

ERASMUS MUNDUS SCHOLARSHIP PROGRAMME

**End-of-life practices and experiences of health professionals
and family members of terminally-ill patients in intensive
care units in Macedonia: a qualitative research**

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**End-of-life practices and experiences of health professionals
and family members of terminally-ill patients in intensive
care units in Macedonia: a qualitative research**

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Declaration

Where other people's work has been used (either from a printed source, internet or any other source) this has been carefully acknowledged and referenced in accordance with departmental requirements.

The thesis "**End-of-life practices and experiences of health professionals and family members of terminally-ill patients in intensive care units in Macedonia: a qualitative research**" is my work.

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Abstract

Objective

To understand the end-of-life phenomenon in the intensive care setting in Macedonia through the experiences of health professionals and family members of terminally-ill patients in its social and cultural context.

Methods

Participant observation in surgical intensive care units and in-depth interviews with health professionals who had professional experience with terminally-ill patient(s) and family members of terminally-ill patients who died or had any limitation of life-sustaining medical intervention are principal methods.

Results

The context analysis revealed opportunity for integration of palliative care in the intensive care units as an alternative to separate palliative care services in the country. The study reveals surgical intensive care units and emergency departments and the professionals providing service to be involved in the treatment of terminally-ill patients. Both withholding and withdrawal of treatment in terminal patients are accepted practices in terminal patients. Social, cultural, economic factors influence the decision making process. Families and patients are rarely involved in the decision making process, especially in emergency cases. Communication is reported as a point to improvement from both sub-samples. Disclosing diagnosis and prognosis, as well as informed consent to treatment, though legally secured, undergo cultural reshape.

Conclusion

How terminally-ill patients are managed in the intensive care setting in Macedonia is shaped through the interplay of professional, cultural, ethical and social factors. The identified factors represent potential threats and opportunities to profile palliative care

programs in the intensive care setting. Limitation of life-sustaining measures in terminally-ill patients is accepted among the medical professionals as an alternative to redundant prolongation of life and time of death. Patient and family inclusion in decision-making and communication is insufficient. Ethical principle of autonomy should be shaped in the cultural context. Public, ethical, professional and legal consensus is needed to improve current practice. Though this research pioneers in the understanding of the end-of-life phenomenon and identified its components and their interaction in the context, more research is needed to describe the role and needs of the patients in terminal condition and their families and decision-making surrogates.

Key words: Palliative Care; Intensive Care Units; Decision making; Health Personnel; Family; Attitude; Culture; Social Perception. (MeSH Database NCBI)

Acronyms and abbreviations

CPR	Cardiopulmonary resuscitation
DNR	Do not resuscitate
EOL	End-of-Life
GDP	Gross Domestic Product
ICU	Intensive Care Unit
Intl \$	International Dollars
NATO	the North Atlantic Treaty Organization
PPP	Purchasing Power Parities
UK	The United Kingdom
USA	the United States of America
WHO	World Health Organization

1. Background and rationale

Intensive care encompasses therapeutic measures for treatment of patients with potentially reversible condition who have a good chance to survive if intensive therapy was provided. But, critical patients are constantly facing uncertain outcome which is difficult to predict.(1) Therefore, it has become more open to accept that intensive care units (ICU) are providing palliative care to the dying patient, as well as appropriate care for their families. (2)

End-of-life (EOL) experiences are inevitable part of every health professional career. Critical care specialists apply ethical reasoning to help decide morally in patient care. On the other hand, EOL is a complex life experience for family members, often excluded from EOL decision making of their loved ones.(3;4)

Ethical reasoning can sometimes conflict with personal morality and feelings. (3) EOL is subject of ethical debates (4) and the practices substantially differ among different societies.(5)

The way people deal with death has innumerable cultural variations. The advancement of technology has turned death into problematic phenomenon. According to some critics, death is postponed and people are deprived of the right of peaceful death. (6)

Legal and ethical regulations throughout the world allow wide range of EOL practices, from extremes like active euthanasia/ assisted suicide/ 'Do Not Resuscitate'

(DNR) directives to health professional discretion of withdrawal and withholding of treatment. Patient/ family members involvement is another point of discrepancy (6-8).

Practices of EOL in ICU patients in literature refer mostly to withholding and withdrawal of treatment if the continuation of medical treatment is futile. Futility has strict definition; it applies in cases when there is no rationale for continuation of life support or if the patient is refractory to cardiopulmonary resuscitation (CPR) or life support.(3)

Studies of influences over the decision-making process, especially attitudes of medical professionals towards EOL decision-making have been undertaken in many countries, such as Denmark, Germany, Italy, the Netherlands, Norway, Sweden, Switzerland, the UK, the USA and France (3;7). International perspectives of EOL with geographically more diverse sample have been studied in large scale survey, revealing considerable differences in the physician's attitudes toward EOL care in the intensive care. (7)

The difference in the practices and attitudes between the studied countries in Europe has been discussed in a European survey. The study show substantial inter-country differences in decision-making in the seemingly coherent union of countries as the European countries. (8).

The difference in ethnicity and cultural background of doctor and patient may lead to troubled communication about EOL issues. It has been proved in the multi-ethnic context in the USA that the communication is related to attitudes toward and personal wishes for the use of life support in the event of coma or terminal illness (9).

We presume there are issues specific for the Macedonian context noteworthy to explore and pinpoint the target points of improvement of care for terminally-ill patients in the intensive care setting.

Current practice of EOL in Macedonia^a is not regulated with written guidelines. Rigorous research has not been conducted to answer questions of attitudes and practices and the social, cultural and socioeconomic determinants that influence the decisions of the end-of life practices. Macedonian medical practice does not differ substantially from global practices, mainly guided by the ethical codex of the medical profession. (3;4)

The decision-making models in medical care are important to explore. The Law for patient rights (further referred as the Law) (10) protects the patient autonomy, but its applicability in the intensive care units is yet to be established. Humane care for terminally ill patients is one of the principles of the Law, but no provisions are stated or further elaborated. The practice of advanced directives is not covered by the Law (10). Furthermore, there is a lack of appropriate facilities for care of terminally ill patients where patient wishes and attitudes toward EOL while the patient is competent to make decisions can be discussed. In cases of incompetent patient, the Law (10) is not clear concerning decision-making surrogates.

^a Macedonia hereby is a reference name for the Republic of Macedonia, which is the constitutional name of the country. The country was admitted to the United Nations by a reference name, the Former Yugoslav Republic of Macedonia as a bilateral reference name with Greece until an agreement were reached with Greece which claimed that Macedonia made territorial claims on the Greek province of Macedonia by its Constitution. Macedonia will be used as a short name for the Republic of Macedonia throughout the text.

The direction toward improvement of palliative care in the efforts to improve the healthcare of elderly and as a reaction to the aging population is clearly distinct; accordingly health authorities issued a strategic plan for the period of 2009-2011. The reforms did not incorporate the care of terminally-ill patients in the intensive care setting. (11)

It is also important to explore the influence of socioeconomic factors on EOL practices and the decision making in this resource scarce setting. In a French survey (12) about the attitudes and practices of EOL treatment in intensive care, it was found that physicians do not make decisions according to the financial implications of the treatment of terminally-ill, which was explained by the existence of universal social healthcare system in the country. Thus, similar results and rationalization are expected in our research.

The anthropological critique of the bioethics is the neglecting of the cultural relativism, or its “ethnocentric, phycho-centric and medicocentric” principles, mainly lead by the North American and Western European cultures. Some values of the bioethics are very clearly accepted from the American system of values of the individualism. Whereas in some cultures the concept of humans as social beings is clearly respected, and practicing group decision-making is a cultural phenomenon (inside the family, the community etc.) (13) The norms of the community or the system, if not the principles of the collectivism is accepted as a norm of the traditional community in Macedonia as well. (14)

Implementation of a policy that would not consider the context, which is common practice in Macedonia, to only adapt and implement a global guideline as already proven could be expected to cause low compliance and reduced applicability of the guidelines driving frustration to the medical professionals and the families. (15)

Acknowledging the fact that ICUs provide not only clinical service to individual patients, but have significant role in the wider society (3), it is imperative to address intensive care issues with multidisciplinary research: clinical research, anthropology, economics and health policy research. Both qualitative and quantitative research approach is welcomed. Qualitative approach is important for deeper understanding of the phenomena surrounding the unique ICU environment in the wider context and its appropriateness to generate important hypothesis for further research.

Thereby, in the context of lack of local research and knowledge, lack of clear policy, as well as culturally diverse setting with restricted resources it is imperative to tackle different perspectives and gain deeper understanding through qualitative research in order to improve practice and inform medical, ethical and wider public as well as policy makers on the insights from the stakeholders in the end-of-life care.

My approach for that purpose will be to gain deeper understanding through qualitative study with health practitioners and family members of terminally-ill patients who died or had limitation of life-sustaining intervention in the studied intensive care units (ICU). The research design includes in-depth interviews with health practitioners and family members of terminally-ill patients in the studied intensive care unit and participant observation in the ICUs as principle methods.

1.1. Research questions

The overall research questions that guided the research are:

- What end-of-life practices are employed in intensive care centres in Macedonia?
- What are the determinants that influence the decision making of end-of-life practices in the ICU from the perspective of the health professionals and the family members?
- What are the attitudes, beliefs and perceptions of end-of-life situations (practices, decision-making) of health professionals and family members of terminally-ill patients in the ICU and how they influence the decision making process?

2. Methodology and data collection

2.1 Context

Republic of Macedonia is located in the centre of Southern Central Europe. It spreads over 25,713 square kilometres with a population of 2,048,619 in 2008. (16)

The population over 65 years is accounted for 11.4 % of the total population and it is reported to be increasing during the past 10 years. Around 58% of the total population lives in the urban areas. (16).

Majority ethnic groups are Macedonian with 64%; Albanians 25% of the population and 11% belong to the other ethnicity groups (Turks, Roma, Serbs, Bosniaks, Vlachs and others). Main religions are Orthodox Christianity and Islam. (17)

98.7% of the population of 15-24 years of age are literate and the primary and secondary school is legally mandatory.

Republic of Macedonia gained independence from the Socialist Federal Republic of Yugoslavia in 1991. Republic of Macedonia is now parliamentary democracy with aspiration toward affiliations to global alliances like NATO and negotiation on membership with the European Union.

Post-socialist period for Macedonia and the Balkan region in the past 20 years is characterized with economic hardship, as well as regional and internal conflicts (the Bosnia war, the Kosovo crisis in 1999 and the internal conflict in 2001). The impact of the regional instability was most prominent to the processes of international integration and socio-economic development.

According to the World Bank, Macedonia belongs to the group of upper-middle-income economies.(18) Republic of Macedonia nowadays has market oriented economy with estimated GDP per capita of 10,550 Intl \$ (PPP) in 2009. (19)

Total expenditure on health per capita in 2006 was 623 Intl \$ and total expenditure on health as percentage of GDP was 8.2%. (20) There was a decrease of this figure to 7.1% in 2008 (21) as part of the economic reforms for improvement of the unemployment rates and attracting foreign investments.

The health system is universal and health care is available and guaranteed to every citizen as a constitutional right. The health system is mainly financed through system of social health insurance. The obligatory health insurance covers both preventive and curative healthcare. Uninsured citizens are covered by different government programs financed through the state budget. (22)

The most prevalent causes of mortality are the circulatory diseases with 57.3% of the total, with stroke being the major cause of death; cancer is the second with 18.5%

followed by endocrine, nutritive and metabolic diseases (mainly diabetes) with 4.2%. Lung cancer is the leading cause of death in the cancer group. (16) Macedonia has a pattern of morbidity that would be expected of a wealthier, industrial or post-industrial society. This is particularly true for cardiac and cerebrovascular diseases as well as malignancies.

The health system is robust as inherited from the socialist period and the orientation toward universal health system with broad Basic Benefit Package makes it highly expensive. The system is organized in primary, secondary and tertiary level. Reforms in the primary health care lead to privatization of the primary care, financed by the social health insurance fund by a “capitation” rate system. There is also a strategy to improve the healthcare by providing opportunities for private-public partnerships. (11) Also, decentralization is a next step in the health reforms to create opportunity for financial independence and tailored healthcare in the different communities.

There are strategic plans for the next 3 years on national level for improvement of the emergency medical services and the palliative care services that could potentially change the environment of the healthcare for the terminally-ill patients. (11)

2.2.2 Intensive care units

The intensive care services in Macedonia are well established in the secondary and tertiary hospitals throughout the country. On secondary level they function as general intensive care centres. On tertiary level there are general and specialized intensive care units. First of all, the division may be on surgical and medical intensive care unit, then by specialties: neonatal, infectious diseases, cardiology, neurosurgical, palliative care, cardiosurgical etc. All the specialized ICUs are located in the capital Skopje.

Primary function of the surgical intensive care units in this setting is managing surgical patients with intensive monitoring and intensive therapy.

Paediatric, neonatal, cardiovascular, medical, cancer, some neurological conditions are treated elsewhere. Though, frequently it is the case patients with these conditions to be admitted to the general intensive care units, especially the tertiary care ICU.

The tertiary ICU also admits patients from the neighbouring countries for treatment, i.e. Kosovo and Albania.

There is only one specialized neurosurgical ICU in the country. It admits both adults and children.

2.2.3 Terminally-ill patients

Terminally ill patients from any aetiology are treated in the ICUs, whether the condition worsened after unsuccessful intensive treatment or new event or sequence of events after being admitted to the ICU.

Alternatively terminally-ill patients are treated in every level of the healthcare system. General practitioners act on primary level, prescribe medication and refer to higher level of care. Emergency departments provide emergency medical care at home, on the place of the event and provide night shift emergency care. There is a system of domiciliary healthcare in some of the medical centres that provide healthcare to patients in their homes. On secondary level, terminally-ill can be treated in the hospitals: in day clinics, on hospital wards and in the medical or surgical ICUs. Day clinics are more characteristic for oncological patients. There are two pain clinics on tertiary level organized in the tertiary hospitals that provide service for treatment of chronic and acute pain, both located in the capital.

Two hospices are available to terminally-ill in two largest cities predominantly treating cancer patients, end-stage of senile dementia and immobile stroke survivors. Two ICUs for terminally-ill function with 10 beds within the hospices. There is no accredited specialization of palliative care. (23) In all levels physicians of different specialties are responsible of the healthcare.

We placed our study in the intensive care units and their associated emergency departments. Terminally ill patients hereby are defined as “persons with an incurable or irreversible illness at the end stage that will result in death within a short time.”(24) “Terminal condition is a progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. A person has an eventually fatal condition if their death in the foreseeable future would not be a surprise.” (24)

Terminally ill patients from different aetiology can be admitted to an ICU to provide release of some symptoms. Thus, ICUs are becoming centres of palliative care.

According to the definition of WHO “palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (3;24)

It is clear that the terminally ill patients in the ICUs receive some aspects of palliative care, especially relief from pain and other distressing symptoms, while other aspects are neglected: integration of the psychological and spiritual aspects of patient care, a support system to help the family cope during the patient’s illness and in their own bereavement, and counseling.

Though there are anecdotal cases of spiritual counseling or service being allowed upon the wish of the families. (25)

ICU terminally ill patients are often comatose or with otherwise impaired consciousness or/and artificially ventilated. ICU patients usually do not have time to give advanced directives or time to express wish for the treatment at EOL. Families of ICU patients are in the early stages of acceptance of the inevitable outcome of their loved ones: confused, angry or in denial.

These essential differences make the phenomenon of terminally-ill patients in intensive care units unique and justifiably studied separately.

2.2. Study population

2.2.1 Study setting

The study was placed in the surgical intensive care units throughout Macedonia.

The study sites included tertiary care intensive care units and secondary care intensive care unit. The affiliated emergency and trauma centers to the particular ICU were also included.

The qualitative design of the study was not primarily intended to produce generalizable results, thus convenient sample of sites and informants was chosen.

2.2.2. Access to the site/ participants

Access to the study sites was obtained through the “gatekeepers”: current managers and key opinion leaders like the senior academic staff and senior professional staff.

Health professionals were contacted directly by the investigator. The investigator was in close contact to the health professionals while observing at the study sites, thus had the opportunity to contact eligible candidates.

Access to the participants from the family members was obtained through the attending physician and/or nurse and while observing at the study sites.

2.2.3. Relationship between the investigator and the research participant

The researcher was an observer on the study sites.

The researcher did not have any role in the treatment and/or decision-making in the EOL practices.

The relationship with the informants from the health professionals is on teacher-student relationship with senior staff, on peer to peer relationship with other residents and co-worker with other staff.

2.2.4 Study period

Study period was April, 2010 to August 2010. The data collection period was from April to July 2010.

2.3 Informants

2.3.1 Health professionals

Eligible informants from the health professionals were all critical care specialists who were permanently employed at an ICU during the study period; all surgeons attending patients in intensive care during the study period; nursing staff permanently employed at an ICU during the study period; residents on intensive care training. Specialists that work only on on-call basis (or attend night shifts) at the sites were excluded.

All the potential informants had experience with at least one terminally ill patient prior to the study period.

In-depth semi-structured interviews and/ or informal conversations or group interviews were performed with this group of informants.

Health professionals were asked for the duration of their working experience in ICU and their religious and ethnic background.

2.3.2 Family members/ patient caregivers

Family members/ caregivers of all adult patients admitted to the ICU who died or had any limitation of life-sustaining interventions in the ICU, which gave informed consent were potential informants.

A family is defined as those who are “closest to the patient in knowledge, care and affection. The family may include the biological family, the family of acquisition (related by marriage/ contract), and the family of choice and friends.”(24)

Other inclusion criteria were the terminally-ill patient to have been citizen of Macedonia and beneficiary of the public health system. Family members/ caregivers of terminally-ill patients who received extra care (which is a system of self-financing care with specific benefits over the standard care) were not eligible for inclusion. Family members/ caregivers were asked about their cultural background, ethnicity and religion for further analysis.

In-depth interviews were performed using topic guide on themes like: experience with their loved ones during EOL, attitudes toward EOL, perceptions, beliefs and recommendations.

2.4 Methodology

A qualitative methodology with phenomenological approach was used to design the study. Further in the text the justification of this approach for the study is exposed.

2.4.1 Why qualitative methodology?

Literature data suggest strong difference between countries and between different centers and health professionals in EOL practices, attitudes and experiences. (8)

Qualitative methodology provides opportunity for deeper understanding and contextual interpretation that would help unmask the phenomenon of terminally ill patients and explain the differences in practices.(26)

This marginalized problem in the intensive care and its complexity with determinants on social, cultural and individual level is motivating the choice and justifies the methodology.

“Phenomenology is based on the paradigm that reality is multiple and socially constructed through the interaction of individuals who use symbols to interpret each other and assign meaning to perceptions and experiences.”(27)

The research questions are placed in the specific context and specific population thus justifying qualitative methodology once again.

This research is not intended to find the absolute truth, but to provide different perspective to the phenomenon of EOL, at this point of time and the specifics of the Macedonian context of the terminally-ill patients in ICU setting.

The qualitative research is not created on the previous theoretical assumptions a priori but instead participants lead the questions and direct the research.

2.4.2 Sampling

The sampling of study sites was purposeful to obtain large number of eligible informants and observation opportunities in a short period. The study sites were selected to obtain a sample that is ethnically and culturally diverse. The sites were chosen to obtain diversity and opportunity to identify potential factors in the care of terminally ill patients.

Sampling of informants was purposeful to allow diversity in cultural, religious and working experience among the informants. All eligible informants were invited to participate in the study by the investigator.

Sample of informants was sufficient when ‘saturation’ was reached. Saturation was reached when no new themes, stories, issues and topics were derived from the preliminary analysis of the gathered data from all the sources and different groups of informants.(28)

Table 1 outlines the study’s modes of data collection, participants and study sessions.

Table 1 Data collection table

Method	Description of participant	No of participants	No of sessions
Observation – patient case studies	Terminal patients in the ICU	13	13
Observation and participant observation – Family conferences	Within the ICU and telephone calls	5	5
Participant observation - Ward rounds	Senior and junior medical personnel Nursing staff	24	45
Interviews, group interviews	Senior and junior medical	14	22

and informal conversations with critical care specialist	personnel Nursing staff		
Interviews with family members	Family members	4	4

2.4.3 Methods

2.4.3.1 Documents research

Research of documents consisted of search of official documents of public character and press releases from the government authorities concerning the research topic, i.e. national strategies, program/project evaluation reports, reports on monitoring of health indicators, official demographic data, etc. Published paper and media articles, broadcasted panel discussions etc. were also searched. The aim was to gather public opinions on the research subject and expert opinions as well.

- Online search engines: Google
- Manual search of books and theses in libraries (University libraries, National and university library, library at the Institute of ethnology and anthropology, University Ss. Cyril and Methodius).
- Personal requests to broadcasting companies.

Key words: End-of-Life, Terminal Care, Life Support Care, Resuscitation Orders, Withholding Treatment, Withdrawing Treatment, Advance Care Planning, Family, Caregiver, Intensive Care Unit, Qualitative Research, Attitudes, Practices, Culture, Religion (together with the same terms in Macedonian, Serbian and Croatian).

2.4.3.2 Participant observation

The participant observation took place at three intensive care settings, in the period of 14 April to 1 July 2010. For observation sessions and mode of data collection, see Table 1.

The researcher was engaged at the daily routine with a role of a resident (an anaesthesiologist in training) in the intensive care units.

To answer some of the research question, the researcher participated during rounds, staff conferences, daily routines, during the communication between the family members and the medical team to obtain information on practices, attitudes and experiences and decision-making of EOL.

EOL as defined above and the role of the specific conditions in the ICU setting and the broader social and cultural surroundings of the terminally-ill patient is the phenomenon subject to participant observation.

The observation of the applied medical care at EOL and the criteria for declaring terminal condition to the patient was noted as reported by the attending physician.

Structured observation accompanied with illustrative narratives to complement the structured observation for richness and depth of the observation was used as a method.

During the observation, the investigator observed the studied phenomenon with its characteristics: physical environment of the phenomenon; involved participants; duration and frequency; processes; objects; individual activities of the participants and interaction; events; emotions that are expressed by the participants and subtle factors, such as connotative meaning of words and non-verbal communication (28).

The observer recorded feelings and impressions about the situation as well.

Preliminary interpretations and ideas for analysis were recorded in the research journal and the field notes form.

Observation notes were recorded manually in research journal (descriptions and accounts of people, events, behaviour, conversation), kept by the investigator. The recordings were organised by time and kept in chronological order.

Field-notes form (Annex III) was used for structured recording of observation in extent. The field notes were transferred to the field notes form no later than a day to reduce memory bias. Both the actual field notes and the full transcription were kept for further use.

The field notes form contained sections: 1. General information of the informants (if the observation is during in-depth interview) or general information of research site/ patient/ process etc. 2. Short summary of field notes; 3. Field notes incl. first contact, situations, feelings, body language, etc 4. Reflexivity 5. Preliminary analysis and interpretation.

2.4.3.3 In-depth interview

In-depth interviews aim to explore deep beneath the surface of answers to obtain true meaning that individuals assign to events and the complexities of their attitudes, behaviour and experiences. This method allows informants to tell their stories in their own words.(28)

The questions were prepared to reflect the basic research questions and to allow freedom in the width and breadth of the answer to the informant.

Open-ended questions were strengthened by using hypothetical scenario-based questions to interrogate some attitudes, as well as probing and contrasting questions to facilitate the flow of the interview.

In-depth semi-structured interviews were performed with the **critical care specialists**.

The interviews were conducted on themes (Annex I): terminally-ill patients in the study site, EOL practices, decision-making at EOL, what influences the decision at EOL, general attitudes toward EOL, perception of EOL issues, beliefs about EOL, recommendations for EOL practices.

The interviews were conducted in the hospital or other place requested by the informant.

Family members or caregivers were interviewed by the investigator.

The interviews were performed on the convenience of the informants at their home or in a private space in the hospital.

The semi-structured interview was guided by topic guide on themes (Annex II): EOL experience of their loved ones, decision-making process, sources of support / other coping mechanisms during EOL experience, patient's position on the matter (perception, feelings, attitudes), perception on the medical care of their relative, perception of their role during treatment of the patient, personal and general attitudes toward EOL, broader cultural aspects of EOL (role of religion and ethnicity), beliefs and/or knowledge of EOL and decision-making and expectations of the medical team / medical system/ other facilities.

Informants were appropriately informed about the research and were asked formally to consent to the interview.

For the mode of data collection, see Table 1.

2.4.3.4 Group interviews and informal conversations

Informants during the observation period on the observation sites from both groups were asked about their opinion and questions to answer some of the research questions.

Their consent to be included in the research was obtained prior and after the group interview and/or conversation.

This method was particularly important to gain broader and richer data on attitudes toward and EOL experiences.

2.4.4. Data analysis

The interviews were audio-recorded by Voice Memo application in iPhone 3.0, transferred to PC in “.m4a” format, and saved under coded names and consequently transcribed using f4 - Version 4.0 beta (for Windows) transcription tool software. The transcripts were saved in “.rtf” format. The documents were saved under the same coded names. Codes were created using codes for the method used, code for the group of informant and consecutive number of the informant. (Annex IV)

The field notes from the observations and the informal conversation were also transferred in “.rtf” format to be used in the analysis.

The broadcasted panel discussion on the topic was also transcribed in the same manner as the other sources of data. Reports and public announcements from health authorities, expert statements, and published articles were also run through analysis.

The transcription was conducted in the native language, Macedonian being the only language used to communicate with informants.

Preliminary analysis of the transcripts was conducted throughout the data collection period to allow interview questions to be refined and new avenues of inquiry to develop.

The analysis approach was descriptive and interpretive.

The analysis was mainly comprised of inductive text analysis to identify themes, generate categories and explanations. The themes were coded using mainly open

coding. Atlas.ti 5.0 software for computer assisted qualitative analysis was used to facilitate data analysis.

Simple counts were used to summarize some informant characteristics and EOL practices. The measures of frequency were rather descriptive than numeric.

Direct quotes or narratives from informants were translated in the final report by the investigator and used to enrich the findings and the explanation.^b

2.4.5 Trustworthiness

The emerging themes and categories were cross checked by constant comparison to the data obtained from different sources (individual interviews, observational field notes) or triangulation.

Themes from single informant were not used as a result.

Answers of one informant were checked for consistency by asking in a different way the same question to the informant.

Validity was ensured by avoiding leading question and use of open-ended questions.

2.4.5.1. Potential biases, reflexivity and limitations

Researching sensitive topic was identified as a problem during the recruitment.

The difficulty of gaining access, mainly because of the limited time to contact family members was a reason for a smaller sample of family members, bringing limitations to the study.

^b When citing sources in the text from the research material, the codes for certain informant/ observation etc is used to relate to the explanation given. The code formation system is given in Annex IV, while quotes referring to the text are presented in Annex V or immediately in the text body.

Informants from the family members, who met the researcher during the observation period, may have expressed “social desirability” during the interview because the researcher may have been perceived as part of the medical team of their loved one.

The legal and ethical issues that surround the end-of-life phenomenon in the practice of critical care may have lead to faulty statements. Social and cultural determinants may have influenced family members to fabricate socially desirable answers, consistent with the ideal model of behaviour rather than the actual behaviour.

As with any qualitative study, the obtained results can infer mostly to the studied population. So, the generalizability of the study is limited to the study population and the study setting.

The researcher is an anaesthesiologist in training so some of the observations and interpretations may be filtered through the lens of member of staff of those ICUs. The lower status as a resident in the hierarchy of the positions in the ICU, might have influenced the accessibility to some of the information during rounds, staff meetings etc. It might have influenced the willingness of the participants to disclose all the information they otherwise might to a peer.

The young age is usually perceived as “inexperience” in the cultural context, so the youth and professional inexperience might have influenced the gathered information.

The medical profession of the researcher might have discouraged the family members to talk about cultural and religious beliefs surrounding End-of-Life.

The status of European student of the researcher might have encouraged perception of “westernized” attitudes toward healthcare and influenced the observed behaviours as well as the answers to research topics. The researcher exposure to European international health education might have influenced the research and the interpretations of the results.

The origin from the majority ethnic group in Macedonia may reflect in the collection and interpretation of the data as well.

The perceived Christian confession of all Macedonians by the Muslim informants may lead to conclusion that some religious determinants of decision making should not be disclosed because of the possibility of misunderstanding or of nature that cannot be easily explained to different religion.

Triangulating of the results with more methods was intended to overcome this limitation.

2.5 Ethics

The ethical principals will be applied throughout the study; confidentiality of the collected data and anonymity of the informants will be assured.

There are no local ethical guidelines that are provided for the researchers, thus the Ethical Guidelines for Good Research Practice issued by the Association of Social Anthropologists of the UK and the Commonwealth (29) and the Code of Ethics of the American Anthropological Association (30) were followed throughout the study.

Written informed consents were acquired from the informants prior to the interview and observation.

Participants were assured that efforts will be made to render transcribed interviews anonymous. Codes were used to mask the identity of the informant. The code is alphanumeric and consists of letter for method, a number for informant group and a number for consecutive informant.

The audio-material and transcripts are held in directory locked with password on the computer of the researcher and on a backup hard disk. The audio-recorded interviews will be destroyed after 6 months of the interview.

No identity information will be displayed during the analysis and in the final reports.

The confidentiality will be guaranteed by the researchers. Nobody except from the researchers will have access to the content of the interview.

Financial incentives were not provided to the informants.

The potential risks relevant to the participants from the family group are identified as anxiety and distress; confusion of the research process with a therapeutic encounter for the family members; and misrepresentation.

The risks were addressed by researcher being clear about the boundaries of the research; by treating informed consent as a process; by being explicit about and reflexive toward their professional backgrounds; and by ensuring that the researchers are adequately trained and supervised.

If cases of distress and anxiety emerged, the investigator was responsible to refer the participant for appropriate care.

Participants were guaranteed that there would be no consequences for their future medical care or job if they decided not to participate in the study.

There are no obligatory regulations for ethical approval in cases of qualitative research locally, in Macedonia. Qualitative research projects, especially ethnographic research are locally conducted and published using globally accepted guidelines and on the principles of good research practice. (31)

Since the research does not engage research with pharmacological and/or behavioral interventions on humans, human biological samples, then it is not necessary to seek approval from the Medical Ethical Committee at the Medical Faculty Skopje.

Since we acknowledge the importance of ethical conduct of qualitative research, this study will be conducted according to the global guidelines for ethical conduct of research and validating the researcher adequate training through the Programme for European Master of International Health, the tropEd network.

3. Results

The results are presented as categories or themes derived from the data collected through the research methods with informants, observer and from documents and panel discussion.

3.1. Informants

It has been found relevant to report some of the characteristics of the informant that potentially influenced the results. It is a small group and the sampling was not probabilistic to draw on conclusion about potential factors, but nonetheless it is important to report whose opinion this study represents. For the group of the physicians, it is the age, gender, the years of working experience, specialty and the ethnicity and religion. The family group characteristics that were collected are age, ethnicity, religion and relation to the deceased. The period of time past the death of their relative is noted as well.

See Table 2 for the characteristics of the informants.

Table 2 Baseline data of informants

Medical professionals	Sub-sample (n=14)	Family members	Sub-sample (n=4)
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Mean age (SD; range), years	44 (11; 30-60)
Gender	Female 11 Male 3
Specialty	Anesthesiology and reanimation specialist 8 Anaesthesiology and reanimation resident 4 Surgeon specialist 1 Nurse 1
Years of working experience in the field	Over 10 years 9 Under 10 years 5
Ethnicity	Macedonian 14
Religion	Orthodox Christianity 14

Mean age (SD, range), years	40 (13; 31-58)
Gender	Female 2 Male 2
Relation to the deceased family member	Son 1 Daughter 1 Wife 1 Son 1
Time past the death of their relative	Over 6 months 3 Under 6 months 1
Ethnicity	Macedonian 3 Albanian 1
Religion	Orthodox Christianity 3 (2 practicing, 1 not practicing) Islam 1

Cause of terminal illness of the loved one	Cancer	2
	End-stage heart failure	1
	Subarachnoidal haemorrhage	1

3.2. Centres for treatment of terminally-ill patients

Primary function of the studied intensive care units in this setting is managing adult and children surgical patients with intensive monitoring and intensive therapy.

Though neonatal, cardiovascular, medical, cancer, some neurological conditions are treated elsewhere, patients with these conditions were frequently admitted to the general intensive care units, especially the tertiary care ICU.

The tertiary ICUs also admit patients from the neighbouring Kosovo and Albania for treatment. (I.1.1)

The study sites involve a total of 35 ICU beds, equipped appropriately for intensive care and monitoring.

The sites collaborate closely with other tertiary and secondary care surgery and medical hospitals. They are also associated to major trauma centres, nationwide.

(I.1.1, I.1.2)

There are intensive care centres in the private hospitals managing postoperative surgical patients. (I.1.2)

All of these centres manage terminally ill patients. Though the study is situated in the intensive care setting, the field findings suggested exploring the setting of the emergency trauma centres as well, as an important site for management of terminal patients. (O.X.4)

Observations revealed that intensive care specialists working at the study sites are the attending specialists of anaesthesiology and intensive medicine, surgeons, and residents in both specialties. Both specialty physicians have decision-making power. Nurses, physiotherapists, psychologists and other medical professionals do not decide on the treatment of the terminally-ill patients.

Psychologists and social workers are not available at the public ICU nor there is a system in place for referral of patient to psychological and social consult if needed. (O.X.1, O.X.2, O.X.3, O.X.4).

Ethical committees on hospital level have been formed to assist in ethical issues in the ICU, consisted of specialty doctors from the hospital. (O.X.1, O.X.2) There was no observation of their activity during the research period.

Additionally, there are offices for protection of the patient rights in the hospitals with advisers to consult for their rights or report violation of their rights. (O.X.1, O.X.3)

3.3. Types of terminally-ill patients in the ICU; Criteria for declaring a terminal condition; Labelling of terminal condition

By the definition of the professionals for palliative care, terminally- ill patients are defined as “persons with an incurable or irreversible illness at the end stage that will result in death within a short time.”(24) and “terminal condition is a progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. A person has an eventually fatal condition if their death in the foreseeable future would not be a surprise.”(24)

During the observation, it was identified that terminally ill patients from any aetiology are treated in the ICUs. Both children and adults were treated at the study sites. (O.X.1, O.X.2, O.X.3, O.X.4)

Case studies of patients revealed patients with multi-organ failure, acute pancreatitis, end-stage cancer, end-stage heart failure, polytrauma, post-traumatic respiratory failure, renal failure, head trauma, cerebral haemorrhage and some rare diseases to be the most frequent diagnosis of terminally-ill patients. (O.X.1, O.X.2, O.X.3)

But, it is important to enclose the definitions provided by the participants of this study since it seems there is a meaningful difference.

The perception of terminal illness is important to emphasise because the opinion that terminally ill patients are very strictly defined group of patients is wide spread. It is perceived that end stage cancer patients and patients in unresponsive coma (even in persistent vegetative state) to be the “true” terminally ill patients. “There are no ‘such terminal patients’ in our ICU” (I.1.2). “We absolutely don’t declare anyone ‘terminal’” (I.1.2)

ICU patients are usually comatose, artificially ventilated or with otherwise impaired consciousness, “with circulatory instability, those that require resuscitation and post-resuscitation condition” (I.1.1) “Dominantly, patients who are terminally ill, have suffered head trauma, that means their brain had suffered. Rarely, we have had opportunity to see patients with different diagnosis, cancer in advanced stage or some degenerative disease like multiple sclerosis or myasthenia gravis, when they become ventilator-dependant” (I.1.1).

Terminally ill patients in the studied ICU are admitted to alleviate symptoms, such as pain and difficulty in breathing (O.X.1, O.X.2, O.X.4, TV.E.1). Sometimes emergency rooms provide care as a day clinic with anesthesiologist in charge. The

medical care provided usually consists of hydration, pain control and artificial nutrition. (O.X.4)

Alternately, terminally ill patients are dying patients being transferred from the wards. This is explained by the “lack of equipment and staff of the surgical wards to handle such patients, as well as lack of consensus for the treatment of such patients and they are transferred to the ICU in desperation”. (O.X.1) “The patients are declared terminal and transferred to die at the intensive care.” (I.1.3)

Labeling patient as ‘terminally-ill’ or ‘terminal condition’ is extremely rare. The terminology for terminally ill patient and terminal condition among the medical staff is various, from “the condition is bad” (I.1.1), “no improvement in the condition” (IFI.1.3), his/her “condition has worsened” , when a patient “goes to worse” (IFI.1.3), “no change” in the condition (O.X.1), “very difficult condition” (O.X.1), the situation is “critical” (O.X.1), “deadly sick” (TV.X.2, TV.X.3).

This labeling is used in communication between medical staff and between medical staff and the patient family.

The connotative meaning of declaring someone terminal is specially pronounced by the attention that is given to those patients by the staff. During morning conferences and especially rounds, physicians either skip those patients, or report “The condition of that patient is not changed” (O.X.1, O.X.2, O.X.3) or the condition of the patient is “very bad”. “When there is scarcity of space for the critical patients, the terminally-ill patients, as a triage, are neglected, that is, if they breathe sufficiently on their own, instead of oxygen, they are left to breathe atmospheric air, if oxygen supply is not available. It is rare to have a terminally-ill patient monitored if there is shortage of monitors, or the nurse decides it is not necessary to monitor a terminally-ill patient. When the ICU is overcrowded, terminally-ill patients are placed in the space between

other two ICU beds.” (O.X.1)

Accordingly, terminal condition and the appropriate treatment are not registered in the medical documentation. (O.X.1, O.X.2, O.X.3, O.X.4)

There is a general feeling of discomfort together with serious concern when the topic on terminally-ill patients is being opened. (IFI.1.1, IFI.1.3, IFI 1.5) Some of the informants also emphasize the importance to open up the topic on terminally-ill patients, as sole factor for improvement of care in the ICU (IFI.1.5, IFI 1.6). In few cases (O.X.1, IFI.1.1, IFI.1.10, IFI.1.11) the standpoint of the researcher was perceived as pro euthanasia in terminally-ill patients, which generated negative response to take part in the study or ‘socially-desirable’ answers when exploring the attitudes (IFI.1.10).

Terminal condition is established usually when a patient is suffering from documented untreatable fatal disease or when the critical patient is refractory to the intensive therapy. The latter being reported more often than the former. (O.X.1, O.X.2, O.X.4, I.1.1, IFI.1.9)

3. 4. End-of-life practices; Medical interventions at EOL

The EOL practice in the ICU in this study is joint label for the practices of withholding or withdrawal of intensive treatment in terminally ill patients where any treatment would be futile. The actual practices were registered while observing as reported by the physician.

Medical procedures of the terminally-ill patients encompass treatment from laboratory tests, surgery, intensive supportive therapy (inotropic support, ventilator support, substitution of fluids and electrolytes, blood and blood derivatives, artificial nutrition, etc) (I.1.1, I.1.2, IFI.1.1, I.1.3, O.X.1, O.X.2, O.X.3) to mild supportive therapy for

comfort and alleviation of distressing symptoms. (I.1.1; TV.X.1, IFI.1.1) “Usually, even if all of those patients are declared ‘terminal’, some times even for months, certain procedures are undertaken for the whole time, they have never been forgotten” (I.1.1). “We don’t give anything, only sedation and analgesia since we don’t know in the terminal stage if and how much they [the terminally-ill patients] had perception of pain, if they had some level of consciousness; they are not allowed to fight the machine [ventilator], we do not let the machines to alarm; so, they need to be stable, only we don’t do procedures of any kind, we don’t take blood for tests, we don’t substitute electrolytes, since we know what to expect from the tests, we don’t give antibiotics, no nutrition... that’s it” (I.1.1). “He was getting analgesia just as required when he was aspirated, just for comfort” (I.1.1)

The criteria and influences to decide what practices are employed when are discussed further in the text.

During the first contact or if directly asked ‘If they [the physicians or the institution] practiced withholding or withdrawal of medical treatment in terminally-ill patients’, they would negate, or would answer that the patients in the ICU are given medical treatment until the very end. But, when observing a concrete case or during a story telling they would identify practices as withholding and withdrawal of intensive treatment in terminally-ill patients. “If you ask me if we ‘pulled the plug’ in some patients, I will tell you right now, we never ‘pull the plug’ until the last moment” (IFI.1.1); “We don’t declare anyone ‘terminal’ and which is very different [from other centers], we don’t give up on anyone.” (I.1.2); “If [the terminally-ill patient] requires resuscitation, independent to anything, we will resuscitate” (I.1.1).

3.4.1. “Not to resuscitate”

Withholding treatment in the study sites usually means “not to resuscitate” orders (I.1.1; O.X.1, O.X.4), “More acceptable solution for patient with initial diagnosis of inoperable, irreversible condition is not to introduce mechanical ventilation or not to resuscitate after such diagnosis, though some therapy is given” (O.X.1). “We confirmed coma [in the patient], wide pupils in both eyes, estimated Glasgow coma scale of 3, and decided not to resuscitate on the place of first contact with the patient.” (O.X.4).

If the patients had established fatal diagnosis prior to the contact with the responsible critical care specialist, they usually do not receive treatment as resuscitation or aggressive intensive therapy, such as mechanical ventilation. (I.1.3; O.X.4; IFI.1.8) “The anesthesiologist takes over the patient [with end stage renal failure due to end stage cancer], monitors his condition, and decides not to resuscitate” (O.X.4). “I decided not to intubate at the moment, since it’s not logical, the patient is in end-stage of the disease.” (IFI.1.8)

3.4.2. “Taking the patient at home to die” or discontinuation of treatment

Withholding treatment is more accustomed practice than withdrawal of treatment. “Therapy is never discontinued; patients are never discontinued from mechanical ventilation once they are introduced. If the patients required resuscitation, they would be resuscitated, unless clearly approved not to resuscitate by a responsible person (senior anesthesiologist at the ICU)” (O.X.1)

There is no observed practice to withdraw treatment at the hospital while the patient is hospitalized at the ICU. There are few practices that could be categorized in this practice.

First, if one patient is confirmed to be in a terminal condition and decided that any treatment would be futile, there is a practice when physician or team of physicians ask if the family wanted to have their loved one taken to their home to die. (O.X.1, O.X.2, I.1.1, IFI.1.1) This suggestion sometimes originates from the family, but more often, it is a suggestion from the medical team. “It was a suggestion, because it was a case of 3 year old child, to explain to the family, to tell them in what condition the girl is, and it is their decision either to take her or to wait for her to die at the hospital”. (I.1.1) The patient would be discontinued of any therapy at the moment of transport if the family decides on this procedure. This practice is favorable; it is considered that “families help” physicians at their decisions for the treatment of terminally ill patients. (IFI.1.1)

3.5. What influences the end-of-life practices?

It is noticeable that there are differences among cases and among physicians in the approach to management of terminal condition. There are numerous factors that have been identified by the informants and the observer influencing the decision making.

The emerged themes from the interviews and field notes were further classified in categories of identified influences to decision-making: the underlying medical condition; certain characteristics of the patient; certain characteristics of the decision-maker, socioeconomic factors, cultural beliefs about EOL, attitudes toward EOL and legal factors. The categories and themes representing what influences the EOL practice are summarized further in the text. Selected quotes from the themes illustrative of what influences the EOL practice, are presented in Annex V.

Characteristics of the underlying medical condition

- **How the underlying medical condition (acute vs. chronic disease)**

influences the decisions

“We always begin with how the patient got to the intensive care, the underlying cause, the primary diagnosis, and if the patient was previously healthy, in that patient, even when you know the diagnosis and the prognosis, all measures are being performed, everything that needs to be done, is done, like diagnostics and procedures... we know the prognosis is bad, but the period to declare that patient terminal is postponed and the period of active treatment in intensive care is prolonged. In those patients that came to surgery in late stage, and the surgery was done because it was necessary and they are now ‘stuck’ in intensive care unit, the treatment period and mechanical ventilation is shortened and that period is the shortest for patient that presented already in terminal state ... “ (I.1.1)

➤ The expected quality of life after intervention

“It is more often to decide to withhold resuscitation or invasive intensive therapy in oncological patients and neurosurgical with irreversible brain damage that would lead to persistent vegetative state” (O.X.1)

Characteristics of the terminally-ill patient

➤ Age of the terminally-ill patient

“We take into account some characteristics. If the patient is young we assume that the other organs are healthy and that this is the first time that these patients have suffered a disease or trauma and we perform, out of mercy, out of desperation all the measures. ...On the other hand, if we had a patient 80 or 85 years old and he was found the same condition, there is no need, we wouldn’t perform anything, he already has 85, what else could we do.” (I.1.1)

➤ The educational level of the patient

“I heard one doctor saying: The patient could not be informed and consent because they were not medically educated, they wouldn’t understand the situation. This is nonsense. What if I [the doctor] was the patient?” (IFI.1.5)

Certain characteristics of the decision-maker

➤ Educational level of the decision-maker

“He was appointed as a contact person, he was chosen because he was literate, since the others [the family] are illiterate, everyone with no formal education, everyone illiterate, coming from rural area...” (I.1.1)

➤ Socioeconomic status of the decision-maker

“Sometimes we have more understanding with the families of patients from the Albanian nationality and lower educational status... these intellectuals... here we have a patient who suffered stroke and his son instead of taking him [the patient] home to provide him care, physical therapy, to provide him care, he leaves him here in the hospital, to ‘open’ pressure ulcers, to ‘rotten’ in the hospital, we don’t have anything more to do to him...” (IFI.1.1)

➤ Age of the decision-maker

“I read somewhere that young people venture more in these behaviours. I would like to say that man discovers this world [with age], then he looks at it more realistically, takes more realistic attitude toward it. What is happening in the treatment of death and everything that happens around death, by the young population, is far from real. Especially nowadays children are being kept away, they are not taken to funerals, they are kept away from hospitals, not to be acquainted with those events; we can see that it is more of abstract nature that these behaviours are being accepted.” (TV.X.3)

➤ Working experience of the decision-maker (applies to physicians)

“I can see that older [experienced] doctors find it easy to do that [withdraw a patient from therapy], while younger, I can see, disagree, they refuse to do it.” (IFI.1.4)

Social and socioeconomic factors

➤ **Economic factors**

“And why do they react that way [not give up on any patient], because they are private sector, they want to show...? I.1.2: No, I can't say because they are private, it is just copied practice from another institution, another system, those [treatment of terminally-ill patients] carry financial burden, but I don't think... I can't even assume how much it costs, every hospital day and such treatment, changing filters for this and that...” (I.1.2)

“She [the patient] said I don't want to go to Vienna to be treated, to spend your [the family's] money and your [family's] time and health and money and exhaust everyone” (I.2.1)

➤ **Social surrounding of a dying person**

“The patient daughter could not come visit her father since she had to take care of her blind and debilitated mother” (O.X.1)

Cultural factors

➤ **Beliefs**

“We don't have practice to withdraw therapy or to withdraw nutrition or care in comatose patients. There are cases, you can ask [doctor's name], he knows who those patients are, who woke up from coma after 10 years” (IFI.1.6)

➤ **Attitudes toward end-of-life practices**

More attitudes identified and quotes illustrating how they influence the EOL practice, see Annex V. Some representative quotes are given further in the text.

“They don't give up on anyone, as futile the treatment seems, everything is done until

the last”. (I.1.2)

“We wanted to have the surgery since going directly to chemotherapy seemed somehow hopeless” (I.2.1).

“After the physical examination, I realized that the whole neck was infiltrated en bloc with the cancer, but I had to help. The family tells you: ‘You got to save the patient’, and I believe as a doctor that you must do everything. As a miracle, the patient was successfully resuscitated with one adrenalin. If I don’t give the treatment that is passive euthanasia”. (IFI.1.3)

➤ **Beliefs about spirituality at EOL and spirituality**

“One other patient, asked to be allowed to make a confession to a priest and he got relieved, he reached peace until the death, he didn’t suffered pain anymore, he didn’t complain on other symptoms as well.” (IFI.1.6)

“ She was upset, but said: Son, whatever happens, do not worry, I, my mission, I clearly remember when we were going to..., I accomplished my mission in this world, you and your sister have become wonderful people, that was my task in this world, from now on, as much as God gives...I am sorry that I have brought trouble to you and that I can’t enjoy with you, but you should know not to be sorry for what is happening to me. “ (I.2.1)

➤ **Cultural habits**

“I wasn’t allowed to remove the tube, they wouldn’t allow me to touch anything around her, together with the hospital bed, the uncle, the one that made all the customs around her... said not to touch her until he said so.” (I.1.1)

➤ **Perception of the needs of dying person**

- **Being close to the family and the family involvement in the care** (I.1.1, IFI.1.7, IFI.1.3, O.X.1, I.2.1, IFI.2.1, IFI.2.2)

- **Pain free, relief of disturbing symptoms and nursing** (I.1.1, I.1.2, IFI.1.1,IFI.1.8, IFI.1.11, O.X.1, O.X.2, O.X.3, I.2.1, IFI.2.1)
- **Allow spirituality** (IFI.1.6, I.1.1)
- **Dignity** (I.2.1, IFI.2.1)
- **Control over the EOL care** (I.2.1, IFI.2.1, IFI.2.2)

After the analysis of the interviews transcripts and field notes from the observations, we can deduct that physicians place higher importance to the first three needs, while families stress the importance to be pain free and symptom free as much as having dignity in the ‘last days’ and having control of the care. No physician acknowledged having control over the care in the patient hands as an important need.

Regulation

➤ Laws and regulations

“All these [EOL procedures] are oral protocols, everything is orally agreed, because we don’t have written protocols, medical protocols, and the Law does not allow euthanasia” (I.1.1)

➤ Ethical issues

“When there is no space for critical patients at the moment, terminal patients are neglected as a triage” (O.X.1)

3.6. Decision-making process

3.6.1. Who is deciding?

During observation and as a question in the interviews, the decision-making process was monitored and noted, including the patients’ and/or family’s involvement in the

decision process.

In cases of emergency, it is the residents that are usually responsible for the decisions on the behalf of the patient's welfare. (I.1.1; O.X.4; O.X.3, I.1.3; IFI.1.2)

In cases of 'Do not resuscitate' and withholding of treatment in chronic condition or in case of planned medical intervention, it is the responsibility of the medical team of senior physicians to decide after reaching consensus and then instruct these directives. (O.X.2; O.X.4; I.1.2; I.1.1)

We can conclude that there is no involvement of the family and the competent or incompetent patient in cases of emergency ('to resuscitate or not to resuscitate'), i.e. physicians decide, either independently or in certain cases as a team of more than one physician. (I.1.1; O.X.4; O.X.3)

Families were minimally involved in the decision-making for the treatment of terminally-ill patients as observed or reported in the interviews. There was no information or reporting of involvement of the dying patient in the decision-making process for treatment in case of terminal illness.

Family involvement is noted in the practice of withdrawal of treatment and taking the patient to die at home. (O.X.1; I.1.1; IFI.1.1; IFI.1.9). Another reported involvement of the family is the insisting on medical treatment in terminally ill patients despite the futility of the treatment; and dying at the hospital of patients with end-stage disease. (IFI.1.3; I.1.1; IFI.1.1)

The involvement of the family in the decision process was differently reported by the families. According to the data gathered from the interviews with the families, it is indicative that families are more involved prior to their point of meeting with certain physician or institution. Families seek opinions and consult until their satisfaction is reached. "We wanted to have the surgery since going directly to chemotherapy

seemed somehow hopeless” (I.2.1). “When we saw there was no change in his [the patient’s] condition, we decided to transfer him in another hospital [private hospital]” (IFI.2.1). The patients, if competent, are also included in the decision-making process together with the family and the most satisfying solution is considered. “We wanted to take her [the patient] to Vienna. She [the patient] said I don’t want to go to Vienna to be treated, to spend your [the family’s] money and your [family’s] time and health and money and exhaust everyone, I trust the [doctor’s name], she [the patient] trusted them, which is true, and she trusted [another doctor’s name], I think they gave her hope and she trusted me and my sister. She knew that we will do everything that can be done here and do it the best way”. (I.2.1)

3.6.2. Attitudes toward decision-making at end-of-life

If asked directly “What they [informants] felt about involvement of the patient and families in the decision making process”, informants would answer that patients and families have the right to be involved. (I.1.1, TV.X.2). But, the level of involvement is perceived differently between the informants and the Patient Rights Law (10).

No physician would have talked about the involvement of the patient or the family in the process of decision making, if not asked directly. In some cases, the decision-making was even perceived as if asked about decision-making involving family in the context of euthanasia. (IFI.1.11; IFI.1.10).

Physicians also perceived the involvement of the patients and families as insufficient. “[The families] mostly criticize, but constructive suggestions or to express a personal wish regarding the patient is very rare”. (I.1.1) [Patients]” should have options, while competent, with clear conscious and complete moral obligation, to sign a document, or some sort of a card, and to acknowledge that in that situation they will not be

resuscitated and nobody will suffer legal consequences for that action, we don't have that". (I.1.1)

Analyzing the interviews with the physicians we can draw an attitude toward involvement of patient and families in the decisions on end-of-life issues: physicians do not strongly stress the importance of involvement of the patient or the family in the decision making process for the treatment of terminal condition. "They [the family] are passive participants; they wait on the information from the doctor; that is their side. They leave the matter in the hands of the hospital and when they know that the outcome is going to be bad, they expect the worst [the death] to be announced, yet they leave it up to the doctors, they leave the patients in the hospital, to be treated, they [the doctors] treat him/her, they [the doctors] decide for the patient, they [the doctors] inform them [the family] about the patient" (I.1.1) " You can not ask the family about that. Of course they [the family] would say to do everything, to save the patient." (I.1.3). "The families leave him [the patient] with the belief that everything will be done and everything will be done, for the truth sake...they [the families] trust the hospital, they believe greatly [in the hospital], even when the things go down..." (I.1.2).

In cases of incompetent patients, who are not able to decide for themselves, family is considered a suitable surrogate for decision-making on the behalf of the patient by the medical professionals (IFI.1.6, I.1.1, I.2.1). Families on the other hand, in often cases, take over the control in the decision-making process. This is common even if the patient is competent to decide for their own best interest. (I.2.1, IFI.2.1, IFI.2.2).

The wish of the patients is usually considered in the decision-making, but it is more often in the circle of the family, then in the hospital. (O.X.1, O.X.2, O.X.3, I.2.1).

3.6.3. Barriers of involvement of patients/ families in the decision-making process at end-of-life

Through the interviews and observations, some of the barriers for involvement of the patients and/or families are identified to be: “Mostly we have incompetent patients, 90% are these patients, we don’t have communication with the patients” (I.1.1); lack of interest on the family side (O.X.1); lack of legal frame for involvement of the patient in the process (I.1.1); perception of psychological instability of terminally-ill and their family leading to impaired decision-making capacity (TV.X.2; I.1.1, IFI.1.1); the educational level of the family: the lower the educational level, the more committed to engage in the care of the terminal patient (IFI.1.1); the educational level of the family: the higher the educational level of the family, the more understanding of the condition of their loved one and more easily accepting suggestions from the physicians (I.1.1; IFI.1.1); lack of appropriate communication skills of the medical staff (IFI.1.1; I.1.1); previous bad experience (I.1.1; IFI.1.3). “

On the patients side, we concluded that families and patients are not that passive participants and only trusting the system, though they acknowledge the presence of barrier to communication and involvement in the decision making process. The communication skills of the medical staff are major concern. “These [medical staff] from anesthesiology were more... we didn’t know them well, they are difficult a bit, I don’t know, there are ‘millions’ sick people in the intensive unit, not just one, you know, you don’t know how to ask the question, not to offend them, with a dose of fear, when I talk to them, not to offend them, not to step on someone’s foot. You don’t feel, here I didn’t feel free in front of them”. (I.2.1) “When I went in the hospital to ask about my mother’s condition, [the surgeon’s name] was hiding and running away from me in the corridor” (I.2.3)

3.7 “Giving information”

Successful communication as vital part of the decision making process and improvement of terminal care (35;36) was addressed accordingly in this research. Communication with the family in this research mainly involved one-way communication with physicians giving information and patients and/or family receiving the information regarding the condition of the patient. Communication between physicians and family members is even labeled as “giving information”, “informing”, “notifying”, strongly indicative for the direction of the communication. (O.X.1, O.X.2, O.X.3, O.X.4, I.1.1, IFI.1.3, IFI.1.1). The involved parties in the communication are physicians (residents and specialty doctors) and family members. (O.X.1, O.X.2, O.X.3, O.X.4, I.1.1, IFI.1.1; I.1.3; IFI.1.3; I.1.2). The communication involves giving information on current condition and when a major medical intervention is being planned or was urgently performed; and rarely prognosis (I.1.2; I.1.1; O.X.1; O.X.4). “No talk about the decision-making, no talk about the patient’s wishes” (O.X.1). Patients are usually excluded in the process. (O.X.1; O.X.2; O.X.3; O.X.4)

Physicians place the problem in the communication segment in the appropriate communication skills of the physician (IFI.1.1; I.1.1; IFI.1.3); on the lack of appropriate space for the families to gather with the physicians and communicate (IFI 1.1; I.1.1; O.X.1; O.X.3); lack of accurate prognostic measures (I.1.1; O.X.1); negative institutional attitude toward giving prognosis and detailed reports to the families (O.X.1; I.1.2); frequent calls for information and contact occasions with the families (I.1.1; I.1.3; O.X.1); the emotional burden that the communication with the families carry (IFI1.1; I.2.1); the low socio-economic status and low educational level

of the families (I.1.1).

“[Patient’s family] have different religious beliefs, because they are people that are uneducated, tradition dominate their actions, religion is dominant, the folklore is dominant, they [the family] don’t trust the professionals and there is no way to explain them scientific things. No matter how we want our approach to be as simple as possible for them to understand, even when we explain, they don’t accept the facts, they even think it is wrong, that our explanations are faulty; they are dominated by folklore, religion, tradition.” (I.1.1)

The analysis of the family’s view on the communication is confirming some of the factors that are derived from the physicians’ point of view. Lack of communication skills is acknowledged from both sides.

“[Doctor’s name] one day called my sister: ‘Your mother... that’s it, the end’... she called my sister, and my sister start panicking. ‘And come quickly here’... That is so not OK, that behavior is so unprofessional. What could my sister do if she went there? What was her [the doctor’s] point? That my mother was going to die, and come and see her? I don’t know, probably she meant that. But those things are not done that way.” (I.2.1)

3.8. “I never told her how long she was going to live”

Disclosing of diagnosis and prognosis was found to be not that prominent problem in the ICU patients, probably not as expected to be. It has been reported as an outstanding issue in all dying patients in the Macedonian context. (32)

There is general discomfort of disclosing prognosis and distrust in prognostic value from the physician standpoint. “It is a general opinion [among ICU professionals] that prognosis is un-grateful.” (O.X.1) “You can predict what to expect though there are

cases when you plan someone to live, you give prognosis for certain diagnosis to live at most 3 months, and they live 3 years.” (I.1.1). “We don’t give prognosis... we don’t use prognostic scales” (I.1.2). “We have problems with the surgeons, they don’t tell us the whole truth, or give up on patients beforehand. I don’t give up on anyone until the last moment. The surgeon told the family that she [the patient] would die. I told the family I wasn’t going to give up. And she is alive today”. (IFI.1.1)

Usually families are given the truth about the patient condition: “The surgeons were close people to us, I mean, generally, good information, what was the truth they would tell us, they didn’t hide anything”. (I.2.1).

Families on the other hand choose according to the patient wish and decide on the patient’s best interest to disclose the truth or some version of it, or to hide the truth. “I still regret everyday that I didn’t tell my mother the truth. She could have lived the last months being aware and I always wonder what might have happened if she knew. Sometimes, I even think she knew; she was aware.” (I.2.3) “In all that rush, I never told her how long she was going to live”. (I.2.1)

4. Discussion

The study findings answered the research question, particularly the ones that were aimed to explore the major issues concerning end-of-life care in the intensive care units in the Macedonian context.

4.1 Integrating palliative care in the intensive care – opportunities and challenges

This study is a first study that addresses issues of end-of-life care in field research in Macedonia. This statement is confirmed by the lack of scientific body material of

medical science, social science, anthropology and ethics. However, there are the ethical (4;33) principles and legal documents (10;33;34) concerning and framing the practice of the medical profession. Expert opinions have been used to institute general attitudes and practices almost always provoked by some media exposed controversial case of a terminally ill patient. (35;36) On the other hand, patients and families are sharing concerns in the offices for protection of patient rights about the care of the terminally-ill and their right to dignified care (37)

Organization of palliative care through the health system is strongly associated with high human development index^c among countries (38) Hereby, we will not argue the importance of establishing such services in Macedonia, though we will consider possible models of implementation.

In the wider context, the former Yugoslav Republics^d in the Balkan Peninsula, that share similar background, culture and tradition, there are insufficient evidence to support a rigorous review of practices and outcomes. Comparable trend that could be identified through browsing of the media announcements of the health officials in Serbia and Croatia as well as the activities of the professional associations of palliative care professionals is the establishment of palliative services on their territories and stressing the need for founding of hospice service for terminally-ill patients.(41-43)

^c The Human Development Index (HDI) measures the average achievements in a country in three basic dimensions of human development: a long and healthy life, knowledge and a decent standard of living.

^d The former Yugoslav Republics hereby refer to Republic of Serbia (Republika Srbija), Republic of Montenegro (Republika Crna Gora), Republic of Croatia (Republika Hrvatska), Republic of Slovenia (Republika Slovenija), Federation of Bosnia and Herzegovina (Federacija Bosna i Hercegovina), Republic of Srpska (Republika Srpska) and the newest country in the region the Republic of Kosovo (Republika e Kosovës).

At the moment, Republic of Macedonia is in a unique position, health policy makers pushing reforms in the emergency medical departments and the palliative services (11), as well as introduction of practice of cadaver transplantation, practices that are considerably influenced by the attitudes and beliefs of the stakeholders of terminally-ill patients. All these changes of practice would require rigorous scientific research not only in the field of medical sciences, but jointly or individually of social, anthropological and finally economical research.

4.1.1 Barriers to implementation of palliative care service

If one system of palliative care of terminally-ill patients was to be implemented there are some issues that were derived from the context analysis that need to be considered.

Every hospital and professional level has developed different cultures and habits in the past years since the system has been established. This is the case since there have been reforms at every level of the health care system: economical, organizational, social and quality control that lead to changes of behavior. Understanding the promoted behaviors and culture within different professional level is imperative to make substantial modification in order to improve the practice.

It is a challenge not just to understand the phenomenon of end-of-life among the patients and families and medical professionals; it is also a challenge to understand the forces that drive the specific “culture” in the setting of healthcare services.

The “western”^e model of universal quality management with evidence based guidelines of conduct of medical care might be challenging in this context. There have been repeated reports of failure to implement adapted global guidelines^f on national level for various specialties. (17;44) In the study findings, oral consensus or case-to-case decision-making is dominated, the Law and the ethical codex being identified as valid regulatory mechanisms, as well as tradition and organizational culture. It used to be the case that University institutions^g formed the opinions on professional conduct, until the Medical Faculty was the only provider of medical and professional education, especially the specialty training. Since new medical schools emerged and especially after the reforms in the health system, where every hospital is considered one subject of policy and practice implementation and economic unit, this system have failed to provide quality control.

Moreover there are numerous variants of models of policy toward implementation of palliative care programs in the countries. In the neighboring countries, Serbia and Croatia (39;40) it is considered the model of separate palliative care services and training palliative care specialists to be the most acceptable model rather than

^e The term ‘Western’ implies for things that come from the Western and North European countries, as well as the North American countries. This term is inherited and accustomed in the general public both referring to the countries of Western Europe and the meaning of developed and/or progressive.

^f Evidence-based guidelines for clinical practice have been issued from the Ministry of Health in 2006, as part of the Project for management in the health sector, supported by a loan from the World Bank. The guidelines were prepared using mainly global models, not adapted to the Macedonian context.

^g Universities in Macedonia are organized in Faculties and Institutes. Academic staff is traditionally highly respected of their opinion by the professional community and usually are the opinion leaders in the professional field as well as the academic field. The academic staff of the Medical Faculty is employed at the tertiary hospitals as clinicians which are then responsible for the clinical education to undergraduates, postgraduates and specialization to future medical professionals.

incorporating palliative care in other specialties, which is the case in western European countries like the Netherlands (41). Currently in Macedonia terminally-ill patients are managed in many levels of healthcare, so implementing separate palliative care service could be too ambitious, demanding and expensive since palliative care is not well established at the moment. Macedonia is characterized as a country with localized provision of hospice and palliative care (38), but there could be shortage of palliative care specialists and facilities to organize high quality palliative care service without considerable capacity building programs.(23) On the other hand, training and re-organizing some of the current capacities could be cheaper and more sustainable solution.

4.2 Implications of the study findings

Humbly, this study is a first step toward understanding of the phenomenon of end-of-life in the specific environment of the intensive care and specific group of people.

The study findings represent the intensive care setting in Macedonia. There are no substantial differences among the intensive care units throughout the country so the results can be generalized to the intensive care setting for the whole country.

The study was carried out in ethnographic manner allowing themes to rise from the stakeholders in the end-of-life phenomenon. The study in large extent describes the experiences, attitudes and beliefs of intensive care specialists and residents, dominantly Macedonian and Orthodox Christians, physicians with both short career and long career in the intensive care medicine; whereas the family members group is very small to extract mutual characteristics from.

The study results indicate that medical professionals providing care to intensive care patients perceive terminally-ill to be “a problem” of other specialty doctors and other

healthcare organizations. They even assert they don't have "such terminally ill patients". It is imperative to change the view of the medical professionals.(42) It might be helpful in changing the perception by changing the label to "End of Life" care rather than terminal care to distinct from the palliative care provided by palliative care organization or hospice. Another challenge is to find the appropriate word since "End of Life" is untranslatable in Macedonian. "Dying" is appropriate but, it represents state of the patients just before the moment of death rather than longer periods as the meaning of End of Life in some cases. Some authors accepted "dying" and "dying patient" as appropriate terms and others "terminal condition" and "terminal patients" or "terminally-ill patients". (2;32) There should be consensus on the terminology since both terms could carry concealed meaning to the stakeholders in the End of Life care.

Acknowledging the fact that palliative care is part of the intensive care, it is the first step to improving care to patients in the intensive care. (2;42;43) Physicians perception of palliative care as the alternative to life-prolonging or curative care, or something that is done when there is nothing more that could be done, rather than simultaneously delivered care, was easily identified and could be a potential threat to integrated palliative care. (42) (IFI.1.11)

Practices of withholding and withdrawing of intensive treatment, as practices of treatment of terminally-ill in the intensive care, have been recognized and described in their contextual manifestation. This study shows that physicians in intensive care units accept limitation of medical therapy in patients as alternative for patients that have confirmed terminal condition. Similar situation is found in large studies reporting more the half of the deaths in the ICU being preceded by some sort of limitation of life-sustaining measures.(44;45)

Predominant observed and reported practice was withholding of treatment over withdrawing of treatment. The rationale to withhold treatment in terminally-ill is simple: futility of introducing any treatment.

Withdrawing is much rarer practice. There are numerous explanations of this fact: could be explained with the perception of withdrawal of treatment as sort of euthanasia among physicians and the public; by the belief that the quality of last moments of life would be poor if withdrawn from therapy and patients would suffer; the belief that prognosticating the course of the disease in intensive medicine is not accurate and fear of early surrender; institutional attitude toward limitation of life-sustaining measures in terminal patients; imprecise regulation to support limitation of life-sustaining measures in terminal patients; the attitude of others involved in the treatment of the patient, both other physicians and the family of the terminally-ill.

The same status is reported in studies in Israel (46) and France (44), as well as southern European countries like Italy, Greece and Turkey (7). The similarities in the conduct among these countries are not reported and explained. North American countries (45) and North European countries (7) prefer withdrawal of treatment. The argument given for explanation of the difference in behavior is the strict and clear legislation of the practices of withdrawal of therapy, thus providing protection of the physicians from legal prosecution. (46)

It has been documented that the perception of withholding medical treatment in terminally-ill patients is more acceptable by the physicians in bio-ethical terms, while bio-ethicists hold the position of equivalence between those two practices. (44)

The wish and perceived attitude of the families to continue therapy, or save the patient by all costs drive the decisions for resuscitation even in hopeless cases of terminally-ill patients. Personal wishes and attitudes of the physicians toward EOL care have not

been reported to influence the decision-making in the treatment of terminally-ill patients.

The study participants, the informants and the observer, show what influences the decisions at EOL. The next step would be to perform quantitative survey in probabilistic sample to confirm these findings and to prove the individual strength of each factor.

Valuable insight for involvement in the decision-making of the families was gained through interviews with family members. Larger, more diverse sample with regard of the cultural background, religion, age and other characteristics is needed to confirm these findings.

Worth mentioning is the need and preparedness of the family to be more involved in the decision-making process. The communication is found to be insufficient and low quality by the both sides, both the physicians and the families. Telling the truth and disclosing the prognosis is valued by the families, though they take the charge to enclose the same information to the patient and the decision to tell the truth or not to tell. To spare the patient the distress of finding out the truth as a cultural phenomenon might be possible challenge of the implementation of “patient autonomy” as one of the major ethical principles. Another possible explanation is the family perception of the justification of their behavior using shared decisions for the family member’s wellbeing. (14)

This phenomenon is confirmed in studies in countries with strong relations inside the family and preference of family and community ties over individual autonomy like in Italy (47) and Turkey. (48) Similar characteristics are described for the Macedonian family. The Macedonian family as patriarchal community exists today with strict hierarchical structure of its members and authoritative type of organization. The head

of the family takes charge of the decision making for the family. (49) The traditional setting opposes modern legal regulations, which are strange and unknown in its core values and which do not take into account the actual family relations. (49)

What else is concerning, though, is the feeling of exemption of the physician of the responsibility once they transferred the burden to the family to disclose the diagnosis or prognosis.

More scientific evidence is needed to make final statements concerning telling the truth in the context of Macedonia and the collision of the cultural relativism and the Western bioethical principles.

Public, professional and legal stakeholders' involvement in the debates of what is ethically accepted behavior is important and it has been reflected in the development of models for truthful disclosure in Italy.(47) While consensus for the majority is important, it remains important to acknowledge minority opinion as well and act accordingly. (50)

Extensive qualitative research with experienced researchers in the field of anthropology is needed to provide the insights of the patients and their families and/or decision-making surrogates.

Participatory qualitative research is appropriate approach to study and to improve EOL practice in the intensive care setting in this context.

4.3 Strengths and limitations of the study

The limited time for data collection reflected in small sample size, especially of the family members sub-sample, as well the representation of certain religious and ethnical minorities.

Some of the limitations and auto reflexive clarification are mentioned in the methodology section.

What makes the strengths of the study is the triangulation of the findings with various methods. Participant observation was the strongest method used since it enabled gathering of valuable data for EOL practices, participants, roles and their interaction and factors influencing the EOL practices, as well the opportunity to directly contact the stakeholders. Informal conversations and group interviews enriched the data of attitudes, beliefs and perceptions as well as enlarged the body of information gained through interviews and observation.

The study of the context provided important interpretations and understanding of the practices, as well as identification of possible opportunities and threats for further improvement of care.

4.4 Generalizability

As with any qualitative data and convenient sampling, this study can only be generalized to the study setting and study population.

The study results mainly represent the intensive care setting and partially the emergency departments, the experiences and perspective of intensive care specialists, the family members of patients who died or had limitation of life-sustaining treatment. Ethnical and religious minorities are underrepresented in the study sample. So, factors in ethnical and religious content are cautiously interpreted in the discussion.

5. Conclusions

How terminally-ill patients are managed in the intensive care setting in Macedonia is shaped through the interplay of professional, cultural, ethical and social factors. The identified factors have influenced the practice so far and represent potential threats and opportunities to profile palliative care programs in the intensive care setting.

Limitation of life-sustaining measures in terminally-ill patients is accepted among the medical professionals as an alternative to redundant prolongation of life and time of death.

Patient and family inclusion in decision-making and communication, as essential step to improvement of EOL care, is insufficient.

Ethical principle of autonomy should be shaped in the cultural context. Public, ethical, professional and legal consensus is needed to improve current practice.

Though this research pioneers in the understanding of the end-of-life phenomenon and identified its components and their interaction in the context, more research is needed to describe the role and needs of the patients in terminal condition and their families and decision-making surrogates.

Reference List

- (1) Sholjakova M. Комуникација и етички аспекти на тимскиот пристап во лекувањето на критичен болен. [Communication and ethical aspects of team approach in treatment of critical patient]. Прирачник за континуирана медицинска едукација; Скопје: Здружение на лекари за критично болни пациенти; 2010.
- (2) Popovski S. Предизвици во интензивното лекување на пациенти во терминална состојба. [Challenges in the intensive care of patients with terminal condition].: Committee for European Education in Anaesthesiology Courses; 2007.
- (3) Tidswell M, Jodka PG, Steingrub JS. Medical ethics and End-of-Life Care. Intensive Care Medicine. 2010. p. 2339-49.
- (4) Williams JR. Medical Ethics Manual. 2nd ed. Ferney-Voltaire Cedex: Ethics Unit of the World Medical Association; 2009.
- (5) van der Heide A, Deliens L, Faisst K, Nilstun T, Norup M, Paci E, et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003;362:345-50.
- (6) Hardon A, Boonmongkon P, Streefland P, Lim Tan M, Hongvivatana T, van der Geest S, et al. Growing old in cultural perspective. In: Hardon A, Boonmongkon P, Streefland P, Lim Tan M, Hongvivatana T, van der Geest S, et al., editors. Applied health research: Anthropology of health and health care. Revised ed. Amsterdam: Het Spinhuis Publishers; 2001. p. 108-11.
- (7) Yaguchi A, Truog RD, Curtis R, Luce JM, Levy MM, Mélot C, et al. International Differences in End-of-Life Attitudes in the Intensive Care Unit. Arch Intern Med 2005;(165):1970-5.
- (8) Miccinesi G, Fischer S, Paci E, Onwuteaka-Philipsen BD, Cartwright C, van der Heide A, et al. Physicians' attitudes towards end-of-life decisions: a comparison between seven countries. Social Science & Medicine 2005 May;60(9):1961-74.
- (9) Blackhalla, Frankb, Murphyc, Michela, Palmerd, Azend. Ethnicity and attitudes towards life sustaining technology. Social Science & Medicine 1999;48:1779-89.
- (10) Official Gazette of Republic of Macedonia. Law for protection of the patients rights. Official Gazette of Republic of Macedonia 2008;82:47-68.
- (11) Ministry of Health of Republic of Macedonia. Стратегиски план на Министерство за здравство за 2009-2011 година. [Strategic plan of the Ministry of health for 2009-2011]. Ministry of Health, Republic of Macedonia; 2008.

- (12) Ferrand E, Robert R, Ingrand P, Lemaire, for the French LATAREA group. Withholding and withdrawal of life support in intensive-care units in France: a prospective survey. *Lancet* 2001;357:9-14.
- (13) Gordon EJ. Bioethics. In: Ember CR, Ember M, editors. *Encyclopedia of Medical Anthropology: Health and Illness in the World's Cultures Topics*. New York City: Springer; 2004. p. 73-86.
- (14) Ashtalkovska A. Поединецот и културата. [The individual and the culture]. Озборувањето како механизам за социјална контрола во традиционалната култура на Струшки Дримкол. [Gossip as a mechanism for social control in the traditional culture of Struga Drimkol]. Skopje: Institut of ethnology and anthropology, Ss.Cyril and Methodius; 2009. p. 115-9.
- (15) Milevska Kostova N, Popova M, Serdiuk V, Kosheleva K. Patient Safety in Eastern Europe and Asia: Baselines and advances. All Ukrainian Council for Patients Rights and Safety & Center for Policy Research and Cooperation "Studiorum"; 2008.
- (16) State Statistical Office of Republic of Macedonia. *Macedonia in figures*. Skopje: State Statistical Office of Republic of Macedonia; 2008.
- (17) State Statistical Office of Republic of Macedonia. *Total population of the Republic of Macedonia by ethnic affiliation, by municipalities, Census of population, households and dwellings 2002*. 2002. State Statistical Office of Republic of Macedonia.
- Ref Type: Online Source
- (18) World Bank. World Development Indicators database. 7-1-2010. World Bank. 8-26-2010.
- Ref Type: Online Source
- (19) Eurostat 2008. <http://epp.eurostat.ec.europa.eu/> . 2010.
- Ref Type: Online Source
- (20) World Health Organization. Macedonia: country profile. <http://www.who.int/countries/mkd/en/> . 2010.
- Ref Type: Online Source
- (21) World Bank. Health Nutrition Population (HNP) At-a-Glance Table: Macedonia FYR. 2010. 8-24-2010.
- Ref Type: Online Source
- (22) Ministry of finance of Republic of Macedonia. Budget of Republic of Macedonia 2010. <http://www.finance.gov.mk/files/> . 2010.
- Ref Type: Online Source
- (23) Adzic M. EAPC Task Force on the development of Palliative Care in Europe. Republic of Macedonia. Lancenster University. International Observatory on End of Life Care; 2006 Aug 7.

- (24) Palliative Care Australia. Palliative Care Australia. Palliative and end of life care glossary of terms. 2008.
Ref Type: Online Source
- (25) Mitashova V. End-Of-Life practices in Macedonia. 2010.
Ref Type: Personal Communication
- (26) Marshall C, Rossman G. Designing qualitative research. 3rd ed. Sage publications; 1999.
- (27) The philosophy, theory and practice of research. In: Bowling A, editor. Research methods in health: investigating health and health services. 2 ed. Maidenhead: Open University Press; 2002. p. 128-9.
- (28) Bowling A. Research methods in health: investigating health and health services. 2 ed. Maidenhead: Open University Press; 2002.
- (29) Association of Social Anthropologists of the UK and Commonwealth. Ethical Guidelines for Good Research Practice. 1999.
Ref Type: Online Source
- (30) American Anthropological Association. AAA Code of Ethics. 2009.
Ref Type: Online Source
- (31) Risteski LS, Trpeski D, Toseva M, Dimitrievski V. Мапирање и студија заснована на истражувањата со заедницата на адолесценти со највисок ризик од ХИВ/СИДА/СПИ. [Mapping and research study in the adolescent community under high risk of acquiring HIV/AIDS/STD]. Skopje: University Ss Cyril and Methodius, Institute of ethnology and antropology, Skopje; 2007.
- (32) Andonov V. Умирање и смрт. [Dying and death]. Skopje: Tabernakul; 2001.
- (33) Boshkovki K. Медицинска етика и деонтологија: Кривично-правна одговорност на лекарот. [Medical ethics and deontology. Criminal and legal responsibility of the medical doctor]. Skopje: NIP Gjurgja; 1999.
- (34) Assembly of Republic of Macedonia. Кривичен законик на Република Македонија. [Criminal Law of Republic of Macedonia]. Official Gazette of Republic of Macedonia 1996;(37).
- (35) Balaban L. Doctors against mercy killing. Dnevnik 2006.
- (36) Еутаназија: Панел дискусија. [Eutanasia: Panel discussion]. Skopje: Skynet Television; 2008.
- (37) Ministry of health. Прославен е Денот на правата на пациентите. [Celebration event of the patient rights day]. 4-18-2010. Skopje, Ministry of Health of Republic of Macedonia. 5-1-2010.
Ref Type: Online Source

- (38) Clark D, Wright M. The International Observatory on End of Life Care: A Global View of Palliative Care Development. *Journal of Pain and Symptom Management* 2007;33:542-6.
- (39) Stambuk A. Palliative Care for Elderly - An Analysis of Needs and Resources in Croatia. Part 1 . 2009.
Ref Type: Unpublished Work
- (40) International Observatory on End of Life Care. Palliative care in Croatia. 2009.
Ref Type: Unpublished Work
- (41) de Graaf FM, Francke AL. Barriers to home care for terminally ill Turkish and Moroccan migrants, perceived by GPs and nurses: a survey. *BMC Palliative Care* 2009;8(3).
- (42) Kelley AS, Meier DE. Palliative Care ГÇö A Shifting Paradigm. *New England Journal of Medicine* 2010 Aug 18;363(8):781-2.
- (43) Troug RD, Campbell ML, Curtis R, Haas CE, Luce JM, Rubenfeld GD, et al. Recommendations for end-of-life care in the intensive care unit: A consensus statement by the American Academy of Critical Care Medicine. *Crit Care Med* 2008;36(3):953-63.
- (44) Ferrand E, Robert R, Ingrand P, Lemaire F. Withholding and withdrawal of life support in intensive-care units in France: a prospective survey. *The Lancet* 2001 Jan 6;357(9249):9-14.
- (45) Prendergast, Claessens, Luce. A National Survey of End-of-life Care for Critically Ill Patients. *Am J Respir Crit Care Med* 1998;158:1163-7.
- (46) Jakobson DJ, Eidelman LA, Worner TM, Oppenheim AE, Pizov R, Sprung CL. Evaluation of Changes in Forgoing Life-Sustaining Treatment in Israeli ICU Patients. *Chest* 2004;126:1969-73.
- (47) Surbone A, Ritossa C, Spagnolo AG. Evolution of truth-telling attitudes and practices in Italy. *Critical Reviews in Oncology/ Hematology* 2004;52:165-72.
- (48) Guven T. Truth-telling in cancer: Examining the cultural incompatibility argument in Turkey. *Nurs Ethics* 2010;17(2):159-66.
- (49) Mirchevska MP. Структура и функции на семејството. [Structure and functions of the family]. Вербални и невербални етнички симболи на Горна Река. [Verbal and non-verbal ethnic symbols in Gorna Reka]. Skopje: University Ss.Cyril and Methodius, Institute of ethnology and anthropology; 2007. p. 54-72.
- (50) Evans LR, Boyd EA, Malvar GL, Apatira L, Luce JM, Lo B, et al. Surrogate Decision-Makers' Perspectives on Discussing Prognosis in the Face of Uncertainty. *Am J Respir Crit Care Med* 2009;179:48-53.

Annex I Topic Guide – Health Professionals

Use of Information Sheet and Consent form to explain aim of the study, role of the participant, ethical issues, potential benefits and risks.

The potential participant will be asked for consent to participate in the study and to use audio-recorder during the interview (all confidentiality and anonymity issues will be assured once again).

Time will be set to around one hour, but the participant will be reminded that it can be terminated earlier, at any time according to the participants wish.

Baseline characteristics:

Sex

Ethnicity

Religion - practicing?

Working experience

Terminally-ill patients in your ICU?

I would like to talk to you about the terminally-ill patients in your ICU.

Probing questions:

What is the referral system?

How do you manage terminally-ill patients?

What parameters should be satisfied to declare terminal illness? Who do you consult?

How do you inform the family if the patient is terminal? Do you have a procedure for information? Where do you usually inform the family?

Can you share some experiences with families of terminally ill patients? What expectation do they have? What do they usually request for their loved one or themselves? How do you handle their requests? How do you proceed if the family members insist on “doing everything” despite the diagnosis?

How do you feel and cope with these situations? Do you have any experience you would like to share?

EOL practices in your ICU?

Decision making? (Sample question: Who is involved in the process of decision-making?)

How do you decide what action to perform at EOL?

Who is involved in the process of decision-making?

Description of processes and procedures regarding EOL

What is most important to achieve in this patients? Sustaining of life (principle First to save the patient), quality of life (comfort and pain free)

During decision making do you apply “acting upon ones best interest”? do you consult the family/ patient and make the best decision together? Do you follow the decision the patient/ family make on behalf of incompetent patient?

What influences the decision at EOL?

In you experience, please tell us what influences the EOL practices and decisions?

Probing questions:

What if the patient had explicit wish for EOL?

Is there a difference if the patient is young or old?

Quality of life considerations

Patient and family member acceptance of the condition

How about religious factors and EOL?

How about ethnicity and EOL?

How about financial conditions and EOL?

How about hospital policy and EOL?

How about ethical principles and EOL?

How about legal considerations at EOL and decision making

How about general attitudes of senior staff at EOL?

How about experience with previous patients and EOL decision-making?

Personal and general attitudes toward EOL

PERSONAL

If you find yourself at a similar position (terminal illness), what would you want for yourself?

Probing:

How would you want it to be decided if you are incompetent to decide for yourself?

GENERAL

Who should decide for incompetent patient at EOL?

How should medical professional act in case of explicit known wish of the patients of EOL?

What is your attitude toward euthanasia or passive suicide?

Perception on EOL practices at their workplace (study site)

How do you view the current practices and decision models?

Do you feel that sometimes you unnecessary prolong the life of some patients?

What are the needs of the families while their relative is in the ICU?

Do you feel you fulfill the needs of the families?

Do you think there is a need for change of the way you practice EOL in your ICU? In the sense of treatment? In the decision models?

Do you think there is a possibility to incorporate patient wishes in the treatment of terminally-ill patients in the ICU?

Knowledge and beliefs of EOL

What regulations about EOL in ICU are in place?

- laws, guidelines, ethical codex
- scientific evidence

How is EOL incorporated in the formal training and education of medical doctors, nurses and other staff?

How is EOL tackled during continuous post-graduation education of medical professionals?

Recommendations for EOL

Please share recommendation for further practice.

Participant will be reminded during the interview to re-consent for some of his/her statements in the study.

The participant will be asked if he/she wants to go through the notes (if any) or review of some of the issues addressed and will be asked to add/remove or consent to the statements.

Gratitude for participating in the study and appreciation for the time and information shared during the interview.

Feedback with the study results after few months.

Contacts for further communication.

Annex II Topic Guide – Family Members

Thank you for the participation in the interview and the willingness to share sensitive information for the purpose of the study.

Have you read the Information leaflet?

Do you have any question?

I will now explain the purpose of the study (use of the Information leaflet)

You may withdraw from the interview in any time.

Demographic data:

Gender

Ethnicity

Religion and if practiced

Relationship with the deceased

Education (finished primary – 8 years; finished secondary – 12 years; university degree – above 15 years)

Member of minority or cultural group? If yes, which?

Narrative

How did your relative got sick?

Tell me more about his/her illness? What happened?

How did you experience the event?

Experience

Please share your experience with you relative illness and hospital experience.

Probing questions:

When your relative was admitted to the ICU, what did you think will happen? When and how that happen?

Can you tell me your experience with the personnel who took care of your relative?

Nursing staff

Physicians

Other

How were you involved in all that yourself?

How did you experience the going to and going back from the hospital?

Were you financially or otherwise burdened by the visit to the hospital?

Who helped you handle the situation? Who was your emotional and spiritual support?

Perception

How do you view the medical care to your relative?

Which parts you wouldn't change?

Which part would you change?

Were you surprised when he/ she died?

Did you feel you were in charge of the situation?

Was his/ her death dignified? What does dignity mean to you? Did you have privacy?

Did he/ she suffered pain? Do you think it was addressed accordingly?

Where did you want him/ her to die? Did dying at home came up in the discussion with the physician?

Did you feel you had enough information?

Did your relative have a wish for his/ her end? Did you talk with the doctor about that?

Did you wish he/she were in another organization (hospice) and not the intensive care unit?

Did you have time to say goodbye?

Did you feel his/her life was aimlessly prolonged?

Attitudes toward EOL

Personal attitudes

If you find yourself in that situation, what would you want for yourself?

Who would you want to decide for you in case you are not capable?

In general, who should decide for incompetent patient?

Expectations and recommendations

What did you expect from the medical personnel?

What did you expect from the hospital?

What did you miss while your relative was in the hospital?

What could have been done differently after the death of your relative?

What advice would you give to the physicians and the nurses who took care of you and your relative? What advice would you give to the hospital?

Do you have anything else you want to add to the interview?

I will remind you to consent once again to the information you provided during the interview.

Would you like to go through the interview notes together?

Would you like to say something more or take something out from the interview?

Thank you for your time. Your participation means a lot to the research.

With your permission, I will contact you once again in a few weeks if you would like to go through the results of the interview.

Please feel free to contact me on my telephone number or via email. You can find the contact information in the Information leaflet.

Annex III Field-Notes Form

FIELD NOTES FORM

End-of-life practices and experiences of health professionals and family members in terminally-ill patients in intensive care centers in Macedonia: a qualitative research

INVESTIGATOR: _____

TIME AND PLACE: _____

INFORMANT CODE:

· ·

GENERAL INFORMATION OF THE INFORMANT/ OBSERVATION:

Observation site/ location:

Demographics of participants:

Work experience in ICU (in years, for health prof.):

Relation to the terminally-ill pat. (for family):

Religion:

Ethnicity:

Gender:

Place of residence:

SHORT SUMMARY OF FIELDNOTES

FIELD NOTES (INCL. FIRST CONTACT, SITUATIONS, FEELINGS, BODY LANGUAGE, ETC)

The setting (physical environment, context, behavior promoted, prevented):

Objects (building, furniture, equipment..):

Participants (who is there? How many? Roles? Who is allowed there?):

Activities (what is going on? Sequence of actions? How participants interact?:

Frequency and duration (how long does it take, how frequent? How typical it is?):

Feelings displayed by participants:

REFLEXIVITY

Emotions

Thoughts

ANALYSIS AND INTERPRETATION

PRIMARY ANALYSIS

Annex IV Code formation system

Codes used to mask the identity of the informants and the study sites were formed as follows:

Type of method.Group of informant.Consecutive number for the informant or study site

Type of method

- I - in-depth interview
- IFI - informal conversation or group interview
- O - observation
- TV - broadcasted panel discussion

Group of informant

- 1 Health professional
- 2 Family member

Consecutive number for informant / study site

- 1,2,3... n Health professionals or family members
- 1, 2 or 3 Study sites – ICUs
- 4 Study site – emergency department

If any element was irrelevant for the code of informants/ sites, the space was filled with 'X'.

Annex V Quotes contributing to the analysis of what influences the decision making process at end-of-life in terminal patients in the ICU.

Certain characteristics of the medical condition

➤ The underlying medical condition (acute vs. chronic disease)

“We found coma [in the patient], wide pupils in both eyes, estimated Glasgow coma scale of 3, and decided not to resuscitate on the place of first contact with the patient.” (O.X.4).

“...and decides not to resuscitate because of the underlying disease and the terminal condition he [the patient] is in.” (O.X.4)

“We always begin with how the patient got to the intensive care, the underlying cause, the primary diagnosis, and if the patient was previously healthy, in that patient, even when you know the diagnosis and the prognosis, all measures are being performed, everything that needs to be done, is done, like diagnostics and procedures... we know the prognosis is bad, but the period to declare that patient terminal is postponed and the period of active treatment in intensive care is prolonged. In those patients that came to surgery in late stage, and the surgery was done because it was necessary and they are now ‘stuck’ in intensive care unit, the treatment period and mechanical ventilation is shortened and that period is the shortest for patient that presented already in terminal state ... “ (I.1.1)

➤ The expected quality of life after intervention

“It is more often to decide to withhold resuscitation or invasive intensive therapy in oncological patients and neurosurgical with irreversible brain damage that would lead to persistent vegetative state” (O.X.1)

Characteristics of the terminally-ill patient

➤ Age

“ And because he was young, I thought the youth was on his side and I thought there was a chance at least to get off the machine [ventilator]” (I.1.1)

“We take into account some characteristics. If the patient is young we assume that the other organs are healthy and that this is the first time that these patients have suffered a disease or trauma and we perform, out of mercy, out of desperation all the measures. ...On the other hand, if we had a patient 80 or 85 years old and he was found the same condition, there is no need, we wouldn't perform anything, he already has 85, what else could we do.” (I.1.1)

➤ Educational level

“I heard one doctor saying: The patient could not be informed and consent because they were not medically educated, they wouldn't understand the situation. This is nonsense. What if I [the doctor] was the patient?” (IFI.1.5)

Characteristics of the decision-maker

➤ Educational level

“We explained once again the whole procedure, so, what was going on, after a few days, I don't know if he [the father of the patient] understood the things he had been explained or because he decided with his own reasoning, out of religious reasons, I don't know, that he wants to take her [the patient] and that he will sign a consent form to take the girl home.” (I.1.1)

“He was appointed as a contact person, he was chosen because he was literate, since the others [the family] are illiterate, everyone with no formal education, everyone illiterate, coming from rural area...” (I.1.1)

➤ **Socioeconomic status**

“Sometimes we have more understanding with the families of patients from the Albanian nationality and lower educational status... these intellectuals... here we have a patient who suffered stroke and his son instead of taking him [the patient] home to provide him care, physical therapy, to provide him care, he leaves him here in the hospital, to ‘open’ pressure ulcers, to ‘rotten’ in the hospital, we don’t have anything more to do to him...” (IFI.1.1)

➤ **Age of the decision maker**

“I read somewhere that young people venture more in these behaviours. I would like to say that man discovers this world [with age], then he looks at it more realistically, takes more realistic attitude toward it. What is happening in the treatment of death and everything that happens around death, by the young population, is far from real. Especially nowadays children are being kept away, they are not taken to funerals, they are kept away from hospitals, not to be acquainted with those events; we can see that it is more of abstract nature that these behaviours are being accepted.” (TV.X.3)

➤ **Working experience**

“I can see that older [experienced] doctors find it easy to do that [withdraw a patient from therapy], while younger, I can see, disagree, they refuse to do it.” (IFI.1.4)

Social and socioeconomic factors

➤ **Social surrounding of a dying person**

“He was treated with analgesics and sedatives and he was left to die [in the ICU], just because the family could not witness the dying process [and the accompanying disturbing symptoms]”. (I.1.1)

“The daughter of the patients couldn’t come to visit her father since she was taking care of her blind and debilitated mother.” (O.X.1)

➤ **Economic factors**

“And why do they react that way [not give up on any patient], because they are private sector, they want to show...? I.1.2: No, I can't say because they are private, it is just copied practice from another institution, another system, those [treatment of terminally-ill patients] carry financial burden, but I don't think... I can't even assume how much it costs, every hospital day and such treatment, changing filters for this and that...” (I.1.2)

“Overcrowding with terminal patients [of the ICU], especially with postoperative complication, is due to lack of equipment and staff of the surgical wards to handle these patients” (O.X.1)

“She [the patient] said I don't want to go to Vienna to be treated, to spend your [the family's] money and your [family's] time and health and money and exhaust everyone” (I.2.1)

Cultural factors

➤ **Beliefs about end-of-life practices that influence the practice**

“Some patients deserve to be given a chance. Their condition depends on the effort made by the doctor. When I said this man will not die, and he didn't die.” (IFI.1.1)

“Plasmapheresis are done till infinity, dialysis are done infinitely, and this continues for days, and weeks, and as a miracle it comes a moment when you stop the dialysis, when you get urine output. You will say... after 10 days dialysis, you will bring him back [meaning impossible]... and he starts producing urine, and it really happened” (I.1.2)

“It is not that the families insist [on treatment], the families leave the patient there with a belief that everything will be done and everything that is required is actually done” (I.1.2)

“We don’t have practice to withdraw therapy or to withdraw nutrition or care in comatose patients. There are cases, you can ask [doctor’s name], he knows who those patients are, who woke up from coma after 10 years” (IFI.1.6)

“Should I leave the patients [terminal patients] without antibiotics? Should I leave them to be ‘nests’ for bacteria?” (IFI.1.1)

➤ **Attitudes toward end-of-life that influence the decisions**

“They don’t give up on anyone, as futile the treatment seems, everything is done until the last”. (I.1.2)

“Something like that, like the Hippocrates oath, but very... if here [the other institutions] that was ridiculed, there it is different. That [the ethical conduct] is like that and no other way.” (I.1.2)

“We wanted to have the surgery since going directly to chemotherapy seemed somehow hopeless” (I.2.1).

“Did she want to die home or at the hospital? I.2.1 At home. ..I told my mother to go to the hospital [to take new X-ray] ‘What? There is no chance for me to go there, don’t make me, please’ She didn’t want to” (I.2.1)

“When we saw there was no change in his [the patient’s] condition, we decided to transfer him in another hospital” (IFI.2.1)

“We didn’t accept ‘No treatment’; we didn’t believe the condition was untreatable.” (IFI.2.2)

“After the physical examination, I realized that the whole neck was infiltrated en bloc with the cancer, but I had to help. The family tells you: ‘You got to save the patient’, and I believe as a doctor that you must do everything. As a miracle, the patient was successfully resuscitated with one adrenalin. If I don’t give the treatment that is passive euthanasia”. (IFI.1.3)

“I have problems here, with my colleagues at work; they think that I am going to withdraw the treatment from the patients. They think that I want to perform euthanasia!” (IFI.1.5)

“The surgeon asked me to withdraw therapy and mechanical ventilation in this patient [suffering multiorgan failure postoperatively due to hip replacement and recent heart attack]. I responded I am not a murderer to do so!” (IFI.1.9)

“Therapy is never withdrawn, mechanical ventilation is never withdrawn if once started; otherwise it is considered as performing euthanasia.” (O.X.1)

“The surgeon, when he saw the patient [with end-stage lung cancer], requested to be intubated, to aspirate the secretion...until the morning when the patient died.” (IFI.1.8)

“To withdraw treatment Yes, but to withhold... I will go back to that; there are things that need to be done to sustain quality [of life] until the very end. But, giving active therapy, antibiotics, additional diagnostic examinations, additional surgical interventions, not at all.” (I.1.1)

“Those patients [terminal patients] should get a morphine drip and peacefully let to die without being tormented. But, the surgeons insist on treatment” (IFI.1.8)

➤ **Beliefs about spirituality at EOL and spirituality**

“One other patient, asked to be allowed to make a confession to a priest and he got relieved, he reached peace until the death, he didn't suffered pain anymore, he didn't complain on other symptoms as well.” (IFI.1.6)

“In the medical science, there is recommendation that says that if you allow the patient to practice their beliefs, spirituality, it leads to unexplainable, moderate improvement of the condition, there is no medical, organ improvement, but probably the psychological aspect of the patient improves, his mood, tolerance of pain,

tolerance of the symptoms he has, the faith itself.” (TV.X.1)

“ She was upset, but said: Son, whatever happens, do not worry, I, my mission, I clearly remember when we were going to..., I accomplished my mission in this world, you and your sister have become wonderful people, that was my task in this world, from now on, as much as God gives...I am sorry that I have brought trouble to you and that I can't enjoy with you, but you should know not to be sorry for what is happening to me. “

➤ **Cultural habits**

“They wouldn't consent to anything, since they were expecting the fiancé of the patient to arrive” (I.1.1)

“I wasn't allowed to remove the tube, they wouldn't allow me to touch anything around her, together with the hospital bed, the uncle, the one that made all the customs around her... said not to touch her until he said so.” (I.1.1)

➤ **Perception of the needs of dying person**

- **Being close to the family and the family involvement in the care**
- **Pain free, relief of disturbing symptoms and nursing**
- **Allow spirituality**
- **Dignity**
- **Control over the EOL care**

“You should not treat these patients [terminal patients]; they should be placed in separate room without any therapy, and call the family to hold their hand.” (IFI.1.7)

“And, they wanted, they felt closeness, they felt duty and probably relief, they probably felt relieved and happy that can contribute and participate in some way, to be able to see the patients...”(I.1.1)

“Some of them will get inside [the ICU]; most of their requests are if they could touch them, of course they could, why not. Usually they would ask to bring them something, of course they can... something like a favorite object, some toy, part of clothing, and we would allow that. They would ask to bring holy water, some religious object like an icon.” (I.1.1)

“The only thing they insist on, they request to seat the whole time by that kind of patient, who is machine-bound or to be allowed frequent visits; they would get inside for a short period, they want to look at the patients, talk to them, they believe they talk to them.” (I.1.1)

“I think the most important thing is to feel dignified. I think that it is the most important, to feel that the people around them, that the ones that are there care for them.” (I.2.1)

“Nursing, hygiene, to move the patient, if he has pain, to turn him from left to right , those fine touches that sometimes are more unpleasant for the patients then, if antihypertensive was given, which she can’t feel; they should pay more attention to it.” (I.2.1)

“My mother had a good death. That day was beautiful. She had a chance to see everyone. She had good meal, previously she didn’t eat anything.” (I.2.1)

Regulation

➤ Laws and regulations

“All these [EOL procedures] are oral protocols, everything is orally agreed, because we don’t have written protocols, medical protocols, and the Law does not allow euthanasia” (I.1.1)

“There is no consensus for the treatment of these patients [terminal patients] and they are transferred to the ICU” (O.X.1)

➤ **Ethical issues (principle of distributive justice)**

“When there is no space for critical patients at the moment, terminal patients are neglected as a triage” (O.X.1)