of ‘proximity’, contact with the ICU staff can also emerge.

"We ended up loving the intensive care, appreciating the intensive care unit and we made the intensive care unit our home. Truly our home. And in fact, when I was informed of a recent health problem of a doctor working in the intensive care unit, I was sad as if he was my close friend; that is, I really felt as if one of my own people was sick, so much." (Anthi, spouse)

In this case, the interviewee claims that she felt intimately to the doctor of the ICU as being her ‘close friend’. Relatives facing the criticality of the patient's health condition, seek a supportive framework to meet their need for emotional contact, while also showing that the emotional response of staff to the patient's family is something that is positively assessed by the latter and contributes to the ‘building’ of contact and interaction relationships (Heyland et al., 2002; Verhaeghe et al., 2005).

From the above extracts, the complexity that shapes the social representation of ICU becomes obvious. Two completely different views seem to coexist regarding the relationships

built between the family members and the medical personnel. ICU patients' relatives talk about the ICU either as a place where they experience discomfort by the distant stance of the medical staff, or else as a place 'like home' accompanied by positive emotions and feelings of tenderness for the staff. Therefore, the overarching theme of 'proximity' and 'distance' seems to be revealed also in the relationship that is formed among the family members and the ICU staff.

Discussion

Delving into family members' representation regarding ICU, made us access meanings, thoughts and expectations with regards to the ICU. As mentioned in the beginning of this article, the leading idea was to explore the social representations of the ICU shared by the relatives of the ICU patients, by understanding their ambivalent feelings and thoughts raised in a controversial context, such as that of the ICU. Interviews with patients' relatives have highlighted since the very beginning the dilemmatic nature that constitutes the social representation of the ICU as it seems to be constructed around two oppositional dialogic pairs of themes, these of safety versus precariousness and proximity versus distance. These antithetical but also complementary aspects contribute to the representation of ICU both as a place of safety that brings people – patient, family and medical staff – close to each other and as a place that signifies danger for the life of the patient and alienates people from each other.

Drawing from the concept of themata as developed by Marková (2000) in the field of social representations, we believe that these two antinomic but complementary themata of safety/precariousness and proximity/distance could be seen under the overarching oppositional pair of life and death. As revealed in relatives' discourses, when ICU is represented as a precarious and distant place, they experience mostly negative feelings. Emotions such as intense anxiety, fear and agony about the patient's life are reported. In the climax of these negative feelings are the hopelessness and helplessness that the family member can experience. The social common-sense aspect that supports the view of the ICU as a non-accessible place that is not for everyone, enhances feelings of frustration to the family members, leading the relatives closer to the notion of a possible coming death for their beloved patient. However, at the same time, the ICU is also presented as a safe place, which allows and strengthens the social ties and maintains the sense of hope for a future where life continues. These interpretations of the ICU seem to trigger the expression of positive feelings and enhance good adaptive skills in the new circumstances to the relatives, giving prominence to the connection between the ICU and the notion of life.

Although psychological research mainly emphasizes the negative experiences and emotions of the families of the ICU patient, our findings indicate that there are also positive meanings connected to the ICU that are in a constant dialogue with the negative ones. The content of the social representation of ICU seems to wander from negative aspects to positive ones, from the idea of death to that of life. Relatives referred to their difficulty faced in the beginning in comprehending the idea of ICU and forming a specific meaning of it, thus having to talk about ignorance on what ICU is, which is inextricably linked to the concept of intensive care as an unfamiliar phenomenon for the relative. However, as made obvious in the present study, gradually and through daily contact and interaction with the ICU environment and the people acting in it, the ICU seems to turn into a more familiar place that allows contact and closeness among patients, relatives and health professionals.

As stated by the theory of social representations, people rely on familiar experiences to make sense of unclear and uncertain information. Thus, it could be argued that in the beginning the relatives made sense of the ICU based on previous experiences that mostly triggered negative feelings such as fear and despair, strongly linked to the notion of death. However, gradually, through the daily interaction with the social subjects acting in the ICU context and the context of ICU itself, the relatives made new meanings for the ICU context, perceiving that life can also be saved and maintained in this environment.

Taking into consideration the circulating nature of social representations, and historical and social change, the findings of the present study attempt to describe the multidimensional experience of the relative in ICU as perceived by the interviewed relatives, living in a specific area of Greece and facing specific ICU characteristics and aspects that could possibly be different in other social and historical circumstances. Therefore, as the aim of this study is to contribute further on understanding the experiences and meanings made by relatives concerning ICU, it becomes evident how relatives' narratives revolve around the dichotomies of safety and precariousness and proximity and distance in order to make sense of the ICU context. Our purpose for identifying the main themata is to highlight the relation between the representation and the practices of the social subjects concerning ICU. The tensions, apart from being the core of social representations, define how people act. Consequently, any intervention must be performed considering the above contradictions in order to assist relatives experiencing these tensions. In this light, by understanding how this particular social reality is constructed by the social subjects themselves, we will be able to support family members to experience ambivalent and contradictory emotions raised in ICU.

REFERENCES

- Agard, H.S., & Harder, I. (2007). Relatives' experiences in intensive care—Finding a place in a world of uncertainty. *Intensive and Critical Care Nursing, 23*, 170-177.
- Alexias, G. (2000). *Discourse on life and death: Medical praxis as a form of social interaction in the Intensive Care Units*. Ellinika Grammata.
- Bergbom, I., & Askwall, A. (2000). The nearest and dearest: A lifeline for ICU patients. *Intensive and Critical Care Nursing, 16*(6), 384-395.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.
- Breen, C. M., Abernethy, A. P., Abbott, K. H., & Tulsky, J. A. (2001). Conflict associated with decisions to limit life-sustaining treatment in intensive care units. *Journal of General Internal Medicine, 16*(5), 283-289.
- Burr, G. (1998). Contextualizing critical care family needs through triangulation: An Australian study. *Intensive and Critical Care Nursing, 14*(4), 161-169.
- Chaboyer, W., Kendall, E., Kendall, M., & Foster, M. (2005). Transfer out of intensive care: A qualitative exploration of patient and family perceptions. *Australian Critical Care, 18*(4), 138-145.
- Chatzimpyros, V., Baka, A., & Dikaiou, M. (2020). Social representations of immigrant patients: Physicians' discourse. *Qualitative Health Research, 1049732320979814*.
- Corbin, J. M. (2003). The body in health and illness. *Qualitative health research, 13*(2), 256-267.
- Eggenberger, S., & Nelms, T. (2007). Being family: The family experience when an adult member is hospitalized with a critical illness. *Journal of Clinical Nursing, 16*, 1618–1628.
- Engström, Å., & Söderberg, S. (2004). The experiences of partners of critically ill persons in an intensive care unit. *Intensive and Critical Care Nursing, 20*(5), 299-308.
- Farrell, M. E., Joseph, D. H., & Schwartz-Barcott, D. (2005). Visiting hours in the ICU: Finding the balance among patient, visitor and staff needs. *Nursing Forum, 40*(1), 18-28.
- Flick, U., Fischer, C., Schwartz, F. W., & Walter, U. (2002). Social representations of health held by health professionals: The case of general practitioners and home-care nurses. *Social Science Information, 41*(4), 581–602.
<https://doi.org/10.1177/13591053030085006>

- Flick, U., Fischer, C., Neuber, A., Schwartz, F. W., & Walter, U. (2003). Health in the context of growing old: Social representations of health. *Journal of Health Psychology, 8*(5), 539–556. <https://doi.org/10.1177/13591053030085006>
- Herzlich, C. (1973). *Health and illness: A social psychological analysis* (Vol. 5). Academic Press.
- Herzlich, C., & Pierret, J. (1985). The social construction of the patient: Patients and illnesses in other ages. *Social Science & Medicine, 20*(2), 145-151.
- Heyland, D., Rucker, G., Dodek, P., Kutsogiannis, D., Konopad, E., Cook, D., Peters, S., Tranmer, J., & O’Callaghan, C. (2002). Family satisfaction with care in the intensive care unit: Results of a multiple center study. *Critical Care Medicine, 30*(7), 1413-1418.
- Jodelet, D. (1991). *Madness and Social Representations London*: Harvester Wheatsheaf.
- Joffe, H. (2012). Thematic analysis. In D Harper and A.R. Thompson (Eds.), *Qualitative Research Methods in Mental Health and Psychotherapy* (pp. ____). John Wiley & Sons.
- Johansson, I., Fridlund, B., & Hildingh, C. (2005). What is supportive when an adult next-of-kin is in critical care? *Nursing in critical care, 10*(6), 289-298.
- Johnson, J. R., Engelberg, R. A., Nielsen, E. L., Kross, E. K., Smith, N. L., Hanada, J. C., ... & Curtis, J. R. (2014). The association of spiritual care providers’ activities with family members’ satisfaction with care after a death in the ICU. *Critical Care Medicine, 42*(9), 1991.
- Jongerden, I. P., Slooter, A. J., Peelen, L. M., Wessels, H., Ram, C. M., Kesecioglu, J., ... & van Dijk, D. (2013). Effect of intensive care environment on family and patient satisfaction: a before–after study. *Intensive Care Medicine, 39*(9), 1626-1634.
- Khalaila, R. (2013). Patients' family satisfaction with needs met at the medical intensive care unit. *Journal of Advanced Nursing, 69*(5), 1172-1182.
- Kosco, M., & Warren, N. A. (2000). Critical care nurses' perceptions of family needs as met. *Critical Care Nursing Quarterly, 23*(2), 60-72.
- Koukouli, S., Alevizaki, A., Lampraki, M., & Stavropoulou, A. (2013). Exploration of experiences of families with patients of Intensive Care Units (IUC) in three hospitals in Crete. *Periegheiritiki Nosileftiki, 1*(1), 131-139.
- Lautrette, A., Cioldi, M., & Ksibi, H. (2006). End-of-life family conferences: Rooted in the evidence. *Critical Care Medicine, 34*(11), S364-S372.
- Liu, L. (2004). Sensitising concept, themata and shareness: A dialogical perspective of social representations. *Journal for the Theory of Social Behaviour, 34*(3), 249-264.

- Marková, I. (2000). Amédée or how to get rid of it: Social representations from a dialogical perspective. *Culture & Psychology*, 6(4), 419-460.
- Marková, I. (2003). *Dialogicality and social representations: The dynamics of mind*. Cambridge University Press.
- McDonagh, J. R., Elliott, T. B., Engelberg, R. A., Treece, P. D., Shannon, S. E., Rubenfeld, G. D., ... & Curtis, J. R. (2004). Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction. *Critical Care Medicine*, 32(7), 1484-1488.
- Moloney, G., Gamble, M., Hayman, J., & Smith, G. (2015). Without anchor: Themata and blood donation. *Papers on Social Representations*, 24(2), 2-1.
- Moscovici, S. (1981). On social representations. *Social cognition: Perspectives on everyday understanding*, 8(12), 181-209.
- Olsen, K. D., Dysvik, E., & Hansen, B. S. (2009). The meaning of family members' presence during intensive care stay: A qualitative study. *Intensive and Critical Care Nursing*, 25(4), 190-198.
- Paparrigopoulos, T., Melissaki, A., Efthymiou, A., Tsekou, H., Vadala, C., Kribeni, G., ... & Soldatos, C. (2006). Short-term psychological impact on family members of intensive care unit patients. *Journal of Psychosomatic Research*, 61(5), 719-722.
- Plakas, S., Cant, B., & Taket, A. (2009). The experiences of families of critically ill patients in Greece: A social constructionist grounded theory study. *Intensive and Critical Care Nursing*, 25, 10-20.
- Pochard, F., Darmon, M., Fassier, T., Bollaert, P. E., Cheval, C., Coloigner, M., ... & Zahar, J. R. (2005). Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. *Journal of critical care*, 20(1), 90-96.
- Rabow, M., Hauser, J., & Adams, J (2004). Supporting family caregivers at the end of life "They don't know what they don't know". *JAMA*, 291(4), 483-491.
- Sinuff, T., Giacomini, M., Shaw, R., Swinton, M., & Cook, D. J. (2009). "Living with dying": The evolution of family members' experience of mechanical ventilation. *Critical Care Medicine*, 37(1), 154-158.
- Söderström, M., Saveman, B. I., & Benzein, E. (2006). Interactions between family members and staff in intensive care units—An observation and interview study. *International Journal of Nursing Studies*, 43(6), 707-716.

- Studdert, D. M., Mello, M. M., Burns, J. P., Puopolo, A. L., Galper, B. Z., Truog, R. D., & Brennan, T. A. (2003). Conflict in the care of patients with prolonged stay in the ICU: Types, sources, and predictors. *Intensive Care Medicine*, 29(9), 1489-1497.
- Verhaeghe, S., Defloor, T., Van Zuuren, F., Duijnste, M., & Grypdonck, M. (2005). The needs and experiences of family members of adult patients in an intensive care unit: A review of the literature. *Journal of Clinical Nursing*, 14, 501–509.
- Wagner, W., Duveen, G., Farr, R., Jovchelovitch, S., Lorenzi- Cioldi, F., Marková, I., & Rose, D. (1999). Theory and method of social representations. *Asian Journal of Social Psychology*, 2, 95–125.
- Wagner, W., Valencia, J., & Elejabarrieta, F. (1996). Relevance, discourse and the ‘hot’ stable core social representations—A structural analysis of word associations. *British Journal of Social Psychology*, 35(3), 331-351.
- Whitton, S., & Pittiglio, L. I. (2011). Critical care open visiting hours. *Critical Care Nursing Quarterly*, 34(4), 361-366.
- Willig, C. (2008). *Introducing qualitative research in psychology*. Open University Press.

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