MASTERARBEIT / MASTER'S THESIS

Titel der Masterarbeit / Title of the Master‘s Thesis

First, do no harm

Care practices and multiple meanings of the elderly's end of life in a Brazilian hospital network

verfasst von / submitted by

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angestrebter akademischer Grad / in partial fulfilment of the requirements for the degree of

Master of Arts (MA)

Wien, 2019/Vienna, 2019

Studienkennzahl lt. Studienblatt / degree programme code as it appears on the student record sheet::	UA 066 906
Studienrichtung lt. Studienblatt / degree programme as it appears on the student record sheet::	Masterstudium Science-Technology-Society
Betreut von / Supervisor:	Dr. Erik Aarden

Acknowledgments

My interest in this theme emerged from my concerns with my grandparents. All above 80 years old, they start to visit doctors frequently and had to face their first hospitalizations. I listened to their worries, the complaints about the several appointments, exams, and pills and started to think if all this should be the norm when a person reaches an older age. More than that, I shared their hopes for pleasant, peaceful, and painless last years. Combining this personal reason with my experience as a journalist covering health for almost 15 years, I decided to investigate how the elderly are treated in the healthcare system in my home country, Brazil. So, Abilio, Bernardo, Isabel, and Rita, this Master's Thesis is dedicated to you. It is a privilege to have your company for so long and to have the opportunity to let my daughter enjoy her childhood with her "bisas". Through you, I thank the support of all my family.

Eva, my daughter, I am sorry for all my absences during this turbulent year. I am thankful for all your hugs and kisses, especially when you realized I was tired or a bit upset. You make me a better person every day and I am doing my best to help you become an adult as nice and sweet as you are today. Remembering one of your favorite songs in the kindergarten in Vienna, "zusammen sind wir stark." I love you and I cannot wait to hear you calling me "Frau Magister"!

Dr. Erik Aarden, my supervisor, thank you for embracing this project with enthusiasm, for your insightful feedback, for being very patient and also very kind. I was not expecting to learn so many things and have new perspectives on health after such a long time involved with this field, but you opened a new world to me. It was an honor to be guided by you during this journey. Through you, I also want to thank the University of Vienna and the STS department for such an enriching experience.

Stefan Lasser and Susanne Kriss, my best friends in Austria, thank you for offering a shoulder and helping me with many other issues during the turmoil of the last year in Vienna.

To the anonymous hospitals and interview partners: thank you for your availability and your openness to this project. This Master's Thesis would not happen without you.

Also, thanks to all my friends in Brazil that helped in many ways: pitching my project to help me get access to the hospitals, lending me an ear when needed, entertaining me, supporting me, and, above all, for always being there for me. I am very lucky to have so many loyal, smart and caring people around me.

Lastly, I want to thank this beautiful city for welcoming me and making my first time living abroad so fascinating: Vienna, you will be forever in my heart.

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1. Introduction

According to the World Population Prospects[1], from United Nations, the number of people over 60 years old will rise from 962 million (2017) to 2.1 billion in 2050 and, by that time, all regions, except Africa, will have at least 25% of the population in this group.

This pressing issue has more profound impacts in developing countries, like Brazil. In less than 60 years, life expectancy in the country rose from 54.2 to 75.8 years. According to the Brazilian Institute of Geography and Statistics (IBGE - Instituto Brasileiro de Geografia e Estatística, in Portuguese), by 2030, the elderly population, which now represents 14.4% of the people, is expected to surpass the children population. This quick transition might have a significant impact on sectors like health care, economics, and social security.

Political measures, such as the National Policy of the Elderly (Política Nacional do Idoso, in Portuguese)[2], released in 1994, and the Elderly Statute (Estatuto do Idoso, in Portuguese)[3], established in 2003, tried to preserve the dignity of the old but did not address complex questions. What should be expected at end-of-life situations in terms of access to healthcare resources, the agency of the elderly, and the employment of procedures to extend life?

Until today, the Penal Code does not explicitly regulate three possible terminal case scenarios. In euthanasia, doctors abbreviate the life of the patient to avoid suffering. In orthothanasia, life-extension procedures are not employed, and death follows its natural course. Finally, in dysthanasia, all measures to prolong life are taken, even with the risk of causing suffering or harm to the patient (Felix et al., 2013). For now, the jurisprudence considers euthanasia a homicide and dysthanasia as a possible bodily injury. Orthothanasia stays in a gray zone, and, to try to fill the void, the Federal Medicine Council released two resolutions. The resolution 1.805/2006[4] enables doctors to withhold treatments that only lengthen the patient's life in terminal cases, and the resolution 1.995/2012[5] allows hospitals and doctors to accept Advanced Healthcare Directives (documents that register the patients'

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[1] World Population Prospects: https://esa.un.org/unpd/wpp/

[2] Política Nacional do Idoso (National Policy of the Elderly): http://www.planalto.gov.br/ccivil_03/leis/l8842.htm

[3] Estatuto do Idoso (Elderly Statute): http://www.planalto.gov.br/ccivil_03/leis/2003/l10.741.htm

[4] Resolução (Resolution) CFM Nº 1805/2006: http://www.portalmedico.org.br/resolucoes/cfm/2006/1805_2006.htm

[5] Resolução (Resolution) CFM Nº 1995/2012: http://www.portalmedico.org.br/resolucoes/cfm/2012/1995_2012.pdf

wishes regarding interventions to extend life). The guidelines, however, do not have the same power as the law.

Legal uncertainty is not the only issue for the doctors caring for older, terminally ill patients. Medicalization and biomedicalization changed the expectations and the meaning of dying (Clarke et al., 2009). Moreover, it transformed the relations between older patients and their families. Dying at home, surrounded by relatives, gave space to dying at hospitals, and the medical interventions became expressions of love (Kaufman et al., 2004). Also, with the possibilities of Medicine ingrained in society's values and with broad access to health information online, the patient's empowerment and the idea of choice are influencing the doctor-patient relationship. The citizen-patient and the consumer-patient are new personas coming out in the hospitals and society (Mol et al., 2008, Mol et al., 2010).

While STS and medical sociologists analyze these concepts on a global scale, a regional investigation can bring new standpoints to the discussion. For that reason, I propose a study in my home country, Brazil, to see how the idea of an emergent economy that is aging fast and is marked by inequality affects doctor's perceptions of these trends.

As pointed by Prasad (2014), despite the efforts to erase cultural diversity from technoscientific and, by extension, medical practices, culture, and science are interwoven. Therefore, in this Thesis, I take culture not as a reductionist approach, i.e., as a way to justify why things are done in a certain way in Brazil, but as one more aspect in the creation of ontologies in Medicine, aging, and terminality.

For Mol (2002), multiple ontologies coexist in health care settings. The same patient and his/her disease acquire different meanings and require diverse approaches depending on how several factors are assembled in a given context. Thus, this Master's Thesis investigates the assemblage of these factors and the discourses employed in the definition of the elderly's end of life. Considering that intensive care units are increasingly becoming the places to die for older patients (Brown & Webster, 2004), this study focuses on intensivists physicians. I will analyze how their perceptions of aging, agency of the elderly, biomedicalization, financial aspects, and the loopholes in the legislation influence the decision-making process at the end of life. Mainly, I aim to explain how these understandings are incorporated into their routines and framed in their interactions with patients, families, and other health care professionals.

Given my experience as a journalist, covering the healthcare field for almost 15 years, I believe that researching the ways the elderly are perceived and treated in health care settings can contribute to discussions on how to best address the needs and desires of this growing part of the population. More than that, this study underlines the agency of knowledge and medical technologies. As political actants, they shape people's lives, demand certain behaviors, and also provoke resistance.

Situated in the biggest country of South America, this analysis will also contribute to foster Science, Technology and Society Studies in Latin nations, which are often underrepresented in the field.

1.1 Structure of the Thesis

This Master's Thesis has seven parts. In the State of the Art, I discuss the social construction of Medicine, aging, and death. I argue that, despite claims of universality, medical knowledge is shaped by local economic, cultural, and social contexts and by the technology it uses. Likewise, it is not possible to detach the body from the patient's background to have a precise assessment of his/her health condition. The patient is not only a passive subject but an actor demanding autonomy and willing to negotiate the employment of procedures that are more suitable to his/her reality.

In society, the embeddedness of medical discourses in people's narratives, the prevalence of health risks among their concerns, and the ways Medicine shapes their ideas of disease, aging, and death are characteristics of bio/medicalization. Aging became something to be avoided, and death left the private sphere to evolve into a trajectory with many interventions in intensive care units (ICUs). However, despite the controlled setting of hospitals and many technological tools to monitor, measure, and intervene at the end of life, a lot of uncertainty and subjectivity still surround the diagnosis and the medical conduct. In these situations, doctors struggle to reach consensus and to avoid harming the patient.

In the Research Questions, I propose an STS perspective on the circumstances shaping the end of life in Brazilian ICUs, on the doctor's viewpoint. Thus, my main research question is:

How do intensivist doctors navigate through different scenarios in Brazilian health care setting to address the elderly patient at the end of life?

I complement this question with sub-questions encompassing the legal situation, the role of technology in shaping medical conduct and patient’s and family’s hopes, socio-economic aspects, and society’s perceptions of aging and dying.

To investigate these aspects, I opted for a qualitative method, semi-structured interviews. My sample is composed of six intensive care doctors with different levels of experience and working for three hospitals belonging to a network in São Paulo. To analyze these data, I drew situational maps (Clarke, 2005, Clarke et al. 2015), to lay out all the elements that emerged during the interviews and understand how they relate to each other.

Framed by Mol's works on multiplicity (2002, 2006), and care practices (2008, 2010), as well as Prasad's investigation of culture in technoscientific practices (2014), my thesis centers on the construction of the elderly's terminal cases in hospital settings. These Sensitizing Concepts are useful to understand how doctors assemble multiple factors to choose a way of dealing with a terminally ill elderly patient over others. Furthermore, this assemblage enacts a reality in which patients, family members, and referring physicians are convinced of the best pathway to a good death, as conceptualized by the intensivists.

The data analysis comprises the legal and regulatory aspects, the variety of care practices, and the interchangeable meanings of age, disease, and death, socio-economic issues, the social embeddedness of care, and the conceptualization of a good death. The results explain that terminality is not an exclusive medical definition, but a negotiated one. The doctors, assuming the role of negotiators, must take into account the patients' multiple roles, social and cultural values, economic concerns, family's hopes and beliefs. In addition, they also have to reach consensus among their peers and stay grounded on the best practices in Medicine.

I conclude by showing that there is a lot of (non-medical) work involved in the attendance of the first ethical requirement of the Hippocratic oath: first, do no harm. My interview partners acknowledge their roles as political actors enacting multiple objects to construct the end of life. Therefore, tinkering with the patient's multiple roles, adapting care practices to specific contexts, and trying to be closer and develop empathy with the people in the patient's close relationship circle is as essential as the ability to diagnose and provide the best treatments. More than that, the combination of these skills is what enables doctors to convince the actors on the best pathway in this situation, and stay true to their beliefs on what constitutes an appropriate level of intervention in terminal cases and on what is a life worthwhile.

This thesis, then, adds to the body of knowledge in multiplicity and care practices and offers an STS perspective that broadens the scope of anthropological and sociological studies on the elderly and the health care system in Brazil. Research in a country in the Global South, I argue, calls attention to voices that are often not heard in the global scientific community and to the diverse ways medical knowledge can develop and be put in practice around the world.

2. State of the Art

To contextualize the elderly's end of life in intensive care settings in Brazil, this State of the Art will present anthropological, sociological (including STS) and political perspectives on Medicine, bio/medicalization, and medical technologies, in a broader sense. Throughout this chapter, I will also explore how these issues fit the Brazilian context.

The first part addresses three themes. First, I offer several conceptualizations of the body and the diseases. Here, I take on biomedicine as technology and reflect on the ways it shapes metaphors and discourses that society employs to define what is to be a human, to be a patient, and to be sick. The idea of the body as a machine allows its submission to scrutinies in the search for localized improvements, i.e., technological fixes. Likewise, as a machine, the expectation is that the substitution of the damaged parts is enough to guarantee the extension of life. Therefore, following this idea of interventions as repairments to lengthen lifespan, I explore how doctors and society make sense of care practices and medical knowledge. I finish this section explaining the power relations that result from these understandings of the body, the diseases, and the patients and how economic interests and cultural values are also changing these relations.

The second part explains how medicalization and biomedicalization permeate society and shape the economy, politics, and individual identities. In the same way, I show how technology and the features of a risk society shape medicalization.

The third part deepens the core of this research: the processes of aging and dying and how these life events changed with medicalization.

2.1 Anthropological, sociological and political views on Medicine

Anthropological and sociological perspectives share the understanding that Medicine and biomedicine are sociotechnical systems, socially constructed and situated in a specific temporal, social, and economic context. The ideas and language employed to help people to make sense of the body and the care practices also shape our views of illnesses and the knowledge associated with health. During the Enlightenment, four characteristics defined Medicine: 1) the rigor of scientific methods in medical practices, 2) the conceptualizations of diseases that can be objectively identified, 3) a clear cause-effect between diseases and symptoms, and 4) a linear evolution of the prognosis. More recently, social scientists and anthropologists are arguing that the body and care practices cannot be objective or universal (Lock & Nguyen, 2018, Samson, 1999).

> Embodiment is constituted by the way in which self and others represent the body, drawing on local categories of knowledge, language, and experience. By taking the lived experience of health and illness and the process of embodiment seriously, the limits of the approach commonly upheld in biomedicine, that the human body is amenable to intervention through standardization and decontextualization, is called into question. (Lock & Nguyen, 2018, p. 4)

Lock & Nguyen (2018) developed the concept of biosocial differentiation to call for the revision of these assumptions and the modification of standardized biomedical practices to make up for human diversity. Biosocial differentiation acknowledges both physical variations of the bodies, made even more explicit with DNA mapping, and social and environmental factors that can modify the body. The authors also frame biomedicine as a technology, from the machines employed in diagnosis and surgeries to the anamnesis and prescription. Thus, in their anthropological observation, biomedicine has agency and politics, is embedded in and validated by a complex social context, and changes our perception of what is to be human.

> Not surprising, then, the lives and hopes of people in virtually all parts of the world are touched to some extent by the promise of biomedicine, even when the majority of its medications and more expensive technologies remain largely beyond the reach of most. (Lock & Nguyen, 2018, p. 20)

Echoing this idea, Samson (1999) points to the role of technology in giving meaning to the body at the same time it is shaped by its developers and Medicine. For the author, two main factors enable a vision of the body as "a territory to be colonized, named and controlled" (Samson, 1999, p. 16). The first is the use of scientific methods to identify diseases and intervene to put the body again on the "right" track. This interventionist approach is complemented by the conceptualization of the body as a machine to be fixed and to have "spare parts" substituted.

This approach also contributes to what Foucault (1977) classifies as the "medical gaze" separating the patient's body from his/her identity. For Samson (1999), this dehumanization - and its consequent reductionism - is intensified by technology. Clinical assessment is currently mediated through machines, allowing even the removal of the body from the diagnostic process. This process is now based upon graphs, maps, and indexes, among other representation formats.

In an attempt to bring objectivity and reduce uncertainty and variability, physicians also try to remove the patient from his/her context. This process is contaminated by the doctors’ own perceptions of the world and by the need to understand the impact culture and ethnicity can have on the patients’ compliance with treatment, for example (Lock & Nguyen, 2018, Samson, 1999). Moreover, context is essential to help the doctors in one of their primary functions: to translate the patient's reports to biomedical terms that can, again, be quantified and standardized.

Responding to the critiques of coldness in the doctor-patient relationship, the separation of the patient from his/her body, the negligence of the socio-determinant factors to assess diseases, and the erasure of individuality, Medicine tries to rebuild its practices. However, a change in practices is difficult due to Medicine's entanglement with political and social structures. For Salter (2004), the changes are small and have the aim to keep everything the same. The patient-centered discourse or the imperative of patient empowerment would be ways to make the patient comply with the doctors, not to distribute power. Moreover, Salter argues that even if the patient assumes the role of a rational actor, informed and capable of negotiating and assessing risks, s/he still relies on the medical power to heal, which makes him/her still dependent on the doctors.

Samson (1999) claims that the patient occupies a sick role and needs help to address his/her problem in an area that s/he does not have expertise. The doctor must validate his/her disease, and s/he has no control over the prognosis. In this position of vulnerability, the patient becomes less able to make choices and, being at a disadvantage when it comes to health knowledge, must comply with the doctors' orders or be accused of contributing to his/her own illness. Zola (1972, p. 490) points out that Medicine, as an institution of social control, classifies as "sorely troubled" people who "break appointments, fail to follow treatment regimen or even delay in seeking medical aid."

In the cultural level, conflicts emerge. Doctors tend to dismiss what cannot be proved by Biomedicine, downplaying the patients' knowledge and beliefs. This reaction contributes to keeping the boundaries between medical and lay-knowledge well defined, under the claims of professionalism and rationality. Thus, doctors keep dominating the interactions with the patients and controlling the decision-making process. However, in recent times, a market-oriented approach is draining the doctor's power and autonomy. They are subjected to managerial and economic interests and have to adapt to a patient-centered model of assistance. This form of care helps to empower the patients, who start to confront the professionals seeking alternatives (Conrad, 2007, Samson, 1999). What is more, the empowered patient questions what is deemed by Samson (1999) a mechanical relationship, ingrained in the doctors since medical school and fostered by the payment models, that privilege cost-benefit instead of reliance in this connection.

> In contemporary health care systems, a vast number of economic and other values, including those of the increasingly well-informed patient, need to enter into the decision-making process. The plethora of considerations impinging on clinical consultation renders the detached, professional Hippocratic model of the physician increasingly archaic. The new, post-modern Medicine does not operate according to any fixed, immutable principles, or ethical codes, but through a certain anarchistic plurality. (Samson, 199, pp.191-192)
>
> Lock & Nguyen (2018) notion of the embodiment of care practices will help me to understand how Brazilian doctors conceptualize the elderly's body and its diseases, at the same time they embrace "universal truths" in Medicine. Investigating the doctor-patient relationship and the interests that influence medical conduct will also help me to understand how they make decisions at the end of life and how they manage the hopes that emerge in a medicalized society.

2.2 A medicalized society

The Enlightenment, with its promise of rationality and scientific methods to substitute religious beliefs in the explanation and control of nature, put Medicine on a high status within society. The hope of cure and prolonging of life legitimized this field of knowledge and its professionals. Now, states all over the world have Medicine as an ally and as an institution of social control, and medical knowledge is encompassing more and more fields of society, increasingly labeling human problems as abnormalities passive of interventions by doctors (Foucault, 1978, Samson, 1999, Zola, 1972). For Foucault (1978), another shift giving Medicine more power is the substitution of the right to death to the power over life. If in medieval times the sovereign had the right to kill a subject that represented a threat or did not comply with the law, now governments declare wars in the name of the citizens' lives, and people are willing to be controlled (to the point of self-governance) by statistics.

> One might say that the ancient right to take life or let live was replaced by a power to foster life or disallow it to the point of death. (…) That death is so carefully evaded is

> linked less to new anxiety, which makes death unbearable for our societies than to the fact that the procedures of power have not ceased to turn away from death. (…) death is power's limit, the moment that escapes it; death becomes the most secret aspect of existence, the most private. (Foucault, 1978, p. 138)

This biopower is consolidated by the anatomo-politics of the human body and the bio-politics of the population. The first frames the body as a machine, to be disciplined, explored and integrated into the economy, while the second supervises the species bodies through regulation and interventions, such as levels of health, mortality rates, and life expectancy (Foucault, 1978). The power over life, with the promise to reduce the risk of death through medical knowledge, was another factor giving Medicine a regulatory function, but, mainly, the high position of Medicine in society lies in the power of definition. Labeling human problems as medical problems contributes to putting the patient in a passive role. In addition, using mechanical analogies to give meaning to the body and its diseases, such as the comparison with clocks, pumps, and pistons, reinforce the material and rational approach to the body. Thus, the passive patient is lead to submit his machine (the body) to repairs by the doctors (Conrad, 2007, Samson, 1999).

Moreover, Foucault lists three aspects of a medicalized society. The quest for normality makes the patient want to fit an average indicator instead of re-establishing his/her health. At the same time that individual health marks must be, for example, lowered to fit the conceptualization of an ideal individual (e.g.,, LDL cholesterol, arterial blood pressure, etc., pathologic anatomy makes the disease unique. And, in the end, the individual patient is placed in a homogeneous and collective space, allowing comparison, despite the peculiarities of her/his condition (Foucault, 1977).

For Conrad (2007), medicalization is "a form of collective action" (Conrad, 2007, p. 9) that has three main reasons. The first is the authority of the medical profession and the expansion of medical jurisdiction. The second is the effort of social movements and interest groups to come to a definition of a problem in medical terms (e.g., alcoholism). The third is the professional organization to define and treat problems, as well as the drawing of boundaries to push other professions away from health care (e.g., the loss of recognition of the professional status of midwives in favor of obstetricians).

Thus, Conrad (2007) argues, medicalization spreads with society's support and its willingness to accept the medical framework to identify, explain, and address problems. Conrad (2007) contests the views of medical imperialism, colonization of the body by Medicine, and moral entrepreneurship and highlights the transformations in society that contributed to the rise of this phenomenon. Among these factors are society's lower tolerance with anomalies and discomfort, the role of corporative actors, such as pharmaceutical and health insurance companies, the evolution of biotechnology, and the growing drive of commercial and market interests in Medicine.

The appropriation of medical terms to explain human problems and the construction of people's identity through their health conditions (Foucault, 1978, Hacking, 2006, Lock & Nguyen, 2018, Samson, 1999) is rising even more since the 1950s. In the post-war, Medicine started to occupy a more representative role in the Gross Domestic Product, and the ratio of doctors per citizen increased (Conrad, 2007). The trend, associated, in the beginning, with higher-income countries, has spread throughout the world, although with an uneven distribution of health services. In Latin-America, a shift from the understanding of health as a right to a market-oriented approach turns patients into consumers and adds, in Murguía, Ordorika & Lendo (2016) words, to "the age-old inequalities in the region" (p.7). While the poorest part of the population is excluded or has limited access to health resources, the richer overuses services and medications, replicating "American health consumerism" (p. 7). In Brazil, where this research takes place, the ratio of doctors per person was 1: 1,988 in the 1950s and 1:459 in 2017. The country now has almost half a million doctors[6], and health care expenditures now represent 9,1% of the GDP[7]. But, confirming Murguía, Ordorika & Lendo's (2016) statements, resources are unevenly distributed. The private sector bears most of the expenses, despite only a quarter of the population having private insurance[8], and the richest regions of the country concentrate most of the doctors[9].

The market-oriented approach and the evolution of technology, that added a yet stronger emphasis in the understanding of the body as an issue to be treated by Medicine

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[6] Censo Médico (Medical Census) - Conselho Federal de Medicina (Federal Medicine Council): http://www.portal.cfm.org.br/index.php?option=com_content&view=article&id=27500:2018-03-19-19-09-56&catid=3

[7] Gastos com saúde crescem mesmo em meio à crise e atingem 9,1% do PIB (Health care expenditures grow even in the middle of the crisis and hit 9,1% of the GDP) - Agência Brasil: http://agenciabrasil.ebc.com.br/economia/noticia/2017-12/gastos-com-saude-crescem-mesmo-em-meio-crise-e-atingem-91-do-pib

[8] Gastos com saúde crescem mesmo em meio à crise e atingem 9,1% do PIB (Health care expenditures grow even in the middle of the crisis and hit 9,1% of the GDP) - Agência Brasil: http://agenciabrasil.ebc.com.br/economia/noticia/2017-12/gastos-com-saude-crescem-mesmo-em-meio-crise-e-atingem-91-do-pib

[9] Censo Médico (Medical Census) - Conselho Federal de Medicina (Federal Medicine Council): http://www.portal.cfm.org.br/index.php?option=com_content&view=article&id=27500:2018-03-19-19-09-56&catid=3

and allowed scrutinies even at a molecular level (Brown & Webster, 2004, Clarke, Shim, Mamo, Fosket & Fisherman 2003, Conrad, 2007) led to the phenomenon of biomedicalization. For Clarke et al. (2009, p. 26), biomedicalization is characterized by its influence in the biopolitical economy, an intense focus on health and fitness, the transformation of biomedical practices through technology, the modifications on the production, distribution, and consumption of knowledge and the transformation on bodies and identities.

This new conjuncture influences the payment models for health care providers, the tendency to consider former normal health indexes as risky, such as those related to hypertension or diabetes, and the spread of technologies to diagnose and treat patients (Clarke et al., 2003). One unfolding of this trend is the creation of anti-aging Medicine that considers medical interventions appropriate at all ages. For this specialty, aging is a painful biological decline and, to prevent it, parameters to classify what is considered normal in health care for the older must be stricter (Conrad, 2007, Mykytin 2010).

These very same conditions can be observed in Brazil, as shown by discussions on the right to die with dignity versus the use of a growing variety of therapies to extend life, even at the expense of the patient's well-being. Dysthanasia, according to Felix, Costa, Alves, Andrade, Duarte & Brito (2013), happens due to an understanding that Medicine can fix conditions related to death, and that death itself should be avoided at all costs.

Despite the growth of medicalization and biomedicalization, medical sociologists express their concerns on what they see as the social control of behavior and the favoritism of medical intervention over social solutions. The "pathologization of everything" (Conrad, 2007) changes the definition of what is normal by Medicine and leads to the commodification of health services. Also, it ignores the uncertainty related to suffering or damages caused by medical intervention, and put the focus on the individual, instead of the context.

Resistance also starts to emerge in society, with pushes to de-medicalize certain conditions and behaviors, like homosexuality. There is a growing awareness that, despite de-stigmatizing certain conditions and behaviors, medicalization also lowers the tolerance to diversity and might not lead to better care. These "pockets of resistance" (Conrad, 2007. p. 146), are, however, punctual and do not seem to threaten the bio/medicalization hegemony.

Several corporate and politically organized players are delineating what is appropriated or not in this medicalized society. Pharmaceutical companies and other health industries finance clinical trials and, consequently, shape the definitions of disorders and diseases. Insurance companies, concerned with the costs, use their payment policies to influence the offer of services. Lastly, patient groups, with the help of the internet, are questioning definitions and conducts in the medical sector and, sometimes, even advocating for de-medicalization. (Brown & Webster, 2004, Conrad, 2007, Dummit, 2012).

From the patients' perspective, health technologies must be employed with a reasonable approach. Benjamin's (2016) work on the biodefectors, people that resist biologically based citizenship opting out of experiments or treatments that seem to threaten their identities, collectivities, or even their health, shows that citizens view technology as something to be chosen, not to be compulsorily used. They are also aware of the limitations and risks involved in the development of science, technology, and medical practices. Moreover, especially for the elderly, accepting a disease's diagnosis and complying with the use of health technologies could mean a "foretaste of social and/or physical death", since "his [the patient] normative expectations are reduced in the same way as the chronically ill and the severely disabled" (Johnson, 1972, p.527).

At the institutional level, the current way of practicing Medicine does not contribute to identifying the patient as the leader of his own care. Kaufman, Sim & Russ (2004) explain that a new kind of ethical knowledge is coming up with the biomedicalization of aging. Nowadays, routine health care overshadows choice, expectations about longevity lead to the normalization of interventions to extend life, and the use of technology becomes a moral imperative.

> Physicians' understanding of the shifting imperative to treat at older ages contribute, pragmatically, to the elimination of any deliberation about treatment options for an individual case, and thus standard practice replaces choice. The idea that Medicine can be expected to intervene, always, even in very late life, is therefore strengthened. That idea is one of the most potent "truths" of the contemporary era. (Kaufman et al., 2004. p. 739)

2.2.1 Medicalization and technology

In the same way medicalization influences society's behaviors, values, and expectations, technology also contributes to shaping the medical knowledge and the profession. Brown & Webster (2004) highlight the way new medical technologies seek to bring novelty to Medicine, with a focus on standardization, while, at the same time, promising individualization. Technology and shifting care practices are also curbing the doctor's autonomy, in an attempt to transform Medicine from "an art to a science" (Berg, 1997, p.11). Protocols, clinical decision analysis based on statistics and tools to support medical decision-making have, on the one hand, contributed to reducing variability in diagnosis, treatments, and outcomes, providing more safety for the patients. On the other hand, these systems' inferences failed to account for the messiness of the real world and the context in which a disease develops. They are criticized for their reductionism and for limiting the doctor's decision-making power.

Like many other technological developments, this one is also justified by the problem-solution dichotomy, as if the problem was laying there, waiting for a solution, despite a less linear and more diverse perspective in the real world (Berg, 1997). Besides, as it happens with medicalization, the power to define the problem also shapes the solution:

> (…) In the early postwar discourse, the problems of diagnostic errors and "unnecessary surgery" were often ascribed to unfavorable circumstances in which physicians were forced to work. Now, however, they are attributed to the occurrence of "pathology" in the physician's decision making.
>
> In line with these changes, decision-support techniques are more and more called upon to aid the physicians' floundering mind, not to amend the structure of medical action. (Berg, 1997, p. 37)

Exposing the doctor's misjudgments to justify the need for decision-support tools also forces new arrangements between doctors and patients and changes the status of the medical profession in society. Tacit knowledge becomes less valuable since standardized indexes and protocols often determine diagnosis and treatment. The patients, with easy access to health information online, also based in statistics and pre-defined standards, ask for specific medical solutions and start to assume the role of customers (Conrad, 2007, Brown & Webster, 2004). The erosion of medical authority and the influence of different players transform health care into a commodity, subject to the payers' demand and stricter management of its services.

Affecting also the medical and individual perceptions on the body, technology is changing the ways doctors handle diseases and the conception of a life course. While the linear idea of birth, growth, reproduction, and death might help the doctors manage health conditions and offer a somewhat logical evaluation, technologies keep pushing these boundaries and raising people's expectations regarding their health and life expectancy.

Interventions on acute conditions are now safer, faster, and easier, but they also contribute to enlarge the pool of chronic patients in society. This transformation is perceived in hospitals, that are becoming places to stabilize the decompensated conditions of chronic diseases (Brown & Webster, 2004).

While contributing to save and even enhance life, medical technologies can result in more patients to be treated and add to the complexity of care practices, since in many cases, one new equipment, drug, or procedure does not substitute the old one. Furthermore, as a strategy to open or enlarge the market for a new technology, technology developers also act to propel the redefinition of disorders and risks. The categorization of the potentially ill and the lowering definitions of risk, that creates new patients like the pre-hypertensive or the pre-diabetic, impact on people's identity, social status, and eligibility for insurance. Diseases are even more a public experience, and patients are encouraged to self-assess their bodies in search of abnormalities passive of treatment (Conrad, 2007, Dummit, 2012). The "expert patient", always up to date with health recommendations, understands that s/he has the power to choose his/her therapeutic options and to shape the disease's course. Governments, health-related companies, and doctors also expect s/he to assume responsibility for his/her treatment and share the burden and consequences of his/her decision. (Brown & Webster, 2004, Dummit, 2012)

2.2.2 Medicalization and risk

A society in which medical knowledge and definitions influence people's identities, the economy, and politics is also tightly connected with the notion of risk and the imperative to preserve life. The idea that risk can be calculated, managed and avoided is crucial to assign power to some institutions and experts and control most of the population that, in a passive role, voluntarily complies to become a subject of government, or in the case of this research, Medicine (Foucault, 1978, 1991, Lupton, 1999).

> In late modern societies, not to engage in risk-avoiding behavior is considered "a failure of the self to take care of itself - a form of irrationality, or simply a lack of skillfulness (Greco 1993: 361). Risk avoiding behavior, therefore, becomes viewed as a moral enterprise related to issues of self-control, self-knowledge, and self-improvement. (…) Because the project of selfhood is never complete, but rather is continuing throughout the lifespan, so too the project of risk avoidance as a technology of the self is never-ending, requiring eternal vigilance.
>
> (Lupton, 1999, pp. 90-91)

For Beck (1999), we live in a risk society, in which: 1) "cultural perception and definition constitute risk" (p. 135); 2) we are continuously looking at future consequences to decide our path of action in the present; 3) the definition of risk reflects our worries and aspirations on how to live; danger and protection come from the same agents; 4) a logic of control dominates the daily life; 5) more knowledge is the cause of new risks; 6) different actors contradict each other, and reflexive societies undermine the very risk logic that governs their ways of living; 7) "knowledge about risks is tied to the history and symbol of one's culture and the social fabric of knowledge", leading to different ways of dealing with the same risks (Beck, 1999, p. 143); 8) there is a loss of clear distinction between nature and culture.

Therefore, in a medicalized society, dominated by perceptions and discourses of risk, even the empowered, knowledgeable patient is in a passive role, willing to accept "technologies of surveillance" that can create even more risks and uncertainties (Brown & Webster, 2004). The medicalization of risk also reflects the dominance of risk in our daily lives and thoughts. Conrad (2007) describes how complaints of health issues are still rising, even though, from a historical perspective, health is improving along time. Dummit (2012) coins the concept of "surplus health": an attempt to avoid risks by continually lowering the thresholds to define a person at risk of developing diseases. In this context, people become patients not because of an actual disease or because of symptoms that can be felt and seen, but because they have risk profiles (Brown & Webster, 2004, Dummit, 2012). Since the line between real diseases and the risk to develop them is not clear, and the indexes to define risks and normality are always lower, nobody can safely claim that s/he is healthy (Conrad, 2007, Dummit, 2012). The awareness of dangers related to medical technology and care practices (iatrogenesis: side-effects caused by the treatment) push people to look for alternatives. Meanwhile, the doctors are persuaded to adopt evidence-based practices that restrain their judgments and courses of action and silence the multiplicity of contexts and health conditions of the patients (Brown & Webster, 2004).

Looking at how bio/medicalization and medical technologies transformed the economy, society's structures, values, and conceptualizations of risk will support my approach to the main theme of this thesis. Recognizing the central role doctors experience in contemporary societies, I am putting them at the center of this research. It is through their perspectives that aging and death are enacted in hospital settings.

2.3 Aging and dying in a techno-scientific era

STS studies are presenting the narratives employed to position techno-scientific innovation as the solution to alleviate the impact of aging in society, to provide a better life for the older, and to fuel the economy. These accounts deem aging as a problem to be tackled, even avoided, if possible, instead of a natural human condition that needs to be accommodated in the society (Joyce, Peine, Neven & Kohlbacher, 2017).

These imaginaries of the older people erase their diversity and agency and position them as passive actors, sick, frail, near-death, and in need of constant medical surveillance (Joyce et al., 2017). Conrad (2007) also points to the medicalization of aging, manifested by "the increasing medical jurisdiction over the whole process of aging- from minor memory deficits to mobility limits to the process of dying" (p. 120). With the expanding surveillance and possibilities of intervention brought by Medicine and medical technology, the discourse of death by aging becomes unacceptable for people that have access to medical care regularly (Brown & Webster, 2004, Conrad, 2007).

Despite the push to amenably accept interventions in order to prolong their remaining years, studies on elders as technology users show that they "create, use and adapt technology to negotiate health and illness in daily life" (Joyce & Loe, 2010). This technogenarians, or graying cyborgs (knowledgeable techno-scientific users) as defined by Joyce & Loe (2010), might employ technology selectively:

> Elders express concern about the sheer number of pills and procedures in their lives and may work to actively resist medicalization in order to accomplish self-care and personal comfort. (Loe, 2014, p. 141)

The biotech ambivalence perceived by Loe (2014) shows that the older welcome the benefits of the advances of Medicine, but are aware of its overuses, rejecting an extension of life that does not come along with the quality of life. In a broader spectrum, however, the elderly opinion might not be prioritized due to family dynamics and social contexts.

As Kaufman et al. (2004) put it, with the new family dynamics, where clinical acts are understood as expressions of love, the hope boosted by scientific findings, and the broadening of Medicine's scope over the management of old age, saying "no" to medical interventions is almost impossible. The authors (2004) also observe that, in the family circle, as expressions of love, the patients are pressed by the need to stay alive, and the relatives feel obligated to press doctors for medical treatment. Adding complexity to this situation, in Brazil, the elderly are also breadwinners: almost 11 million people depend on their retirement money to survive[10]. Despite having their rights to health and autonomy assured by the

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[10] Número de lares que dependem da renda de aposentados cresce 12% em um ano [Number of homes that depend on the retired income grows 12% in one year] https://economia.estadao.com.br/noticias/geral,numero-de-lares-que-dependem-da-renda-de-aposentados-cresce-12-em-um-ano,70002402366

National Policy of the Elderly and the Elderly Statute, there are still studies exposing the infantilization of old patients. Also, media portraits help to shape the elderly as someone that is a burden to society (Côrrea, Santos, Rolim & Coutinho, 2016, Floriano, Reiners & Sudré, 2012, Santos & Almeida, 2002, Gandolpho & Ferrari, 2006).

Brown & Webster (2004) also underline the current mindset among health care workers and providers, that concentrates efforts to avoid early deaths (younger patients), despite the initiatives to remove age as a basis for diagnosis (Conrad, 2007). Still, at the end of life, for the doctors, the risk of harm is evaluated in the face of the quality of life, that is, the ability to give back to society a patient that is functional and able to keep up with the economic and social demands. For the patient, the risk of harm is mainly evaluated in the face of the fear of suffering (Lawton, 2001).

What being old or being at the end of life means is, however, disputable. Factors like medicalization and the launch of new medical technologies are also reshaping the notions of normality and abnormality, and the range of problems that can be tackled by Medicine. More than that, bio/medicalization enables the emergence of new ideas about diseases and the meaning of death, that, instead of being a regular event in life, now is "the result of the constellation of diseases, germs or complications that set in." (Brown & Webster, 2004, p. 135)

Death, now, happens inside a hospital, and it is not natural anymore but caused by a specific clinical condition.

> Medicalization might be said to have three consequences: first, medicalization often means that the process of dying is prolonged simply because of the impact and use of life-extending technologies (such as advanced ventilatory or resuscitation techniques); the second consequence is a sense of loss of control over death, experienced especially by the elderly people, who may be excluded from the decision-making process surrounding the termination of their lives; and finally, a third consequence is the medical administration of death, whereby by dying and the dead need to be accounted for in terms of the economic costs their end-of-life clinical care will incur. (Brown & Webster, 2004, p. 135)

2.3.1 The end of life in hospital settings

Brown & Webster (2004) claim that the medicalization of death is the result of a combination of social and technological factors. As a way to cope with death, religion was substituted by the secularized idea that death can be managed by the patient, that is able to opt for a healthy lifestyle. Moreover, the idea of control comes from the constant monitoring of the body to postpone its decay, for example, and by medical knowledge and technology. Dying also became an individualized experience, instead of a social event, marked by medical diagnosis and clinical interventions. This shifting paradigm turns the progressive deterioration of the body embarrassing. To handle the loss of the functions, avoid the burden on relatives, and assure the quality of care, people turn to hospitals to hide the dying process from the public view.

Inside the hospital, intensive care units, with all the technology available to monitor vital signs and to support the extension of life, became the most important places to manage death. With all the resources available, and despite standardized practices to handle the end of life, death is not easily defined. This definition depends on the consensus on different specialists' views, on negotiations with patients and their family members, adaptation to the legal landscape, ethics requirements, and the cultural and social context of the patient and the doctor. Instead of a sudden event, death becomes, then, a trajectory, socially constructed and with ramifications in biology, social-policy, and the patient's subjective perspectives. Mainly, it is the result of the loss of ability to live independently, a concept defined, most of the time, according to comfort, dignity, and quality of life criteria, that allow the withdrawal of efforts to keep the patient alive. (Brown & Webster, 2004, Lawton, 2001)

Kaplan & Schneider (2001), nonetheless, argue that diagnosis and assessment of risks and outcomes related to one specific treatment are not always reliable, especially when it comes to chronic diseases that challenge the binary traditional biomedical models (a person is sick or is not). Despite efforts and models developed to measure the quality of life, the end of life, survival rates, and effectiveness of medical interventions, much of the variance in outcomes is unexplained. In patients with multimorbidities (the coexistence of several health problems), which is often the case with the elderly, new diagnosis have a small impact on life expectancy, and the risks of side effects are higher.

When cost-benefit is considered, more procedures and the employment of technologies to extend life do not result directly in a better quality of life or higher life expectancy, which lead to discussions about medical futility. For Kaplan & Schneider (2001), one intervention can be considered futile if it did not work in a hundred consecutive cases or if the measures taken cannot result in a conscious patient, able to survive outside the hospital. The authors also point that therapeutic obstinacy (or dysthanasia) can have ethical, economic, and health policy implications, like the high-costs of the interventions and, in many cases, painful outcomes that do not contribute to re-establish the health. According to

Pessini & Hossne (2013), in these cases, "instruments for cure and care are transformed into tools of torture" (p. 36).

The distinction between appropriate medical care and dysthanasia, however, conflicts in practice with the doctors' understandings of their professional duties, negligences, and the dichotomy between doing whatever is possible to prolong life and do no harm. Besides, the prognosis of terminality must be communicated to the patients and their family members, so they can express their wishes regarding interventions and have their autonomy guaranteed. In the case of older patients, miscommunication can happen due to their difficulty in understanding the situation, or due to the denomination of a proxy, that might have different opinions than the patient on what should be done (Kaplan & Schneider, 2001). In Brazil, the situation is worse because of the lack of legal directions when it comes to euthanasia, orthothanasia, and dysthanasia (Felix et al., 2013). Trying to compensate for an outdated Penal Code, that did not consider the changes in medical technology and in the epidemiological profile in the last 60 years, the Federal Medicine Council tried to bring clarity to the matter by issuing resolutions that exempt doctors from the accusations of malpractice in the case of orthothanasia. In line with the Elderly's Statute, the resolutions also envisage the patient as an autonomous citizen, able to register his/her last wishes in Advanced Health Care Directives.

Pessini & Hossne (2013) situate Advanced Health Care Directives as a middle ground between the medical paternalism and the patient's autonomy. The authors also support a critical revision of the Brazilian legal standing at the end of life scenarios, which seems crucial to assert the patient's will. A study conducted by Felix et al. (2013) shows that the Brazilian doctors are willing to accept these document but they also acknowledge the need for regulation to make the expression of the patients' last wishes valid (Felix et al. 2013).

More than tools to assure the patient's autonomy and a way to make doctor's share the power of decision at the end of life, Advanced Care Directives can also be understood as a means to de-medicalize death. However, de-medicalization alternatives are also falling into the Medicine realm. Aware of the "highly unnatural death" (Brown & Webster, 2004, p.145) imposed by technology, doctors are trying to mimic a natural death, responding according to the contingencies, offering palliative care, or gradually withdrawing life-extending technologies. In the end, a good death is a negotiated definition, but "doctors are still the gate-keepers of medical treatment" (Conrad, 2007, p. 142) and hold the prerogatives to make a health-related decision.

This State of the Art started exploring how Anthropology and Sociology conceptualize Medicine and its role in shaping society's hopes towards technology to offer a cure, define the body and the diseases and establish power positions in the doctor-patient relationship. Omnipresent in contemporary societies, Medicine became an institution of social control and also changed the experiences of aging and dying. At the same time, it was shaped by society's evolving developments in culture, politics, and economy.

In Brazil, the site of my research, a rapid epidemiological change might be speeding up the bio/medicalization of aging and dying. In a context of increasing discussions about the adequacy of the law to attend terminal cases, restricted resources to invest in health, and the downplaying of an ever-growing share of the population, this study aspires to offer fresh perspectives on the doctors' line of thoughts when caring for the elderly. Further, it hopes to set discussions about what is a desirable death, a theme that is still a taboo in the country, and how to best address the older patient's wishes in hospital settings.

3. Sensitizing Concepts

Ambiguity and uncertainty surround the end of life, and its meaning is contingent on time, location, cultural values, and the doctor's own perceptions and experiences. Nonetheless, several models and formulas try to make the assessment of the terminality objective and disconnected from the social context.

Aware of the limitations and dangers of these and other strict measures related to care practices, Mol (2002) suggests the incorporation of uncertainty and multiplicity in Medicine. She rejects the idea of contradiction and points out that divergences are the result of meanings that serve different objectives. Instead of looking for what is real or what is the truth, the author advocates the pursuit of goodness.

> If faithful representations no longer hold the power to ground us, we may still seek positive interventions. Thus, instead of truth, goodness comes to the center of the stage. Or rather, not goodness, as if there were only one version of it, but goodnesses. Once we accept that ontology is multiple and reality leaves us in doubt, it becomes all the more urgent to attend to modes and modalities of seeking, neglecting, celebrating, fighting, and otherwise living the good in this, that, or the other of its many guises. (Mol, 2002, p. 165-166)

The pursuit of goodness, nonetheless, is complex and requires the mediation of several interests, expectations, and needs. One obstacle in this pathway, miscommunication, or merely the divergence about what is good, already influences the enactment of the objects, i.e., the patient and his/her condition, with a direct impact on what to do. Beyond protocols and scientific evidence, the medical practices need to be established in each case, to account for the varieties in identities, bodies, diseases, life values, and expected outcomes. (Berg & Mol, 1998, Mol, 2002, Mol et al., 2010)

Therefore, to explain how the doctors navigate through multiple understandings of the elderly patient, his/her condition, and his/her context to frame aging and terminality, this thesis will use three sets of concepts as theoretical framework: 1) the multiplicity of the medical practice, the body, and the aging patient; 2) care in practice and logics of care; 3) culture in medical practices.

The idea is to gain a deeper understanding of the construction of the elderly's terminal cases in hospital settings, encompassing patient's autonomy, family relationships, the appropriate level of intervention, legal aspects, and financial pressures, among other issues. In combination, these three sets of concepts will help me to situate the physician's agency and discourses, focusing on the power relations, uncertainties, and ambivalences involved in the reasons appointed by professionals to choose a way of dealing with a terminally ill elderly patient over the others.

3.1 The multiplicity of the medical practice, the body, and the patient

In intensive care units, different understandings of the body, the aging patient, and the appropriate medical conduct to treat the elderly patient must converge to reach a decision at the end of life.

Introduced by Mol (2002), the concept of the body multiple will help me to analyze how all these meanings coexist in the same patient or the same situation and also how they can change due to the circumstances. Her case study about the diagnosis of lower-limb atherosclerosis in a Dutch hospital shows how patients, pathologists, radiologists, and surgeons experience and define the same disease in different ways. For the pathologists, atherosclerosis is a thickening of the intima through a microscope. For the patients, is a leg that hurts when they walk. For the surgeon, the materialization of atherosclerosis only happens when the patient complains, and s/he can verify the disease checking the bad pulsations in the dorsal foot artery. For the radiologist, is the lumen loss showed in an angiography. Therefore, a single patient, with what appears to be a well-defined condition, contains multiple diseases and multiple bodies.

As explained by the author, this is not to say that the view of the patient is fragmented, but rather that it is multiplied. Reality is enacted according to the arrangement of the objects by different health professionals and situations. The definition of a disease, a condition, or even of the patient himself/herself cannot be studied disconnected from the care practices, and these same practices are dependent on the object identities and the articulation of these identities. The result is also multiple ways of handling a patient and his/her condition, from the interactions in the doctor-patient relationship to his/her assessment by a multidisciplinary team.

Therefore, a terminally ill older person is not only a patient but also a citizen, a customer, a father/mother, and a breadwinner. His/her persona and his/her condition have different meanings for healthcare professionals, family members, and legislators, but all these identities coexist at the same time and must be coordinated to reach a diagnosis and define the medical conduct.

Also, age has multiple, coexistent meanings. It defines politics, changes the way society and family members see the patient, and, in medical practice, can be considered just a number, an impending or challenging factor to a procedure or a justification to not pursue further treatment. This does not mean that doctors' perspectives change over time or that they are employing the discourses that seem adequate to reach their goals but that the reality changes according to the enactment of the objects in care practices.

Finally, the medical practice, entangling cure and care even at the end of life, can be interventionist and comforting, cold and warm, technical and human, based on guidelines and led by subjective factors and tacit knowledge. The idea of unity in Medicine, then, gives space for diversity, variations, uncertainty, and plurality (Berg & Mol, 1998):

> (…) Medicine is not a coherent whole. It is not a unity. It is, rather, an amalgam of thoughts, a mixture of habits, an assemblage of techniques. Medicine is a heterogeneous coalition of ways of handling bodies, studying pictures, making numbers, conducting conversations. Wherever you look, in hospitals, clinics, in laboratories, in general practitioner's offices - there is multiplicity. (Berg & Mol, 1998, p. 3)

Even inside the medical community, in spite of the appearance of unity, variety prevails. Evidence-based Medicine may guide clinical conduct, but a "juxtaposition of countless procedures: conversational techniques and staining methods, medications and operations, graphs and photographs" (Berg & Mol, 1998, p. 5) can result in different approaches and outcomes.

Moreover, Medicine also takes into account the suffering and social practices. Citing Barbara Smith's article on black lung disease, Berg & Mol (1998) show how X-Ray was not enough to construct the illness' reality. Black lung disease has one meaning for the shareholders of the mine companies, i.e., how black is the lung to define compensations, and a different one for miners, i.e., how much they suffered and were limited by this condition. Western Medicine also started to embrace different knowledges and practices, combining techniques deemed scientific to other healing practices more attentive to the individuals. Finally, the idea of the present is substituted by the coexistence of the past and the present. According to Berg & Mol (1998), a new technique gains the market by comparing its specificities to the previous one and appropriating the discourses of novelty and future. However, "older" technologies, knowledges, and procedures are often reallocated instead of substituted, making time multiple. Instead of discarding the past, present contains it; instead of following a linear trajectory, present "takes the form of folds of loops and spiral" (Berg & Mol, 1998, p. 5).

Finally, the patient is not a unity, a single body, anymore, but "(…) a composite picture involving many measurements, numbers, intuitions, habits, humans - not to mention dead ends and (often unresolvable) contradictions." (Berg & Mol, 1998, p.7)

All these frictions and tensions contribute to configuring a body inserted in the realm of Medicine and the political world. Medical practice, then, is political "in the way that disease is established, the body is touched, patients are treated, cells are counted, and problems are solved." (Berg & Mol, 1998, p.8)

3.1.1 Politics of Medicine and multiplicity

Instead of looking for a precise depiction of the reality of terminal cases in hospital settings, I propose an investigation focused on practices. For Mol (2002), the realities of an object only exist within the practices in which they are manipulated, and the social is always embedded in these practices, therefore "reality moves" (p. 165). The objects of research, or, in this case, care practices, also assume interchangeable roles. For Mol, in spite of having their bodies and problems framed and shaped by Medicine, the patient is not a passive object, but one that comes "into being and disappear with the practices in which they are manipulated" (Mol, 2002, p.5). This patient keeps his/her agency by using the objectification, i.e., his medical identity, to become a self (Berg & Mol, 1998).

The activities to coordinate the enactments of objects encompass different concerns, impact factors, and understandings. At the same time, they build the body as a boundary object, with enough commonalities to facilitate the communication among several specialists, allow the local adjustments of protocols and turn the patient's disease into a manageable condition, visible through different techniques and subjected to classification and protocols (Mol, 2002). The ontology of the body and the disease is, thus, situated, incorporating implicit knowledge and embedded in social, cultural, and political values and contexts.

> Ontologies are, instead, highly topical matters. They inform and are informed by our bodies, the organization of our health care systems, the rhythms and pains of our diseases, and the shape of our technologies. All of these, all at once, all intertwined, all in tension. If reality is multiple, it is also political. (Mol, 2002 p.6)

Seeking the truth among multiple ontologies and a reality that is not solid, but enacted, becomes an impossible task, that should be substituted for the pursuit of goodness.

Under the “politics of who” (Mol, 2002, p.166), good is to assure the patient’s autonomy, a goal that often clashes with medical premises of trying to cure or, at least, offer care to guarantee comfort. The definition of what counts as good depends on the role of the actors involved in this multiple reality. Following the logic of the market, doctors must present the treatment options like products, and the choice becomes individualized, fitting the patient’s specific needs. A civic perspective ties medical interventions to policy measures, and the citizen-patient must argue why a given route is the best for his/her case. His/her autonomy limit is bound to not causing harm to others, albeit this definition is also not so obvious. The problems with the “politics of who” are the dilemma between the right to choose and what needs to be done, the de-contextualization of choice from the moment it is made, and the failed attempt to reduce doctors’ power to decide. In the end, doctors hold the knowledge and are the guardians of health technologies, and, because of this, they can present the diagnosis or prognosis in a way that shapes the patient’s evaluation of their conditions (Mol, 2002).

According to the “politics of what” (Mol, 2002, p. 172), a normative profession, like Medicine, tries to set parameters to decide what to do to achieve its goals, namely, improve health and prolong life. However, in the pursuit of goodness, the naturalized norms followed by doctors aiming at survival do not account for the complexity brought by higher life expectancy and chronic diseases, for example. Avoiding suffering also becomes a central concern, and quality of life measures arise. Mol (2002) criticizes the adoption of yet another standard to support decision-making, since quantification naturalizes the index, silences political concerns, and prevents broader debates about the consequences of its adoption.

The author proposes to unveil the politics and economics of every activity related to care practices and to explore the ways of doing good, from the establishment of the concept to the setting of limits, i.e., how multiple goods are enacted in a given situation. This approach raises questions about the right of the actors (doctors, patients, family members, regulators, legislators, payers, etc.) and their adequacy to define what counts as good. Further, it spotlights the norms in Medicine that might naturalize one pathway instead of the other; the framing of the health condition and the following communication (prognosis); and, finally, the trade-offs involved in the decision-making process at the end of life (Berg & Mol, 1998, Mol, 2002, Mol, 2008, Mol et al., 2010).

> The world we live in is not one: there are a lot of ways to live. They come with different ontologies and different ways of grading the good. They are political in that the differences between them are of an irreducible kind. But they are not exclusive.

> And there is no we to stand outside or above them, able to master them or choose between them: we are implied. Action, like everything else, is enacted, too. (Mol, 2002, p. 181)

Multiplicity, as a sensitizing concept, helps me to take the focus away from contradictions and understand divergences as the results of a specific configuration of reality. Thus, highlighting the routines and the multiplicity of realities, practices, bodies, and diseases puts attention on the politics of Medicine and the interlacing of inside and outside, of what is cultural and what is scientific, what is social and what is technical. The process of forming a terminally ill patient, then, enacts the elderly's end of life in intensive care units.

3.2 Care in practice and logics of care

With a shift of care from the domestic realm to health care institutions, new meanings of the body, the appropriateness of interventions, the doctors and patients' roles emerged, drawing the attention of the sociologists and philosophers to the matter. Analyzing practices of care for humans and animals in different settings, Mol, Moser & Pols (2010) point to how technologies, knowledges, and care practices are interdependent and fluid. The best way to think about their development and employment is by looking at how they change or adapt in relation to each other. In intensive care units, this is reflected in the ways doctors assemble these three resources to reach what they deem as the best outcome for individual patients, beyond what is determined by protocols or the resources available. For the authors, this is the definition of care as embodied practices:

> Rather than requiring impartial judgments and firm decisions, they demand attuned attentiveness and adaptive tinkering. Crucially, in care practices, what it is to be human has more to do with being fragile than with mastering the world. This does not imply a docile acceptance of fate: care is active, it seeks to improve life". (Mol et al., 2010, p. 15)

Looking at the data through Mol et al. (2010) conceptualization of practices of care will help me to understand why some attitudes and practices are fostered and considered good, and others are avoided and deemed as a bad performance. Beyond common sense, in a complex end of life scenario, ambivalence and unintended consequences weaken this dualism and even transforms the good in evil and the bad in good. Practices and logics of care will also help me to highlight power structures and the social embeddedness of care.

According to Mol et al. (2010), academics tend only to analyze the appropriateness of care. They view the receiving end of care as the weak link, relegated to a passive role or with limited options and possibilities to exercise their wishes due to the constraints imposed by the disease. Meanwhile, the caregivers are mainly worried about “putting right something that is failing” (Mol et al. 2010, p.9), instead of with the person submitted to it as a whole. However, this somewhat limiting view ignores the practices of self-care (e.g., taking medications, following diets and exercise programs, etc.), for example, and the social changes that culminated in the current roles assigned to patients: customers and citizens.

Therefore, the idea of medical dominance and paternalism is slowly giving space to the assessment and even the questioning of the care practices. Proper medical care must be focused not only on efficacy and conducts based on scientific evidence, but also on the respect of the patient’s wishes (Mol et al. 2010). The new “ethics of care” (Mol et al., 2010, p. 13) follows less rigid principles and searches for solutions that are good enough for that context, taking into account less palpable criteria, such as compassion, fairness, and kindness. Thus, while safety and the resolution of the case remain at the core of doctors’ work, it is also their job to adapt to the specificities of the patient’s situation, employ their skills to make “human life worthwhile” (Mol et al., 2010, p. 16), and negotiate the terms of the medical decision to fit the expectations of all the parts involved.

This point is particularly interesting for my research, since, in terminal cases, efficacy, commonly related to healing or survival, is less important than the patient’s well-being and the assessment of what constitutes a life worth living, both by the patient as well as his/her family members and his/her doctors. Thus, this idea opens space to approach the importance of the doctor-patient relationship and the communication flow to evaluate risks and make a decision at the end of life.

The logic of care nowadays is also entangled with the logic of choice, as pointed by Mol (2008), that aims to empower the patient and raise his/her satisfaction. With the growing influence of market discourses in society and the commodification of health, the patient often assumes the role of a customer, regulating the demand, choosing hospitals, doctors, and procedures and asking for what s/he is paying for. Another strand is the citizen-patient that has the autonomy to decide about medical interventions and requires respect for his/her legal rights related to care. However, I am aware of the concerns raised by the authors in labeling the patient as a consumer since, in many cases, health care is a vital need, and it is impossible to refuse, compare or negotiate the line of treatment proposed. The same applies to the citizen-patient since the disease might compromise mental faculties and his/her ability to decide. Also, these two roles may not be entirely fitting to the medical practices or hospital settings, because they can hide embodied care practices and constraints imposed by the disease. Furthermore, these labels put the burden of decision on the patient's shoulders, even though a patient's choice will be contingent on time, an idea of linearity in medical conduct, and on a forecast that may not be accomplished (Mol, 2008, Mol et al., 2010).

> Introducing patient choice into health care does not (finally) make space for us, its patients. Instead, it alters daily practices in ways that do not necessarily fit well with the intricacies of our diseases. My argument is that the tradition of care contains more suitable repertoires for handling life with a disease. (Mol, 2008, p.2)

Mol (2008) challenges the idea of an individual able to make reasonable choices by his/her own, pointing to the interdependence of humans and arguing that people are "tricked" into making choices, often lacking the resources to do it (e.g., knowledge or the real dimension of the consequences of a given pathway). The author proposes a look at what is deemed logical in one specific care practice, also considering the patient's agency.

In this multifaceted scenario, goodness and ethics become multiple, coexisting, and relative terms. Individual autonomy must be synchronized with the laws and rights designed for the collectivity, and with the attention, specificity, and safety requirements demanded by the professional regulations and hospital policies, for example.

> To care, in this setting, is rather to meticulously explore, test, touch, adapt, adjust, pay attention to details and change them, until a suitable arrangement (material, emotional, relational) is achieved. (Mol et al., 2010, p. 16)

Tinkering with ethics and knowledge, and experimenting and putting the doctors' experience to adapt the machines to the situation or the situation to the available technology may transform even the "ultimate bad" (Mol et al., 2010, p. 18) into a good death.

3.3 Culture in techno-scientific and medical practices

As demonstrated in the State of the Art, Medicine, like any other science, incorporates society's values and perceptions at the same time it shapes society. Therefore, to understand what influences the medical decision-making at the end of life, it is crucial to know the impact of culture on the doctor's rationale in a broader sense. How does the culture of the medical community influence the care, assessment, and communication with the patients? How does Brazilian culture influence the understanding of the end of life? How can culture be used as a rhetorical tool to justify terminality approaches, or the patients' and relatives' behavior in this scenario?

Despite the critique of stereotyping people and hiding socio-economic aspects affecting health and behavior, the focus on culture as “a fluid concept”, “not static or totalizing” (Lock & Nguyen, 2018, p. 8), offers lenses to understand how doctors and patients might think and react in a given context. The “medicalization of culture” (Lock & Nguyen, 2018, p. 8) allows an alternative approach to the medical gaze (Foucault, 1977), with doctors seeing the patient not as body parts, but as a whole belonging to a context. However, it can also work to keep the Medicine as an institution controlling the body: cultural aspects are used to blame the patient for not following treatment or to dismiss beliefs considered irrational.

A focus on culture is also valuable for this research because it highlights the influence of the practices of the Global North in the routines of Global South intensivists. As pointed by Prasad (2014), despite attempts to make scientific findings neutral, timeless, and universal, it is impossible to separate science and culture and, currently, Global North, Eurocentric science is deemed modern science. Here, I extend this argument to modern Medicine and also argue that today, what is considered up to date and rational is not defined only by European trends but also by the United States' strong position in the development of medical technologies and knowledges.

Following regional stereotypes as in the MRI cultures in India, Britain and United States, the argument of lag (in the development) and lack (of resources and skills) can be used to explain why there are different patients’ and doctors’ understandings of the end of life, and why there are different levels of access or ways to employ resources in this situation. Moreover, claims related to the national identity or the historical background of the country and Medicine in Brazil help to circumscribe the Brazilian doctor’s practices in a specific social context. These claims are used as arguments to have different methods to handle terminal cases, in spite of the recognition of European and North American practices as state of the art in Medicine.

Researching an intensive care unit in a hospital in the Northeast of Brazil, Biehl & Moreira (2004) argue that, in practice, on-site arrangements overlap the supposedly neutral science of terminal cases. The authors define as "local bioethics" the informal agreements among the intensivists in this hospital do accept death. The consensus on the level of investment on a patient is also based on trust among the professionals; a "feeling", i.e., interpretation based on experience, not on data provided by the monitors; the following of implicit norms; and the perception, by almost all the ICU team, that death is near, beyond what is written in the medical protocols.

Looking at cultures inside medical and scientific communities, despite the prevailing notion that this is a “culture of no culture” (Prasad, 2014, p. 99) will allow me to investigate the attempts to purify medical knowledge and to draw boundaries between expert and lay knowledge. These efforts are a way to separate Medicine from the social values and to claim that its conduct, findings, and decisions are based on purely rational reasons. According to Prasad (2014), despite being “fictions”, these distinctions “constitute a “reality” in which such exclusions and appropriations seem natural and logical (p.8)”. Besides, analyzing the connection between culture, practices, and technologies and their presence in the doctor’s discourses, practices, and ways of thinking I will be able to see what Knorr-Cetina, cited by Prasad (2014), labels as the “conscience collective” that reproduces the “techno-scientific norms of the dominant groups” (Prasad, 2014, p. 9). Business, epistemic, and health care concerns in the intensivist’s community might also help me to make sense of their decisions and beliefs.

For example, in Prasad's study (2014), despite the “transnational flows of technologies, knowledges, discourses, and peoples” (Prasad, 2014, p. 100), the cultures of MRI were deeply connected with the characteristics and imaginaries of the three countries. In the U.S., the use of big science to reinforce the country supremacy over other nations, its position as the largest health care market in the world, and the use of marketing and business strategies to strengthen this techno-cultural imaginary demanded the introduction of new technologies in care practices and fostered the adoption of MRI. In Britain, despite the truism that Britons are “good at inventing and bad at developing (Prasad, 2014, p.103)”, the reasons for the “lag” in MRI development were manifold. Prasad (2014) cites the resistance to follow the U.S. research culture and the influence of big companies, for example. In India, colonialism kept influencing research practices, with its strong focus on hierarchy, on bureaucratic measures to fund scientific research, and a still prevalent belief that India was at the “periphery” of science (Prasad, 2014, p.108).

With this sensitizing concept, I am acknowledging that techno-social structures and, by extension, medical structures, and culture “are mutually constitutive and entangled within hierarchical and exclusionary networks of power and administration (Prasad, 2014, p. 112)”. This approach will help me to shed light on the beliefs of the dominant groups and their influence in the constitution of the cultural imaginary (Prasad, 2014, p. 113) of care practices in the end of life in Brazil, including the reimagination of past, present and future of these practices and the roles and behaviors expected from the patients. Therefore, I am admitting culture as one more object in the enactment of the terminality in Brazilian ICUs. The way Brazilian care practices and cultural aspects are arranged by the doctors helps to constitute one specific reality among the multiple realities at the elderly's end of life in the country's hospitals.

4. Research Questions

My thesis acknowledges the role of bio/medicalization in shaping society's expectations regarding aging and death. The rise in life expectancy, the evolution of technology and medical knowledge, and the perception that death is a path that can be lengthened with specific adjustments turned the ICUs into places for dying.

Therefore, adding up to Brazilian studies that, separately, investigate the role of the older in society and the health care system, I propose an investigation focused on the interlacing of society, technology, and medicine at the elderly's end of life. This STS perspective focusing on the enactment of objects by doctors to create realities (Mol, 2002) has the aim to shed light on the power relations, articulations, values, and beliefs that rule this context.

Interviewing intensivists, I analyzed how doctors interact with the law, patients, families, referring physicians, and the Brazilian imaginaries of aging and death to negotiate a terminality diagnosis and come up with one therapeutic conduct in an irreversible case.

Thus, as the main question, I propose:

How do intensivist doctors navigate through different scenarios in Brazilian health care setting to address the elderly patient at the end of life?

The following sub-questions will address the four main topics influencing the medical practice in this setting:

1) *How does the current legal situation affect the decision-making process?*

Currently, the Penal Code does not offer clear directions regarding orthothanasia and dysthanasia, but the Elderly's statute ensures the patient's right to decide. On the other hand, the Federal Medicine Council guidelines already authorize the withdrawal of treatment in terminal cases and the acceptance of Advanced Health Directives written by the patients. How do doctor's position themselves in the face of these two distinct situations?

2) How does the increasing availability of technologies and knowledge to intervene in terminal cases shape the medical conduct regarding the elderly?

Several authors show the impact of biomedical technologies on the doctor-patient relationship, medical practices, the understanding of risks and diseases (Berg, 1997, Brown & Webster, 2004, Conrad, 2007, Dumit, 2012). How does the combination of these factors influence the Brazilian intensivists?

3) How do doctors deal with financial pressures and class differences when caring for the terminally ill elderly?

In a country marked by inequalities, including in the access to health services, socio-economic aspects will help me to address both the doctor's conceptualization of the Brazilian health system as possible conflicts with the payment sources.

4) How do doctors', patients', families' and society's perceptions of aging influence the assessment of health conditions and the decision-making process at the end of life?

As discussed in the State of the Art, despite the attempts to purify medical knowledge and disconnect the patient from his/her environment, external values, judgments, and conceptualizations permeate medical practice. I intend to see how the intensivists keep the boundaries between expert and lay-knowledge and to what extent they negotiate with the involved actors to incorporate their values in the patient's final evaluations.

5. Materials & Methods

Considering that Intensive Care Units are increasingly receiving elderly patients at the end of life (Kaplan & Schneider, 2000) and that doctors are still the gatekeepers of technology and knowledge in the medical field (Conrad, 2007), the central point of this study is the intensive care doctor. Thus, I investigated the agency and discourses of the intensivists in the face of different end of life scenarios in Brazilian health settings. My research took place in three high-complexity hospitals belonging to a network in São Paulo, the major city in Brazil.

The first institution is a big, private, middle-class hospital that only assists insured or out of the pocket patients. I called it Hospital A.

The second is a medium, private, high-class hospital, with a stronger focus on hospitality, that also only assists insured or out of the pocket patients. I called it Hospital B.

The last one is a nonprofit hospital, totally dedicated to the patients coming from the public health system, Hospital C.

Pseudonyms identify my six interview partners:

Antônio - ICU coordinator, male doctor, 13 years of experience, cardiologist and intensivist, working for hospital A.

Vera - ICU coordinator, female doctor, 17 years of experience, working for hospital A.

Francisco - ICU coordinator, male doctor, 12 years of experience, working for hospital B

Plínio - Male doctor, five years of experience, one year in hospital B. Also works in a public hospital, but in a clinical setting

Roberto - ICU coordinator, male doctor, ten years as a cardiologist and intensivist, works for hospital A and hospital C. He is being prepared to assume an administrative position in hospital C, which is the focus of the interview.

Joana - Female doctor, not Brazilian, ten years as an intensivist, four years in hospital C.

5.1 The Brazilian Health Setting

Brazil is the biggest country in South America and has a population of 210 million people. Since the 1960s, population growth is decreasing, and the demographic profile is changing quickly, with a sharp decline in fertility rates and a rise in the elderly population. Between the 1940s and the 1970s, the children represented 42% of the population, but, in the last census, in 2010, they were 25.5% of the people. Meanwhile, the average age rose almost seven years between 1980 and 2010. IBGE, the national organ responsible for the statistics, projects that the elderly population will grow from 14.2 million people in 2000 to 66.5 million people in 2050. Among the reasons to explain this new scenario are: better educational levels, broader access to contraceptives and the postponement of maternity, lower child mortality rates, urbanization, better sanitation, and access to health (Simões, 2016).

According to Simões (2016), the country is not ready to handle this impact in several areas, like health and social security. Hospitalizations among the elderly are three times higher than among the children, and their costs are 36,7% bigger. Besides, Brazil is going through an epidemiological transition. Contagious diseases represented 40% of the deaths in the 1950s, but only 10% in the 2000s, but cardiac illnesses that account for 12% of the deaths, now represent more than 40%. The prevalence of chronic diseases among the elderly is 75,5% (IBGE, 2009).

Adding complexity to this scenario, the inequality of the country is also reflected in the access to health services. Life expectancy is lower in poorer regions, and one of the reasons is the restricted access to health care.

The Brazilian health system that claims universality through its Sistema Único de Saúde (SUS), also allowed, by the Constitution, the offer of private services, regulated by the Agência Nacional de Saúde (ANS - National Health Agency). Despite being complementary, now, private services are responsible for more than half of the health care expenditure while attending only 30% of the population. However, the insurance plans are adopting measures to control the rise in costs. The usual payment, fee-for-service, in which each procedure, material, drug, and hospitalization is remunerated following a price previously agreed, is being questioned. Now, payment sources are defining beforehand what each case requires, both to try and pay for a package of services and share the risks with the hospitals, as to prevent interventions that are not supported by the literature.

Although I could not reach the public hospitals and deliver a comparative study, as planned, I partially addressed the role of inequality in the health assessments at the end of life with the interviews in the nonprofit hospital. In Brazil, philanthropic hospitals have to dedicate at least 60% of their beds to SUS and are paid according to the public services compensation table. Also, the media often debates the role of inequality and the change in the age pyramid in the country. Thus, even doctors in private institutions get an idea of the impact of socio-economic aspects on the health of older people.

5.2 Research and Data Analysis Method

This research used a qualitative method: semi-structured interviews. The aim was to grasp the doctors' perceptions of decision-making at the end of life when treating older patients. All the interviews were performed individually, face-to-face, in the hospitals. I followed a constructionist approach in which meanings are mutually constructed between interview and interviewee, and the common assumption is that "experience is always embedded in a social web of interpretation and re-interpretation” (Silverman, 2006).

This method fitted my sample and my sensitizing concepts. Having the questionnaire prepared before the interviews helped me to stay grounded to the research questions, while the semi-structured approach allowed me to change the order of the questions to the flow of the conversation. Stimulating the intensivists to reflect on the roles and feelings of the patients and the family members helped me to see how they use these assumptions to build on the relationship with these actors and negotiate the terms of the end of life.

A focus on the construction of meanings, rather than a search for hard facts or an approach to take the interviewees' answers at face value, sheds light on the line of thought that leads to a decision in the ICU and the discourses to justify one approach over others. Finally, co-constructing the meanings with my interview partners allowed me to adapt my questions to the profile of each doctor and to follow up on unclear or contradictory answers, while still letting their opinions guide the interview, and controlling the impact of my perceptions on their responses.

The data analysis was based on Situational Analysis, considered by Clarke (2005) as a new approach to Grounded Theory. Instead of a focus on the “basic social process” offered by traditional Grounded Theory, this method proposes to go beyond the knowing subject and put focus also on the situation of the inquiry, through the drawing of:

1) Situational maps: to identify humans, non-humans and other elements in the research situation and the relations among them;

2) Social world/arena maps: to recognize the places, institutions, and contexts in which the interviewees are engaged;

3) Positional maps: to spot the positions taken or not taken by the interviewees during the inquiry.

To attend the scope of this Master's Thesis and the time-plan, I focused on Situational Maps. This tool helped me to depict all the following topics and actors that might influence the doctor's decision-making process: doctors, patients, family members, legislation, regulation, socio-economic aspects, technology, and biomedicalization. Situational Analysis was particularly helpful to analyze the data collected in this research because of the possibilities to: identify important relations among different elements mentioned during the interviews, draw my attention to diverse perspectives offered by the data and help “silences speak”, by pointing to absent positions and actors in the discourse (Clarke, Friese & Washburn, 2015). Since the elderly were at the core of the research, but could not be directly interviewed (i.e., self-represented), the maps were used to provide insights on the construction of the elderly as actors in health care settings and their influence in the decision-making process at the end of life. Situational Analysis also let me use my experience as a healthcare journalist and the preliminary finds of the Literature Review to draw the first situational map that supported the interview guidelines (see Appendix 1).

5.2.1 Interview Guidelines

The State of the Art of the exposé conducted my interview guidelines. Following Clarke's et al. (2015) suggestion, I drew a first situational map during the design phase, to guide data collection. My questions emerged from the most critical elements identified in the literature review (see Appendix 2).

Firstly, I pinpointed the main factors/actors that might influence the decision-making process: doctors, elderly patients, family, socio-economic aspects, legislation, regulation, technology, and biomedicalization. Then, I organized the components that looked more related to the main elements:

Doctors - The three main aspects related to this element were the professional dilemma (acting/not acting and its implications), the perceptions of aging when diagnosing, treating, communicating, and assessing the older patient and the subjectivity in the definition of the end of life.

Elderly patients - The patient is linked with elements related to the biomedical practice, such as the need for medical surveillance and the detachment of the body from the identity. Their agency is also a relevant topic in this situation, and I worked with the contrast between the knowledgeable patient (technogenarian), that expresses his/her wishes vs. the passive one, the biotech ambivalence vs. quality of life assessment, and how ICUs might erase their opinions.

Family - The family and the way its members perceive aging and the autonomy of the elderly play an important role because it might influence the patient (pressure to stay alive) and put pressure on the doctor (intervention as love). Its members might have conflicting expectations with the patient, which becomes problematic if one of them becomes a proxy (deciding for the patient).

Socio-economic aspects - This actant exposes the Brazilian social inequalities, at the same time pointing to the different social contexts of the patients and highlighting the financial pressures in medical practice.

Legislation - Here, I emphasized the legal loophole in Brazil: the Penal Code is not specific on end of life situations. Euthanasia and orthothanasia can be considered homicide, and dysthanasia can lead to an accusation of bodily injury. Moreover, the Elderly Statute gives the older people autonomy when it comes to medical interventions, but the family could sue a doctor in the case of orthothanasia or dysthanasia.

Regulation - On the other hand, the Federal Medicine Council, through its regulations and guidelines, makes the roles of the doctor's and patients clearer, even with specific directives to withhold treatment in irreversible cases and to accept the patients' last wishes. These regulations, nonetheless, are not fully supported by law, despite the acceptance of some judges.

Technology - Also bound to biomedicalization, technology helps to frame aging as a problem or disease and leads to essential modifications when it comes to treating the elderly. With more knowledge and technology that makes interventions at older ages safe, doctors might face the moral imperative to use all technology available to save lives, but at the cost of sacrificing the patient's well-being.

Bio/medicalization - This element was meant to be my sensitizing concept, but, during the course of the interviews, I realized that this was not an overarching theme. Although crucial in my State of the Art and Data Analysis, I realized that bio/medicalization should be a topic as important as the ones described above. Bio/medicalization, then, helped me to question society's and doctor's perceptions of end-of-life interventions for the elders. Relying on the fact that biomedicalization is transforming medical practices, I tried to understand how the meanings of the body (detached from the patient's identity or using a disease or medical condition to define the person) and of the aging process (painful, not normal and something that can be fixed by medicine) were influencing the doctors decisions.

Opting for open questions, not so focused on the doctor's reactions to a patient that refuses treatment (the first proposal for this thesis), allowed me to shift the direction of the research. Right at the beginning of the interviews, I realized that, in this hospital network, refusing procedures to extend life in a terminal case was not an issue. In fact, the doctors were advocating for it. The interesting aspect was the way they negotiated the diagnosis and the therapeutic conduct, incorporating many social and personal elements of the families and patients, i.e., acknowledging multiplicity and coordinating the objects to create the reality. Thus, I let the data guide me and decided to change the scope of my thesis, adopting new sensitizing concepts and new authors to support my findings.

Thus, my interviews encompass the intensivists' imaginaries about aging, the Brazilian health system, and the socio-economic aspects that might influence their practices and their conceptualization of a good death. They also reflect on the role of the patient and of the family when it comes to choosing therapeutic options and the need and convenience of medical interventions. In the end, I tried to summarize their arguments, stimulating them to come up with a definition of a good death.

5.2.2 Ethical considerations

An ethical reflection is part of any social sciences research, but, for me, this topic was even more important since I was investigating a controversial subject in the medical field. My interview partners used examples but took care never to be too specific as to allow the identification of the patients. I also avoided questions that could lead them to break medical confidentiality when discussing patients' examples.

In the description of the sample, I am not talking about the size, exact profile, or specific location of the hospitals to keep them unidentified. The doctors remained anonymous and received pseudonyms throughout the data analysis. Not even my supervisor had access to the full transcription of the interviews or the real identities of my interviewees.
All the interviews were face-to-face and individual. They happened in meeting rooms near the ICUs, but I did not ask to visit the units or to have access to the patients, their family members, or their medical records.

At the beginning of this project, I considered the potential of ethnography as a useful way to identify areas of agreement and disagreement between the actors and offer a broader understanding of what factors influence decision-making. However, this proved unfeasible, both because of concerns regarding the patients' privacy as due to the ICU's routine, which requires constant monitoring of the patients, quick interventions, and special precautions concerning sterilization. Also, I abandoned the first idea to combine the results of the interviews with patients, family members, and doctors because the scope would be too big for a Master's Thesis, and this approach could lead to unintended conflicts among these actors in an already stressful situation.

I first approached my sample by the administrative area of the institutions. I asked the hospital directors to authorize the doctors' participation and sent them a letter, signed by my supervisor and me, describing the purpose of my study. These directors chose the doctors I would interview, and then I asked the intensivists directly if they wanted to participate. Considering the risks inherent to any research, but especially in the health area, all the participants signed informed consents. This document stated the purposes of the research, acknowledge their right to leave the interview at any point, and assured the researcher responsibility for the storage of the data and the anonymity of the interviewees and their institutions.

I recorded and transcribed the interviews using my own devices, no data was shared with a third party or other researchers, and I committed not to use the material collected for other purposes without the interviewees' previous authorization.

As a way to be transparent and thank my interviewees, I promised to share my thesis with them and with the hospital's directors after the corrections and translation.

5.2.3 The methods in practice

My conversations with the doctors ranged from 34 to 75 minutes, and I attribute this difference to the open-ended character of the interviews. I started with broad questions, and some intensivists addressed most of my topics right at the beginning, allowing me to skip part of the questions, while others needed more stimuli to develop their ideas on the theme. Differences in the hierarchy, professional experience, familiarity with managerial topics, and shyness and extroversion might also have influenced the length of the interviews. None of them asked to leave or to withdraw their data after our conversations, and they answered all the questions.

I believe my previous experience as a health journalist mentioned when I introduced myself, the academic character of this investigation, and the anonymity made the doctors comfortable with the interviews. They used jargon and were not afraid to describe the process of dying or the procedures they employ at ICUs. I risk saying they enjoyed sharing their viewpoints, in the hope that fostering studies on terminality will help to de-stigmatize death and palliative care, a concern often mentioned in our conversations. One aspect worth attention is that they all knew that, in spite of being Brazilian, like them, I am in an international Master's Program in Austria. This helps explain the references to culture, values, and medical practices in Brazil and their emphasis on the supposedly different approaches in Europe and the United States. I never asked them to compare their realities to the ones in different countries, but this came out during the interviews.

Regarding the transcriptions, I opted for the gisted transcription method, removing uttering and unnecessary words, but still keeping the exact words of my interview partners (condensed transcript) (Paulus, Lester & Dempster 2014). I decided to not translate all the interviews from Portuguese to English, just the parts that I used as citations in the data analysis. For me, it was better to analyze the data in my mother tongue, in which I am more aware of the subtleties, word plays, metaphors, and intonations that put the doctor's answers in context. However, I wrote the memos with my first impressions in English, to contextualize the interviews for my colleagues and supervisor and to facilitate feedback on the data analysis. In the data analysis chapter, I opted for a free translation of the doctors' quotes, since a literal translation would not reflect what they meant in that context. The original answers, in Portuguese, are in the Appendix 4.

I organized the data with open coding, as proposed by Rivas (2018), labeling blocks of data according to the essence of the pieces of text. Color coding the blocks of data with the software Atlas.ti helped me to see the prevalence and relevance of each code and facilitated the selection of the best quotes to support my findings. I use 37 codes, grouped in the eight axes of the interview guidelines: doctors, elderly patients, family, socio-economic aspects, legislation, regulation, technology, and biomedicalization.

To draw the situational maps, I used the mind map software Coggle. Following the first coding, I wrote sentences for every topic that emerged in the interviews. For me, sentences worked better than keywords, because they allowed me to remember the background of the codes and facilitate the connection with similar perspectives in different axes. I drew one map for each interview, and, in the end, I drew another map summarizing the common points of the six conversations (see Appendix 3). This visual method kept the amount of data under control, facilitated the comparison among the interviews, and helped me to understand what the data was showing.

Situational Analysis led me to quickly realize that my former sensitizing concepts (biomedicalization and decision-making at the end of life) would not help me to make sense of the data. Moreover, this method revealed the shifting concerns and conceptualizations of the elderly and the end of life in the doctors' narratives. Therefore, my first proposal, to investigate the doctors' reactions in terminal cases, was substituted by research on the way doctors combine multiple elements and understandings of the end of life to assess the patient, recommend a conduct, and convince the other actors to accept this pathway.

The maps, resembling a network, allowed me to see juxtapositions and oppositions in the doctors', patients', and family members' perspectives and called my attention to the role of the doctors as negotiators. Rather than keeping the final word, in this research, they emerge as political actors, arranging arguments and attending different needs to lead the case to an outcome they consider dignified for them and for the patients.

6. Data Analysis

This data analysis has five parts, following the research questions. First, I approach the legal and regulatory aspects, as well as the guidelines and their impact on the decision-making process at the end of life. Second, I discuss the relations among technologies, knowledges, and practices and how they can shape the medical conduct regarding the elderly. Third, I will expose the intensivists' perspectives on the socio-economic aspects influencing their routines, such as financial pressures and class differences. Fourth, through the doctor's viewpoints, I will analyze how the perceptions of aging and terminal cases by patients and families, reflecting society's culture and values, impact the decision-making process at the end of life. I will conclude tying the analysis to the sensitizing concepts to show how these doctors navigate through different scenarios in Brazilian health care setting to address the terminally ill, older patients (see also appendixes 3 and 4).

6.1 Legal and regulatory aspects

In Brazil, the legal landscape regarding the end of life is in a mismatch with the advances in Medicine and the demographic and epidemiologic reality. Despite the growing life expectancy, the rise of chronic diseases, and the sophistication now found in intensive care units, there are no clear laws to guide doctors or patients in this situation. The terms euthanasia, dysthanasia, and orthothanasia are never clearly mentioned in the Penal Code, but the common understanding is that euthanasia is forbidden and equivalent to manslaughter. Besides, the paragraphs providing directions for death in terminal cases were written in 1940 and were not updated after that. In this setting, for the legislator, the elderly patient that faces terminality today is stranded in the same context and epidemiological profile as the patient from almost 80 years ago.

On the other hand, the *Conselho Federal de Medicina - CFM* (Federal Medicine Council), constantly in touch with doctors and patients, publishes new guidelines often to adequate medical practices to the development of technology, knowledge, and cultural values. The two main resolutions regulating practices at the end of life put the older patient in the position of a citizen, assuring his/her right to autonomy and citing the Federal Constitution, which forbids torture and degrading treatment. Dysthanasia is understood as the extension of suffering without benefits. Therefore, the council allows doctors to withhold treatment in terminal cases and to make the patient's last wishes valid by simply registering, in the medical record, the option to favor comfort measures and prevent interventions from prolonging the life.

In their routines, the intensivists have to face the uncertainties of the Penal Code or resort to their professional council. In my interviews, they were unanimous in choosing the CFM guidelines, that were considered clear and updated. For them, CFM resolutions are good enough for legal protection and for keeping up with the best practices in intensive care. Despite not having the power of law, CFM is indeed an influential institution in Brazil, and, as one of the most powerful professional councils, it is able to back up its associates and influence juridic outcomes.

> The Penal Code is the least of our concerns [in terminal cases]. Everything we do is based on literature, we do not, at any time, raise the dose of a drug or do anything else to shorten the life, but always to alleviate the symptoms. (Dr. Roberto)

Besides, the legal risks seem to be more a matter of miscommunication than of malpractice or of a deliberate attempt to perform euthanasia. The interviewees often mention their caution when writing the medical records and their efforts to respect the patient and family wishes.

> My priority is always the patient's wish and what I can do to make him/her more comfortable without bringing him/her suffering. When I take this into account, I do not worry about the juridic aspects. Of course, I always write everything on the medical record, in case a family member later tries to know what happened. I make everything explicit, but I never had a problem with this conduct. (Dr. Plínio).

This does not mean that doctors are unaware of the legislation or that they do not bother to obey the law: euthanasia, according to the doctors, is never performed, because it is illegal. Dr. Vera and Dr. Roberto tell me about two cases were the families and patients insisted on euthanasia, even consulting lawyers, but with a solid legal basis, both cases were denied. However, instead of inaction or of employing measures that they consider damaging to the patient (dysthanasia) due to the lack of clarity in the Penal Code, they prefer to apply what is a consensus in their communities and what is validated by their council, that is, orthothanasia. The perception that this is the best way to handle the situation is reinforced by the fact that none of them was sued or even knew a doctor that was sued in cases like that.

Besides, death is an expected outcome in this situation, especially now that the intensive care unities (ICUs) are mainly becoming spaces to stabilize acute events of chronically ill patients and to receive cancer and elderly patients at the end of life. Therefore, controversies about medical conduct are almost nonexistent. Reassurance also comes from the documentation of any procedure and of the patient's desired pathway in the medical record that, as doctor Joana reminds me, is a document valid as proof under the Brazilian law, and it could be used in the doctor’s defense.

For these intensive care doctors, following the guidelines, keeping a good communication flow, being clear about the patient’s conditions, and the consequences of the treatments and giving the families time to get used to the situation are the best policies in this scenario. Supported by the hospitals, these measures, in their opinions, also help to avoid controversies, accusations of incompetence or negligence or, in more extreme cases, legal processes, that could put them in jail, or inquiries about malpractice, that could cost their medical licenses.

Moreover, the line between euthanasia, in the sense of abbreviating the life of a patient in suffering, and orthothanasia, meaning letting the disease follow its natural course and supporting the patient with comfort measures, is blurred. Perceiving death as a trajectory, instead of a sudden event (Brown & Webster, 2004), doctors can have a different understanding of the cause of death and relate euthanasia to intentions, instead of outcomes. Giving the patient medications to control pain, for example, can depress the respiratory system and, as a consequence, shorten life. For my interview partners, a case like this is not considered euthanasia, because death is a consequence, not an expected outcome of the intervention.

> If the patient agreed to prioritize comfort, to using a sedative to make him sleep, I think this is not euthanasia. It is more of a comfort measure, and we have the double effect of the medication. It will abbreviate life, but I am ensuring that s/he is not going to suffer. (Dr. Francisco)

6.1.2 Advanced Healthcare Directives

The role of the citizen-patient is also the factor guiding the movement for the adoption of the Advanced Healthcare Directives (AHD). Despite gaining the news in the last few years, supported by CFM since 2012 and recommended by lawyers to guarantee the patient's right to autonomy, they are still not spread in Brazilian healthcare setting. At the end of life scenarios approached in my interviews, the doctors did not feel the need to have any other document to support the patient’s wishes and to register their practices, besides the medical record. Possibly because the intensivists already feel safeguarded by their council's resolutions and have as a routine practice the negotiation of the limits of intervention with the patient and family members, a document registered in Notary Offices does not seem necessary to validate their choices. There is no effort by the hospitals to inform the patients about the AHD, and it is rarely seen in the ICUs routines. In the rare cases it is presented, usually, it is brought by a family member or a patient with a chronic disease or cancer. This patient knows his/her case will eventually become acute and wants to prevent interventions that would prolong his/her life without assuring his/her recovery, like intubation and cardiopulmonary reanimation.

Some of the doctors, however, do think that the Advanced Healthcare Directives would be a useful tool to reinforce the patients' wishes, inform the families about them, and facilitate discussions about terminality. “Among doctors, we discuss what we would want or not want if we end up with a terminal disease, but this is not common among the population,” says Dr. Joana.

To keep it simple, instead of a legal document, Dr. Roberto suggest the adoption a “terminality plan”. The plan would follow the concept of the birth plans, in which doctors, patients, and families would discuss the disease’s course and register the desired path for the medical conduct inside the hospital, without the need of lawyers or registration in notary offices, as in the case of the AHD.

Talks about the end of life are still a taboo in Brazilian society, be it by fear or lack of information. For the doctors, the patient's final days, as well as the job of the intensivist treating him/her, would be easier if people discussed the subject openly. Dr. Roberto, for example, supports euthanasia and relates its acceptance to "evolved nations":

> Assisted euthanasia is a thing of developed countries with higher per capita income and better education. Who knows, maybe someday my great-grandchild will see that Brazil evolved to this level. (…) I think this is a patient's right; people should have the free will to decide if they want to live or die in a terminal case. (Dr. Roberto)

In the doctors' narratives, when the legal aspects are at the center of the discussion, what prevails is the citizen, savvy, autonomous patient, with the right to health, but also capable of deciding for the interruption of the treatment. Concerns about legal uncertainty disappear when the understanding is that the patient was co-responsible for the outcome since he freely expressed his/her wishes, and these wishes were attended by the hospital staff.

6.2 Interchangeable meanings and variety of practices

The data collected points to the flexibility and multiplicity of meanings, definitions, and the employment of protocols in the ICUs routines. Surrounded by machines and constantly measuring vital signs, intensivists rely on numbers and the standardization of diagnosis and procedures to guide their assessments. Reducing variability in procedures is a way to bring more quality and safety to hospital settings but, at the same time, at the end of life of an elderly patient, doctors also praise individualization and try to keep all the actors involved satisfied and supported. This helps them to navigate through uncertainties in a complex scenario, with multi-morbidities, the fragility of the older body, and the lack of studies to treat this patient. Attending to individual wishes is also a way to relieve the burden of decision-making and the let the patient perform the roles of a citizen, with autonomy, and a customer, choosing the procedures that fit his/her conditions and expectations and improving satisfaction with the health services.

Thus, in intensive care, despite guidelines, tests, indexes, and protocols, the definition of the end of life is not purely technical, but one which is negotiated among family members, other specialists, and the patient.

> The best way to define the efforts' degree, how far are we going [with one patient] is always to share the decision with the referring physician, with the family, and including the patient, if s/he is lucid. (…) As much as we are grounded in science, this [the decision] cannot be one-sided, of one doctor. (Dr. Antonio)

The doctors are aware of the limitations of medical knowledge and technology and try to reach a consensus to support their definitions of the end of life.

> Terminality is a hard issue, even among different doctors, the perceptions are different. (…) When we look at the literature, at the American consensus, the recommendation is to discuss it even after the diagnosis. (...) We have to present to the patient the ways his/her decision can evolve and ask what are his/her wishes when this time comes. The problem is how people interpret that. Sometimes a doctor, even with a patient in intensive care, in need of artificial support for all the organs,

> mechanical ventilation, dialysis, hemodynamics, and daily blood transfusions, still cannot assume this definition. (Dr. Francisco)

Albeit more common in private hospitals, like the one where Dr. Francisco works, which requires the referring physician to admit the patient, sharing the decision with other professionals is common in ICUs. The intensivists explain that they do not “own" the patient. Usually, the referring physician (cardiologist, oncologist, geriatric, etc.) makes most of the decisions, mainly because of his/her strong links to the patient and family, especially when treating a long term disease. Because of that, this doctor can have a heavier influence on the course of the treatment. In my interviewees' narratives, one common complaint is precisely the distinct meanings and practices used by doctors in different specializations. Referring physicians might have heterogeneous interpretations of the medical consensus because "they feel guilty of the outcome" (Dr. Francisco), because "they do not believe in palliative care" or in the pathway suggested by the intensivist (Dr. Vera) or because "they had a different training in the past" (Dr. Plínio).

Knowing that a consensus on what is a terminal case is hard to reach, and trying to make their knowledge count, the intensivists have to go beyond their technical education and develop soft skills, like empathy and the ability to negotiate. In their discourses, I often see their roles as mediators in an effort to achieve a common ground and pursue what they believe is the best outcome for the patient. They try to convince the referring physician to support palliative care, anticipate situations to narrow the gap between expectations and reality, adapt their discourses to reach patients in different social classes, and manage conflicts among family members, among other acts. For this group of doctors, taking care of communication is as important as being able to provide the best clinical outcome for the patient.

> “[We solve the problems] by seating together, talking, taking off the medical coat so the person can see that I am like anybody else… Looking for certain proximity. This is not to act like an actor but to, somehow, share that moment with the person.” (Dr. Antônio)

For Dr. Vera, the effort to reach a consensus goes as far as acknowledging family conflicts and trying to overcome them.

> At this time, we have to be available to the family. We cannot think: 'I already spoke to them during the visiting hours. I will only talk again tomorrow.' That is terrible. We have to be always available to clarify the doubts; to try to align the family's expectations and, I know it is not easy to anticipate the situations. Even inside the same family, this can be complicated: one accepts it, the other does not. I had a situation like that at the end of last year. A terminal case with two daughters [involved]. One accepted the other did not. Besides that, they quarreled and did not talk to each other anymore. We even had to share the visiting hours, so they will not meet each other. It is very hard to try and put them together with all this mess. (Dr. Vera)

Albeit restrained by protocols, safety measures, and the technological environment of an ICU, the doctors try to minimize this impact and turn the ICU into a more human place for the patients. Instead of sticking to technicalities and protocols, the intensivists try to be flexible to address the patient’s wishes. For my interviewees, this flexibility is the result of the most significant change in intensive care in Brazil throughout the years: humanization. It is interesting to see the doctor's nominating a non-technological factor as the biggest revolution in care in recent times. Some of them remember the ICUs as cold places, with restricted visiting hours and several rules to be followed by doctors and patients in the name of safety. Now, they consider that trying to make it a warmer setting is the best thing that could happen to the patients. They do acknowledge the evolution of technology and knowledge, but, for them, this is not surprising; it is the norm in Medicine.

For my interviewees, “the human factor”, especially in terminal cases, is as important as the technology and medical knowledge. In these hospitals, humanization results in more time to be with the family, with some of them allowing visitation 24 hours a day, and relaxation of protocols since it is well known that the cure is not possible anymore. Terminal patients have a less restrictive diet; some festive dates, like Christmas, are celebrated inside the ICUs, and, when it is possible, the patient is allowed to go home, even with catheters, oxygen support, or feeding tubes. Two doctors give me examples of this bending of the hospital rules and the medical guidelines to attend the patients' last wishes:

> I discharged one of my patients to celebrate the 15-year birthday of her granddaughter. Technically, she did not have the conditions to leave the hospital, but, talking to her doctor, we decided to let her go. She went, came back after the party

> and died two days later. I think we have to let the patient live her last pleasures. I believe that, in terminal cases, everything is worthwhile. (Dr. Antônio)

> One of my employees was here, in the ICU. She was above 70 and had a terminal cardiac disease. We knew she would not come back [home, with good health conditions]. I talked to her and to the daughters and said that I had to stop the medical efforts because if I continued, she would suffer. She asked to see her dogs, eat chicken broth, and panettone. She wanted to eat salt [because she spent many years on a restrictive diet]. I let her do everything. She got worse and died, but she died with dignity, respect, family support, and having her last wishes attended. (Dr. Roberto)

Demarcating the differences in care practices in Brazil and other countries, Dr. Joana supports her view with a cultural trope: "the warmer Latin people". For her, the search for closer relations between doctors and patients and the attempts to make the patient feel at home are regional characteristics.

> Here, in this continent, Latin America, the human side still excels. In other places, this is diminishing. I do not know if they are more practical [the others, non-latins] or if we are more sentimental. And we still have all the emotional load behind us. (Dr. Joana)

Humanization appears, then, as a mechanism to offer care when the impossibility of cure is established. Additionally, in the cases mentioned above, the doctors become all the more aware of the risks of iatrogenesis (side-effects and even illnesses caused by medical practices). All my interview partners say that they privilege comfort measures in these cases and share the belief that dysthanasia is the worst possible outcome. For Dr. Vera, distanásia "postpones the suffering" and "deludes the family", that might think that the procedure will make the patient's condition better. Dr. Antonio points to the limitations of technology to measure suffering:

> I believe dysthanasia is the worst harm. There are non-invasive monitoring to check the level of sedation, for example, but even in this case, there are things that cannot be measured. What is the patient hearing? What is s/he thinking? (…) Likewise, I do not know what he is feeling when I am putting a tube in his/her chest. This is very

> complex. I do believe that dysthanasia is killing twice. Here, we have a reality that is different from Brazil, because I do have intensive care beds, more than 200 in this hospital. I do not have problems with the lack of beds; I do not need to fight for palliative care to solve my problem. It is more the human viewpoint. What are we doing with this patient? (Dr. Antonio)

Dr. Plínio shares this concern and gets disturbed with the suffering he sees in his routine.

> For me, the worse is, for sure, an ill-suited procedure to extend the life and its consequences. We see the patient daily in situations that, for example, to give him/her a shower, we have to administer medication to make the pain bearable. Why should I do something that I do not even know if it is going to benefit him/her only to see if s/he lives a little longer? This makes me very worried and bothers me much more than the opposite situation. (Dr. Plínio)

Nonetheless, in spite of the doctor's beliefs, dysthanasia happens. Mainly because the next steps are not clearly defined and, in the emergency setting that is the ICU, the priority is to save lives, or because the legal guardian disagrees with the patients' directives.

> It is a very hard situation. We get very troubled by that. We try to explain [the case] the best that we can to convince [the proxy], but when we see that we are not going to make it, we have to comply with the wishes of the legal guardian [when the patient gets unconscious]. (Dr. Plínio)

When there is no consensus, the doctor might also opt for a procedure to extend life. “The majority of the doctors get uneasy when it comes to limiting life support, because they know one of the family members can question his decision.” (Dr. Francisco)

One doctor recalls a case in which the patient did not manifest her wishes, and the husband, in a former conversation, told the doctors that he wanted them to do everything to save his wife. However, he was not present when the doctor had to tackle her respiratory insufficiency. “I did what I had to do: I intubated here. When he came back, I told him that she would never leave the tube, and now we would have to wait [for her to die].” (Dr. Joana)

For Dr. Roberto, when dysthanasia happens, it is because hospitals and doctors made a mistake, mostly by not communicating well with the families and patients, i.e., not aligning expectations and probable outcomes.

> We have to talk to them before this happens, not when it is happening. When it is happening, it is damage control. We will do it [the procedure] because the patient will die otherwise. But we made a mistake: we did not tell them that this could happen. (Dr. Roberto)

6.2.1. Visions of aging in Medicine

The intensivists interviewed for this thesis navigate through multiple views of aging. They are all quick to affirm that the end of life is not related to age anymore, as they emphasize function over age when evaluating a patient. Nevertheless, going deeper into the interviews, they acknowledge the body limitations that come with age and also the lack of medical knowledge and technologies to handle the complexities of treating multi-morbidities in a fragile body. For them, aging lost importance in diagnosis and treatment because living conditions improved, people live longer and have more active lives nowadays.

> We have a different elderly profile [nowadays]. A few years ago, the sixty-year-old patient did not work, s/he stayed at home and all. Today, there are eighty-year-old patients that work, that are functional. So, before defining [the diagnosis] from aging alone, I have to see how much s/he is functionally dependent or independent. If s/he is independent, I will not look at her/his age. If s/he is dependent, at which level? Then I will establish the priorities. But age, alone, today… I already had a 102-year old patient that was discharged. Lucid, conscious, oriented. (Dr. Vera)

In these accounts, age is portrayed as just a number, and all the doctors highlight, sometimes with admiration and excitement, how very old patients, above 90 and sometimes even above 100-year-old, survive complex surgeries and are able to be discharged and have a fulfilling life.

> Life expectancy is changing; the cultural standards are changing. These people [the patients] are coming old, but super lucid and independent. How many FHCs[11] are in

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[11] Fernando Henrique Cardoso, President of Brazil from 1995 to 2003, who is now 88, is the head of his political institute and still gives interviews and speeches.

> our daily lives? Today I was with an 82-year old-patient, historian, lyrical tenor. I was speaking with him for one hour. (Dr. Vera)

> We handle many patients above 80-90 years old, and we often see that age is just a number, something that we could not take into consideration. We have 90-year-old patients in intensive care that live the life of a 60-year-old: totally healthy and functional. (Dr. Plínio)

The changing perception of what is naturally expected during the aging process influences medical practices, patient's and families' expectations about the possibilities offered by Medicine, and the infrastructure of the hospitals that are now raising the number of ICU beds. For my interviewees, ICUs are, now, mostly a place to treat decompensated conditions of chronically ill patients, usually in a higher age-range (above 60, according to Dr. Vera), instead of handling sudden diseases and unexpected events, like traumatic injuries.

> Primarily, what changed [in ICUs] is the incorporation of technology and the aging of the population. The profile throughout the time changed a lot. We see more and more older patients using technology. (Dr. Vera)

Instead of being cured and going definitely home or dying in ICU due to the severity of the case, many patients go back and forth from the hospital to their homes and the hospital again. and, as Dr. Vera puts it, "the end of life is not a single moment in people's lives anymore."

Dr. Joana tells me about a case in which she knows the patient will come back to the hospital do die.

> One of our patients will be discharged now. There are no more therapeutic options for him. He has an unresectable tumor. We initiate chemotherapy to try and reduce the tumor for the surgery. However, he entered the group of the few patients that react so badly to a chemotherapy section that he almost died due to the infections. We were able to take him out of this phase. Clinically, he is in a good moment, but he knows nothing else can be done. We are managing his pain and feeding him through a tube. We explained everything, and he wants to go home. So, this is the moment to do it. We know that he will come back with some sort of complication. It

> will be a pulmonary infection because he has bronchoaspiration, but this is his wish. And for us, this is right. He will come back when needed. (Dr. Joana)

For Dr. Francisco, these expectations and changes in infrastructure are related to “a culture that does not tolerate dying at home." This change that also influences the understanding of the natural evolution of a disease, however, can also be bad.

> Some older patients here spend one week at home and two months at the hospital. The understanding is that a person is old, is at the end of life, but while the eyes are open, we have to try. It has changed [the idea of natural evolution], but not always in a good sense. Since we have more support and resources, sometimes we keep the patient alive, despite the damages in the quality of life. (Dr. Francisco).

Considering that employing more resources does not mean that they are doing good to the patients, the doctors ponder with multiple meanings of aging. More technological resources and better living conditions turn age into just a number, one among many factors in doctor's health assessments, but they also recognize that "the body changes with aging" and that they can only help "until a certain point" (Dr. Joana). Here, the appeal of the natural course of a disease is stronger than the allure of technology and medical knowledge to postpone death. That is why, for the elderly patient, comfort measures are the priority, and not always the most up to date technology is the better.

> For an older patient, we are going to look for what is less invasive, not always what is more technological or the last generation. We are going to try to cause minimal harm to what we will do. For example, a central venous catheter. Formerly, to give the patient medication, we had to obtain the venous access through the neck or another larger vein. Nowadays, we have the peripherally inserted central venous catheter, which is inserted in the arm. So, it is much less invasive than to puncture the neck. This kind of technology is much welcomed, and we are going to prioritize it for the elderly. We always try to do what is less invasive and what brings fewer risks for a patient that already lives with many comorbidities.” (Dr. Plínio)

Here, it is interesting to observe the medicalized meaning of aging. An older patient will have comorbidities, caused by several chronic conditions, and this will lead to polypharmacy (when the patient takes several drugs), that makes diagnosis and treatment more complex and limits the therapeutic options. While taking several medications to manage risk factors like hypertension and hypercholesterolemia can help the patients prevent strokes and heart attacks, their interactions also make the patients more “fragile" to other procedures and drugs that might be needed in intensive care.

> For all of our patients with comorbidities, we have to evaluate his/her clinical condition and do medication reconciliation. We have to work with a multi-professional team to see what illness the patient has now, and to what extent this comorbidity influenced the disease and can impact the treatment. For example, we will have to stop the medication of a patient admitted with an infection and with a history of high blood pressure, because he is at risk of being in hypotensive shock. Or someone who suffers from Parkinson's diseases, for example. If we had to intubate and to pass a probe, we know that the absorption of the Parkinson's drug will be impaired. Thus, we will have to plan the diet or even to stop it to give him/her medication. It is very complex, and we need to have this multi-professional look of the comorbidities. (Dr. Francisco)

> Our biggest challenge is polypharmacy, the comorbidities, and the side-effects of the drugs and devices that we have at our disposal. Sometimes, an older patient does not tolerate a given drug that we would use on a younger patient because s/he has kidney failure, previous pulmonary problems, or cancer. Usually, this is the biggest limiting factor. That is, a patient can have serious pneumonia, be intubated, in dialysis, and still have a 3% chance of death. But if I have an 80-year-old patient, even without previous conditions, just because s/he is 80, the chances of death are ten times higher. (Dr. Antonio)

In yet another facet of the aging patient, the doctors highlight the self-governed individual that must be aware of his/her health-related risks and work proactively to manage or avoid them. In this case, the prevention discourse is prevalent. For the doctors, risk management throughout life helps the patients avoid acute episodes of diseases and leads to a rise in life expectancy. Some of my interviewees related what the patient did over the years to their health status at the end of life and limitations in the therapeutic options, for example, smoking or an inadequate diet, which makes the patient's body "weak" to support interventions at older ages.

> Dr. Osler[12] used to say that the patient does not die because of the disease s/he has now, but because of what s/he carries with him/her. For example, previous pulmonary diseases caused by smoking. Thus, what the patient brings from her/his past, increases his/her chances of dying [in comparison with a healthy patient] and multiplies the limiting factors, especially in the case of the elderly. (Dr. Antonio)

> No doubt, the majority of the patients in ICUs are older. In the private [sector], maybe they are even older, because they had better living conditions than the patients of a public hospital, in which, in the transition from adulthood to old age, they carry a disease that was not treated. (Dr. Francisco)

Likewise, the intensivists' view on biomedicalization is multiple. They condemn interventions that do not come with clear benefits and praise palliative care as a resistance movement against the consequences of biomedicalization, like the indiscriminate use of technology that can lead to dysthanasia. However, palliative care is also a way to medicalize the dying body: instead of giving up on the patient completely, the doctors focus on managing the pain or the shortness of breath, for example. Moreover, the idea of an older patient dying at home is never present in their discourses. They know that a terminally ill patient, even if discharged to go home, will return to the hospital to spend his final moments, maybe not in intensive care, because there is not an acute case to treat anymore, but at least in an infirmary bed.

> "We know that s/he will go back eventually, but everyone is aligned and conscious of it. (…) When this time arrives, we propose comfort; we talk about the need of the patient to feel supported by the family. That is better to stay at the infirmary [with palliative care], surrounded by family members, than to die alone in a cold intensive care bed." (Dr. Joana)

Since death is not coming unexpectedly anymore, but, instead, is often a consequence of the slow decay of the body, and considering that dying at home is becoming a rare event, palliative care is mentioned by my interviewees as one of the paradigmatic changes in ICUs. They relate the evolution of intensive care knowledge to a "natural

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[12] Sir William Osler (1849-1919), canadian physician, one of the founders of Johns Hopkins Hospital. Dr. Osler was an advocate of bedside training and of doctors investigating the patient's history before coming up with diagnosis. [Lopes AD, Lichtenstein A. (2007) William Osler. *Rev Med (São Paulo)*. 86(3). pp.185-188]

perception” of death and terminality by the doctors (Dr. Plínio), and a better understanding of palliative care. Instead of an interventionist approach, labeled by many of them as “a heroic measure to save the patient", they would rather work with a multidisciplinary team to tackle the two “scariest conditions” (Dr. Joana) of the end of life: pain and the difficulty to breathe.

> Not during my time, but today, the intensivist has the palliative care discipline during Residency, from the basic concepts, like euthanasia, dysthanasia, and orthothanasia, to the best approach in terminal cases. Even though technological support has increased, the intensivist nowadays has the opportunity to have the knowledge needed to offer the patient a dignified death, to not cause dysthanasia, an artificial extension of life. (Dr. Francisco)

In Brazil, hospices (hospital-like institutions focused on terminal cases) and home care are not so common. Besides the generational and knowledge gap among physicians taking care of terminally ill patients, these factors make it harder for the intensivists to convince families and referring physicians that palliative care is the best option for the patients. Meanwhile, the hospitals have to push insurance plans to change their approach, paying for palliative care AND other health-related activities in the ICU, since, for now, the idea is that one excludes the other.

> We started talking about palliative care, in a more structured form, three years ago, with the participation of specialized professionals, a multidisciplinary team. But I think we still have a lot to evolve. We are still slowly walking towards it, and we still have a lot to learn. (Dr. Vera)

> Both the families, some doctors, and the insurance plans understand palliative care as doing nothing more for the patient [except offering comfort measures]. But this does not mean that the patient will never leave the hospital. It means that the treatment will have more focus on his/her comfort, not on his/her main disease. I am not leaving the patient to die. I will do whatever is possible to take the patient from the ICU and transfer him/her to a common bed in the hospital or let him/her die in comfort in the ICU. Whatever I can give to the patient, any procedure or exam that might help him/her, I will do it. We give the patient only sedatives, food, and oxygen when s/he is really in his/her final days.” (Dr. Antônio)

6.2.2 Competing meanings of technology

My interview partners acknowledge the multifaceted character of technology. Whereas technology supports their decisions, it can raise life expectancy, make the procedures safer and more comfortable for the patients, it also involves risks, even if minimal, and might be expensive and pointless in terminal cases.

> It [technology] helped us to see things, to come up with a decision faster. On the other hand, technology made people live longer, and we are not prepared for that. For example, I already had a 102-year-old patient in the ICU, that is completely out of our assistance curve. When you have to handle [patients with] an age that you never worked with, what do you do? What is expected at this age? We have to be constantly updated. Our life expectancy [in Brazil] is around 70-80 years old, and people are living until 100. So, there is a gap: there are things that we did not know they could happen. (Dr. Roberto)

> Many times, the use of technology is leading us to dysthanasia. We want to use it and think that, if it is less invasive, we can do it, not understanding the situation of terminality. (…) We think: it is so small, it does not need a cut, it is only a puncture. But it does not make sense to do it, even being easy.” (Dr. Vera)

Mentioning a common condition in elderly patients, aortic stenosis, two of the doctors point to the advantages of a catheterism procedure to change the aortic valve, which does not require open-heart surgery, and it has been performed frequently in patients above 80.

> I am sure this gives a better life expectancy to the patients. They recover the functions faster, and the trauma is smaller (…) The surgery was often contraindicated to older patients because they would not have the health status to survive the surgery. Now we do this procedure with tranquility, without major problems during the postoperative period. (Dr. Plínio)

The procedure, however, is expensive (more than 100,000 reais[13]), and, exactly because it is minimally invasive, its use is considered “tempting” (Dr. Vera). Dr. Antonio emphasizes outcomes instead of safety when evaluating the use of this kind of technology.

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[13] Around €22,000 (Brazilian Central Bank - Official exchange rate on September, 30th, 2019)

> It is relatively safe. I already saw a patient die during the surgery to put a cardiac bypass, and he was only 50. Even when the procedure is minimally invasive, like elective catheterism, the patient can die. It happened to me once, and it is the worse feeling for the doctor. The patient comes from home and dies during the exam. (...) Also, there are contraindications because of the costs. I will not put an implantable defibrillator cardioverter in a patient with lung cancer, brain, and intestines metastasis, and that has a very low life expectancy because then the costs become too high [compared to the benefits]. All this is based on the protocols [safety and cost-benefit analysis]. (Dr. Antonio)

For my interviewees, it is the doctor's job to evaluate the real indication for this procedure, to avoid dysthanasia and the rise of unnecessary costs in medical assistance. The primary metric to do this is Quality-Adjusted Life Year (QALY), combining the quality of life and the patient’s life expectancy. But this assessment is not always clear-cut, both because the metrics employed can conflict with the patient's understanding of the quality of life and because the majority of medical studies still neglect people above 65. In ICUs, where often the average age is higher than that, all decisions have to be individualized, based on the patients’ health indicators, comorbidities, the drugs they are already taking, etc. In this sense, it seems that the age profile is evolving faster than the academy/medical schools' capacity to develop studies to support the technology use, leading the doctors to rely on individualization and empirical experience, instead of literature to make their decisions. This situation confronts the intensivist with the uncertainty in his/her profession and the limitations of knowledge to treat patients with this profile, raising the fear of making mistakes.

> The doctors live under pressure 24 hours a day. I have a life in my hands. If I make a mistake, if I do not think well, something [bad] can happen. That is why many doctors have depression, take medications to keep them alert, or to control anxiety. And medical schools do not prepare us for that. We have to learn in practice. (Dr. Roberto)

This feeling of “learning on the go” is also shared by other doctors, who recognize that the assurance to decide comes with time and experience, both when it comes to indicating a procedure that is still not supported by literature as to deciding how far they want to go to save a patient.

> Everything has a limit. Of course, my first impulse is to save the patient's life, but I have to be very rational to decide how far I will go to save a life and where is the limit before I cause him/her harm. I believe there is a clear limit, but it is not a cooking recipe. The more one sees critical patients, the more one feels safe to define it. In the beginning, we are afraid of everything, even of being sued. With time, comes assurance. (Dr. Vera)

Even though doctors mention literature, scientific-based evidence, and guidelines as the basis to define the medical conduct, a big part of the decision-making process is based on their experiences and feelings/intuitions. This helps to explain why, when confronted with the same case, doctors disagree on the path to follow (for example, when they complain about older referring physicians that are adamant to palliative care).

The tacit knowledge is hard to explain and cannot be grasped with public access information. That is why the spread and easy access to information via the internet, a category that I labeled "Dr. Google", with the doctor’s help, it is seen initially as a threat. A typical first reaction is to feel challenged by this "unfair competition". “Dr. Google affronts us every day. He has all the information, knows everything, never sleeps, and is always updated (Dr. Roberto)." Used to the monopoly of knowledge, the intensivists feel uncomfortable when the patient or the families start to discuss therapeutic options or question the medical conduct.

> In the beginning, every doctor is known for not wanting to talk. S/he thinks s/he knows everything, that s/he is right. It becomes an issue: Wow! Are you going to contest me? Then you start to get used to it and to realize that this is the reality nowadays. Everyone has access to information and wants to know what is happening, what is the best option. Today, for me, this is completely common, an expected routine, but, In the beginning, I found it a bit strange and uncomfortable. (Dr. Plinio)

Besides feeling uneasy when a patient challenges his/her decision, these intensivists are afraid that lay-people looking up the internet for medical information are prone to misinformation that might bring mistrust to the doctor-patient relationship.

> I think we have to be open, transparent, and show: if a patient googles [for information], what is real? What is charlatanism? This happens a lot at these end of life situations. We had a typical example when that doctor in Ribeirão Preto brought the “cancer pills".[14] We had a few terminally ill patients that brought the medication. Is it approved by Anvisa[15]? [the national health surveillance agency] Is there evidence in the medical literature? If not, the patient is not going to use it here. (...) We have to be aligned with the institution policy. We have to evaluate it. Is it ethical? Is there literature about it? It is grounded on what? If not, [the patient] will not use it. We have to be transparent [because] this is a hard moment for the family. We have to be confident and docile at the same time, to not create confusion. (Dr. Vera)

On the positive side, “Dr. Google” might make doctors more humble about what they do not know, more open to dialog, and “more human” (Dr. Antonio).

> I think this is the fundamental role of a hospital services coordinator. S/he might not know the information at that time, but s/he has to be honest and tell the patient when s/he does not know about a study, ask for a few days to read it, and think about the pros and cons. (…) We must have a partnership with the patients and families for everything. Let's talk, I am not against anything, but I have to work grounded on scientific evidence. We have to talk and convince the patient. We have to listen to what the patient is saying because s/he is desperate. We have to be able to develop the doctor-patient relationship. (Dr. Roberto)

For the patients and families, the free flow of information on the internet makes them more knowledgeable about that specific health condition and empowers them in the discussions about the therapeutic options.

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[14] In 2015, a group of patients went to court to have access to the synthetic fosfoethanolamine, a substance developed by the chemist Gilberto Orivaldo Chierice that would cure cancer. The public outcry was so big that, even despite the lack of studies to prove its efficacy, a law authorize its use and the national health surveillance agency had to approve the commercialization as a food supplement. Until now, the studies could not prove the benefits of the substance. (G1, 07/20/2019 - “Só vai ser reconhecido daqui um tempo', diz amigo de professor que criou 'pílula do câncer”: https://g1.globo.com/sp/sao-carlos-regiao/noticia/2019/07/20/so-vai-ser-reconhecido-daqui-algum-tempo-diz-amigo-de-professor-que-desenvolveu-pilula-do-cancer.ghtml)

[15] Anvisa - Agência Nacional de Vigilância Sanitária (National Health Surveillance Agency)

> I believe the free access to information has positive sides: people find out what is happening, and it obliges us to be more human, to give the patient all the information, and talk about the limitations. The negative side is that the person is reading something that is not prepared for the lay-people understanding. Sometimes we are pushed to offer a treatment that will not solve the problem for that patient. That [the diseases and the patient's context] does not come with a manual. This is the bad side of the free flow of information. Hence, we have to build a relationship with the patient. (Dr. Antonio)

The most common way to mark the doctors' position and convince patients and families that the therapeutic conduct proposed is the best for that case is to purify the knowledge. This often means ignoring the role of tacit knowledge when talking with patients and families and affirming that they would only employ procedures and drugs based on scientific evidence and substantial medical literature. Dr. Roberto, for example, assures me that "if there is scientific evidence, I will not discuss it. The patient will be submitted to it [the procedure or drug]."

However, if the option brought by the patient or the family is scientifically strong, but the doctor still believes this is not the best practice for that circumstance, the strategy is to individualize the case. Bringing context back to the conversation, the doctors explain that, albeit there is evidence that a drug/technology would work for that disease, the patient's condition does not allow the use of this resource or that this specific patient would not benefit from the procedure.

> It happens. We have to explain the context, why it does not work in that case. I try to clarify the doubts, but if the patient pushes, I have to say that I will not do it. If s/he wants to look for a second opinion, it is his/her right, but I try to explain as professionally as I can why this is not how things are done. (Dr. Francisco)

Enacting terminality in ICUs, my interview partners have to handle the multiplicity of aging, technology, and their own practices. Here, the assemblage of these objects creates realities that, at first, seem contradictory, but, in practice, attend to the nuances and complexity of the situation. The older patient is healthier than in the past to explore the medical technologies to reverse his case and still faces the biological decay of his body. S/he is more knowledgeable, has more information to decide, and still cannot fully grasp the therapeutic possibilities. The worsening health indexes are a consequence of aging and the outcome of inadequate behaviors. These interchangeable meanings and varied practices help my interview partners to cope with their patient's end of life and keep their attention to the particularities of each case.

6.3 Socio-economic aspects

In all the interviews, in the public, middle-class private and high-class private hospital, the doctors emphasize that they have access “to all the technology available” (Dr. Vera) “enough beds to serve all the patients that need intensive care” (Dr. Antonio) and that they work in a “unique environment” (Dr. Joana). This, however, "is not the Brazilian reality." Some of them had previous experiences in the public sector, but not in ICUs (one in ambulances, the other in clinics). Thus, the comparison is based mainly on conversations with their peers and on the prevailing view in Brazil that the public sector is chaotic and continually struggles with the lack of resources and bad administration. While this might be true when one sees the common media portrait of the public sector and hears the complaints of the people that can only resort to the *Sistema Único de Saúde* (SUS), I must acknowledge that their assumptions are not based on experience.

In the non-profit hospital, the two doctors that I interviewed said the institution does not lack resources, and they have all they need to treat the patients in intensive care. However, Dr. Roberto mentioned a mechanism of the governments to give a financial complement to the hospitals, to compensate for an outdated price list that does not even cover the costs of the procedures. He also works on the private middle-class hospital of this network and says that even the private hospitals work with presumed losses due to “ things we know the insurance plan will not pay."

> We start the fiscal year knowing that we are going to have losses. If we do not work with at least 200,000 to 300,000 reais a month of presumed loses, the hospital does not work. This gives us support to keep good practices and avoid legal action. (Dr. Roberto)

My understanding is that, for now, the lack of money is an administrative problem, that is not affecting the medical practice. The financial pressures are also not affecting the doctors directly, but they are conscious of this aspect. My interviewees often mention their worries related to spending money, time, and technology on patients that will not recover from their diseases.

> I think this is one of the main causes of the intensivists' burnout: how much we invest in a patient that will not have a good quality of life, that we are going to give back to society in a worse situation, and that is going to result in more costs. (…) What are we doing? We are making the patient suffer, increasing the costs of the health system, producing very high costs to society, and not bringing any benefit. (Dr. Francisco)

These intensivists also see a movement coming from the insurance plans and even from the hospital administrators to question the adequacy of their conduct, especially related to the cost-effectiveness of the procedures and the use of new and expensive technologies. This appears mainly in the testimonials of the ICUs coordinators. According to Dr. Antonio, the recommendation is to avoid any procedure that has a cost considered too high for the benefit it brings or that presents high risks for this group of patients. Doctors should only resort to this kind of technology as a last resource.

> Nowadays, insurance plans have a strong emphasis on cost-benefit analysis. They are all over us. It does not do any good to say there is new technology if it is going to cost 250,000[16] reais for only one patient. What are the criteria, what are the basis for it? This is never a doctor-only decision, and it is never easy, but it is an ever-growing reality. (Dr. Vera)

Dr. Roberto explains that the doctors have to justify every procedure and request in writing and, then, an auditor working from the insurance plan checks if the therapeutic conduct is supported by medical protocols and guidelines. If it is not, the insurance plan either does not authorize it or, in an emergency case, when the procedure is done before the authorization, it does not pay for it. Inside the hospital, the auditor has a lighter approach and tries to convince the doctor only to do a procedure if he is sure it is adequate for those cases.

When the situation reaches a point where a needed procedure or drug is not authorized or, in the public sector, is not available in a hospital, the patients and families appeal to the Public Defense Office and often get an injunction to do what is needed. This process is known as the judicialization of health. For Dr. Roberto, the problem with this tactic is that the judges and clerks working for the Justice Department do not have the skills to access the impact of their measures on the health system or the real need to authorize the

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[16] Roughly € 55,000 (Official Exchange rate in October, 2nd, 2019)

procedure, especially in the public sector. “The judges are not specialists in Medicine. They do not know that we have to control the costs. I’m not saying that they have to deny it [the treatment], but they have to question it." (Dr. Roberto)

In Brazil, the right to health is guaranteed by the Constitution[17]. Thus, often, the judges understand that access to services, drugs, and technologies is unrestricted, even when it is beyond what the contract with the insurance plan provides or when it surpasses the State's ability to pay for it.

A final socio-economic aspect is the manner poorer or richer families and patients receive a diagnosis of a terminal case. For the doctors, wealthier families are more demanding, push for more procedures, and have a harder time to accept the end of life.

> Especially here, maybe because the families have a bigger purchase power and access to more information about Medicine, they demand more and have some difficulties in accepting palliative care or proportionate care. (…) They think there is always a way to solve the problem. (Dr. Plínio).

> This insistence can culminate in arrogance.

> I would rather assist a patient in the public sector than one with an insurance plan. This public [with access to private services] feels entitled. They throw at your face that they are paying your salary. I think higher income influences negatively when it comes to putting pressure on the doctor. Incredible as it may sound, the low-income people understand better [the end of life]. The richer think they can afford the best treatments. And the poorer know the limit because they are seeing, listening, and participating [in the patient care]. (Dr. Roberto)

Also, in general, the doctors mention cultural level or basic education (meaning values and behavior, instead of instruction) as a factor that influences the way the families react to terminality, more than income.

> Some patients are very humble and are able to understand better than many people that are financially rich but extremely poor when it comes to ethics, morals, and intellect to understand something so complex as the terminality, for example. I

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[17] Article 196 from the Brazilian Federal Constitution: Health is a right of all and duty of the State.

> believe that the differences are more related to personality than with the amount of money a person has. (Dr. Antônio)

6.4 The social embeddedness of care

More than navigating through their multiple perspectives on aging, technology, care practices, and what is suitable for the patient, the doctors also have to consider the patients' and families' views on these subjects. As it happens with the doctors, conflicting feelings and conceptualizations coexist, and, to reach a consensus on terminality and treatments, everyone's expectations need to be aligned.

On the elderly's side, when hope to revert the case is lost, there are three main fears: to die, to suffer, and to become a burden for the family.

> What I realize here is that the majority of the patients do not want to give their sons and daughters a hard time. They are aware that everything has a limit and that they are approaching it. They do not want to be in a vegetative state inside their children's house. They do want to prioritize comfort and not the support of a life that does not make sense anymore. (Dr. Antonio)

For the doctors, the fear of death is a cultural issue, that brings obstacles to the conversations about terminality and leaves the decisions about the therapeutic conduct to the last minute.

> Most of the people do not have a clear idea of their last desires. How much quality of life are they willing to lose when submitted to a certain treatment? This is only discussed when the patient is submitted to acute care." (Dr. Francisco)

This might push the patient to abdicate his/her right to decide, if s/he feels too scared or overwhelmed, and poses new challenges for the doctors. Under Brazilian law, CFM regulations, and the Elderly Statute, the autonomy to decide is the norm if the patient is lucid and conscious.

> We talk directly to the patient, and s/he reacts surprised. Nobody is ready [to die]. Sometimes, they do not respond, only cry. (…) In general, maybe because they are fragile [emotionally and physically], they let other people decide: the children, the wives, or husbands. (Dr. Joana)

When the patient does keep his/her right to decide, s/he will find resistance if the option is for what the doctors call “futile treatment”, meaning conducts that only prolong the life without the possibility of cure or of recovering some functions. For the doctors, the patient only pushes for further treatment because s/he has not the full dimension of the consequences.

> I can say ok for further treatment, but I will tell her/him that I will not let her/him in pain or with shortness of breath. The painkillers can lead to comatose; the machines to help her/him breathe can cause recurrent respiratory infections. When I start to open the whole range of possibilities, the person understands that it is not a single medication that will save his\her life and starts to change his/her opinion. (Dr. Roberto)

Thus, autonomy may be restricted due to the lack of medical knowledge and also because the doctors tend to simplify the communication, to facilitate the decisions.

> We try to explain the case and not all the interventions. Otherwise, it becomes a street market. (…) Obviously, if he wants something that leads to dysthanasia, I will try not to do it [by trying to change the patient’s opinion]. But I never had this experience.” (Dr. Antônio)

Even if made independently, decision-making will also have external influences: the patient may decide to do what the family wants him/her to do or to give up on treatment to avoid being a burden to the family. "Sometimes, they say it is better to stay here [in the ICU] than at home, giving trouble for the family.” (Dr. Roberto).

At the same time, the patient fears loneliness and wants the family to be present in his final days or even to re-bond with his/her relatives. They often ask to go back home, since the intensive care setting, despite humanization efforts, is still a cold and sterile environment. This, however, may not be possible due to the patient's condition, the lack of infrastructure in the house the patient will stay, or due to the unavailability of caregivers.

6.4.1 The role of the family

According to the intensivists, families are usually present and have a heavy influence on the decision-making process at the end of life for the older patient. Sometimes, believing that the patient is not capable of deciding anymore, despite keeping his/her cognitive functions, or thinking that knowing the diagnosis will bring him/her more suffering, they ask to decide for the patient or prevent the doctor from informing him/her about his/her terminal case. For Dr. Plínio, "exactly because the family has an idea that it is responsible for them now, even if s/he is lucid, oriented and capable of making decisions, the family is the hardest [thing] to handle". When this happens, the doctor has to interfere to ensure the patient's right to decide.

> Sometimes, the family is too dominant, does not accept the patient's decision, and we have to explain that the patient must participate in this process. The family has no rights; autonomy is his/her. Of course, if the patient is impaired, confused, or sleepy, it does not make sense to discuss with him/her. But if s/he is conscious, we make it clear that the decision is his/her. (Dr. Francisco)

> In my opinion, the patient's word is the final, if s/he is conscious. Nonetheless, sometimes, even the referring physician is against the patient's wishes. We have to try and reach a consensus. Every time is different, and, as an ICU coordinator, I have to deal with different egos and personalities. I need a different approach for each one and a special way to reconcile [all opinions]. The patient has a decisive role and has this right guaranteed by the Constitution. (Dr. Vera)

In practice, however, the doctors prefer to manage conflicts and have patients and families agreeing on the same medical conduct.

> It is a complex scenario. In the first place comes the patient's wishes. But our mission, beyond ensuring the patient's comfort, is to mediate the conflicts and try to mitigate the family suffering. The family members will carry guilty throughout their lives if there is a feeling that we did not do everything possible [to save the patient's life]." (Dr. Francisco)

In the majority of the cases, the doctors relate the efforts to find a cure for the patient, the difficulty to let the patient go and all the care provided for the patient in his final days to acts of love and a need to reciprocate all the care that the family members received from the elderly when they were kids.

> What I see, especially when the family takes a reality's punch, is that they feel a paradox. It is ingrained, at least among us, Brazilians, that the parents are made to take care of us [while we are kids], and, when they grow old, it is our turn to take care of them. We have to change roles. They feel that I am interrupting this moment of their taking care of the parents. Initially, there is this cultural issue, which is not wicked, but really related to love. I think this is the predominant factor. In the majority of the cases, it is the love aspect, the need to retribute what has been done for them. The same way the father changed their diapers, they think they have to do it for their father. Initially, in the first contact, when we talk about terminality, they understand that: I cannot contribute to their father's death. (Dr. Antônio)

Driven by love and the assumption they have to “payback" their parents and grandparents, and without having a previous idea of the patient’s wishes, since terminality and death are not discussed, they often do not know how to react to the diagnosis. Dr. Francisco affirms that “people do not want to contribute to their parents or relatives' deaths." More than that, they express the wish to do something to help the patient and always hope the case can be reverted. “The family member is in a situation where s/he sees that a beloved one is suffering and s/he has to say goodbye. S/he feels powerless because s/he cannot really help." (Dr. Francisco)

When the reality is assimilated, they might opt to change their routines to be closer to the patient, with some of them “spending the day here, taking care of the 90-year-old mother or father, stopping to work and changing their whole lives” (Dr. Francisco). When the family members are absent during aging, they try to compensate for it pushing to extend the patient's life.

> There are cases here in which we try and talk daily to explain [the terminality], but it is hard. Usually, this happens when the parents were absent during aging. I think that, maybe, somehow, they feel they did not do what they could and now they think they can help. But they end up disturbing instead of helping. (Dr. Plínio)

Faced with few options, the relatives start to research alternative treatments, or second opinions or even resort to their faith. My interviewees cite religion as a significant factor in shaping the family members' opinions about the end of life. The understanding that "while the heart is beating, there is life still" (Dr. Francisco) or the hope for a miracle makes it harder for them to accept the terminality.

> In Brazil, in Latin America as a whole, we have a viewpoint that it is a bit different from the one in Europe and the United States, which is the strong religious aspect. Sometimes this is a hard barrier to overcome. Some religions, and here I am not criticizing or making a value judgment, but we know that some religions have a hard time to accept it [a terminal case diagnosis]. (...) They start to talk about many possibilities of cure by miracles, alternative pills, sanctified oils, blessed cloths, etc. This aspect becomes stronger. It is the Latin-American context. (Dr. Vera)

> The family puts a lot of faith that the religion will revert it [the case]. I do not discuss it, and I am in favor of many things. It is their faith, and they are going to find solace in it. Or they are going to expect a miracle. We see the family's faith intervening [in the decision-making process]. They want to bring people to pray; they organize prayer chains. (Dr. Roberto)

While praying groups and other religious activities are respected, they, again, use science, formal knowledge, and the hospital guidelines as arguments to stop measures that they find harmful to the patient, like alternative medicines or experimental treatments. But, overall, the main tactic is to keep communication channels open and to try to be available most of the time to support the families and clarify their doubts, anticipate outcomes, make arrangements to accommodate everybody's wishes, and manage expectations.

> Each family is different. They always keep their hopes and expectations. Firstly, we opt to talk with the one that takes care of the patient directly. When this person is not able to understand it, we would rather talk with someone calmer, for example, the children. In general, with all the family members in a group, we explain that the father or mother that we consider to be the last stage. That our main goal is to give him/her comfort, to avoid suffering. Almost all of them accept it because nobody wants to see a loved one suffering. We try to give, for the person who is against our medical

> recommendation, more time to adapt to the idea that this is going to happen [the death]. (Dr. Joana)

> Sometimes we have to bargain, make agreements like: if the case gets worse, we will not give antibiotics again. We explain what can happen, what we can do in each case, and that we prioritize comfort measures. (Dr. Plínio)

> We have to be resilient and manage conflicts. All the multidisciplinary team must be prepared to receive the family, and remind them of what is going to happen. ‘We talked that we would not intubate the patient when he develops respiratory insufficiency’, ‘the patient will be uncomfortable until we find the right dose for the medication’... And anticipate it [the prognosis]. Like this: this is happening, and the probably next steps are the lowering of the heart frequency and the sleepiness. We have to show them what is happening, and make them feel safe, make them sure that the patient received the best treatment. (Dr. Francisco)

The usual discourse among the doctors is that they do not want to make the patient suffer, and, in the end, most of the families agree with that. In this case, religious people rely, again, on their faith, understanding that this outcome was “God's plan” (Dr. Joana).

More than being concerned with what happens inside the hospital, the intensivists also have to be sensitive to a wilder context that might make consensus hard to reach. Now, the doctors also have to take into account previous disagreements and more complex family arrangements, with kids from two or more marriages, for example, or consider the role of the family member as the breadwinner.

> We have to aim at the palliative care, but we must also talk with the families, know their anguishes, what they have pending. For example, if the patient was the cornerstone of the family, who will be the next [to assume this role]? Who is going to receive the information [that the case is terminal]? How is this person going to react? What is going to happen afterward? (Dr. Roberto)

> At the end of life, the elderly patient is not only a machine-body reaching the end of his/her lifespan. To make the doctor-relationship stronger and facilitate communication among the actors affected by this situation, the intensivists put the patient back in his/her social context. The older patient, is, then, a citizen, a

> father/mother, a breadwinner, a beloved husband/wife, and a fragile human being afraid of dying. All these roles coexist and emerge according to how the set is assembled by the doctors.

6.5 What is a good death?

The idea of a good death has different meanings depending on the time, on one specific patient, or on the discourse the doctor employs to either facilitate the patients' and family members' understanding of the situation or to reach a consensus on the medical conduct. Despite the claims that an older patient follows the same protocols than a younger patient in the ICU, the idea of a natural life cycle is still strong among some intensivists and facilitates the acceptance of death.

> It is natural to talk about terminality in a case involving an elderly. It is not the core of my work, but to talk about terminality in babies is extremely complex. In a 40-year-old patient, that still has a mother and a father, besides his/her children, and you have to deal with two generations related to him/her, it is hard too. It is easier with an older patient because, somehow, we are prepared to bury our parents. We are not prepared to do the opposite. (Dr. Antonio)

> Between an older and a younger patient, they will both receive all the treatment they need. However, the younger patient has a better chance to recover from his/her illness, to get back to an active and productive life. Without disregarding the elderly - I will do everything that is needed, but I would try harder [with a younger patient]. (Dr. Joana)

What seems to connect the varied practices and definitions in ICUs is the common understanding that a functional body is equal to the quality of life. More than that, the general opinion is that the burden and suffering endured by a terminally ill patient are also spread to society and to his/her closer relationship circle. For my interview partners, this means understanding when it is time to stop the medical efforts, to not incur in dysthanasia, to hear the patient and do what is possible to let him/her live his/her last days according to his/her wishes, tackling symptoms that affect the quality of life and comforting patients and families in the physical and emotional levels. In sum, to end a case with everyone's minds at ease.

> My aim is to ensure that the patient will suffer at least as possible: that s/he is not in pain, that s/he will not experience breathlessness, that s/he will not be restless. Both for the doctor as for the patient and his/her family, this would be a dignified death: without suffering. (Dr. Plínio)

> For me, a good death is to let the patient live his/her last pleasures. I believe everything is legitimate in any terminal case. Everything that is well explained and agreed upon is worthwhile. If the patient tells me s/he wants to drink a bottle of brandy, why not? If this depends only on me, I will allow it. (Dr. Antonio)

> A good death is when the family and the doctor know that everything that could be offered was offered. That there was nothing excessive and that we managed to relieve the suffering. In short, everyone is sure that among what could be done, everything was done without extending the suffering. (Dr. Francisco)

> The aim is that the patient does not suffer, that s/he feels welcomed by the hospital staff. I am a doctor, and I do not want to be intubated, resuscitated, or kept alive by machines. For me, dignity is to be sedated, at ease, surrounded by my family, so I do not feel alone and scared. (Dr. Joana)

> A good death is when the patient dies with dignity. When s/he accepts a disease that s/he did not cause it and that we still do not know how to treat it. When s/he has respect, s/he is in an appropriate place, supported by the family, and with his/her wishes attended. Dignity is to give the patient the maximal amount of comfort that we can, regardless of the efforts we have to make. (Dr. Roberto)

6.6 Multiplicity, care practices, and cultural claims in terminal cases

The marks of the elderly's end of life are deeply embedded in the cultural and social context of the doctors, patients, and family members. Even in a hospital setting, following health parameters to assess cognitive, motor, and bodily functions and adhering to guidelines to define diagnostics and treatments, terminality is not purely a medical definition. Instead, in the hospitals visited for this research, the concept is constructed among all the actors participating or influencing a terminal case, and there is an effort to individualize the decision about it.

The approach to negotiating meanings and roles at the end of life helps the doctors share the decisions and responsibilities for the outcomes, embraces the uncertainties and limits of medical knowledge, and highlights the multiple roles of the older patient. Rather than trying to exclude the patient of his context and searching for diagnosis and prognosis purely based on scientific evidence, multiplicity is embraced to understand this moment.

The elderly's ill-body, at the same time, follows a natural decay and is not the main factor in defining medical conduct. It can stand new minimally invasive interventions while it is also too complex to intervene due to the co-morbidities. Thus, an older patient in intensive care demands a holistic view and a personalized approach because intervening to tackle only one problem may lead to several unintended consequences. Protocols and evidence-based studies support decisions but are not always followed to the letter. Instead, they are adapted to accommodate the patients' and doctors' understandings of well-being.

Likewise, the older patient does not fit one single category, but his/her multiple roles appear in a hierarchy according to the situation. S/he is, predominantly, one different persona for the judges, one for the society, one for the family members, one for the referring physician, and another one for the intensivist. My interviewees describe him/her in different roles, that coexist in the care practices and medical assessments. Under the law, s/he has the autonomy to decide about the treatments but is restricted by the legislation that does not allow euthanasia, and it is not precise about orthothanasia and dysthanasia. In the hospital, s/he is a citizen with rights guaranteed by the Constitution, a customer choosing the best options for his/her case, a lay-person with limited medical knowledge a human scared of death and pain and a fragile person, whose physical and mental impairments might compromise his/her ability to decide. The family members transit among the roles of dominant, resistant, disturbing, loving, caring, supportive, and understanding.

In this network, ICUs treat mostly chronically ill patients of older age. Thus, the rush to save the patient's life and to prioritize interventions aiming the cure gives room to practices to manage discomfort and a focus on the personal relations and wishes of the patient. The imperative to do no harm is stronger than the call to save the patient, which leads to ambivalent feelings related to technology. The artifacts that support the decision, improve monitoring, cause less damage, and raise life expectancy can also be the source of risks, suffering, and financial losses. Whereas scientific knowledge and technology are still at the core of the intensivists' practices and what can effectively help the patient, in their assessments, is welcomed, the focus on side-effects is stronger, and the benefits have to be substantial to make the doctors run the risks. That is why they are wary of experimental treatments. As a standard practice, they emphasize the individualization of the cases, which allows them to adapt the knowledge to assist a patient that is often not included in clinical trials.

In this setting, the doctor's goal to do what is good also imposes the development of skills that go beyond medical knowledge. Empathy, availability, and good communication are essential to reach consensus, keep families and patients satisfied, and avoid legal risks. The intensivist, then, must be a capable doctor, an advisor, a good listener, a comforting figure, and, above all, a negotiator. What is more, despite the claims of building a diagnosis of terminality together with patients, referring physicians, and family members, the intensivists do have an established idea of what goodness means at the end of life.

Mirroring Mol (2002), my interviewees, as "gatekeepers of technology" (Conrad, 2007) and with the knowledge that validates their standpoints, actively work to shape other actors' views on the situation. What connects the varied practices and definitions in ICUs is their common understanding that a functional body is equal to the quality of life and that the burden and suffering endured by a terminally ill patient are also spread to society and his/her closer relationship circle.

Therefore, therapeutic obstinacy must be avoided at all costs, and the doctors employ several artifices to achieve what they consider a dignified death. They demand a solid scientific basis before considering alternative treatment, while also explaining to the patients and families that a new procedure is not suited for that specific case, despite having the benefits proved. They follow protocols but also tinker with the guidelines to adapt the conduct to an elderly patient. They listen to the patients, families, and referring physicians' concerns while keeping their view on the best pathway on that terminal case. They resort to metrics, such as Quality-Adjusted Life Year or cost-benefit analysis, to justify their positions and avoid controversies, as well as inform the patients of the trade-offs of each choice and leave some options open to fit the patients and families' beliefs. As a last resource, they refuse to do something that, in their opinion, will cause harm, as a conscientious objection.

In sum, they are the articulators of the resources and actors in the enactment of goodness at the end of life, following what Mol et al. (2010) label as the new "ethics of care", i.e., adding humanization to technical procedures and considering what makes the life worthy. Instead of doing what is right, the doctor's aim is to provide the patients "a good death". The effort to reach a consensus on what this means help the actors involved in this situation to embrace uncertainty while keeping the trust, and to enhance the patient's feeling of dignity: instead of passive and subjected of all sorts of interventions, s/he can have his/her voice heard.

These different roles and positions do not contradict each other, but, in fact, are complementary and changeable to account for a varied of practices, situations, and individuals that can coexist in one single case.

6.6.1 How the Brazilian culture shapes medical practices and discourses

In this research, it is possible to see how culture is strongly connected to the care practices, doctor's assumptions, and medical discourses at the end of the elderly's lives in Brazil (Prasad, 2014). While doctors rely on standardization, metrics, and technologies deemed universal, Brazilian characteristics are often mentioned to justify an approach or behavior.

Sentimentality and humanization become characteristics of the Brazilian medical assistance, as well as the closer doctor-patient relationship, the effort to take care of the patients and families also in the emotional aspects, and the flexibility to attend the patient's last wishes. In contrast, the cold and technical understanding of terminality is what defines their ideas of care practices in the Global North. The attributes considered Brazilian are used to demarcate these intensivists' ways of doing Medicine and to reinforce their authority to define what is a good death, in spite of their acknowledgment of the Global North setting the directions for the best practices in the field.

The common sense, what "everyone knows", in Brazil or inside the intensivists community, also shapes their answers. They all emphasize palliative care in ICUs as a way of helping the patient, without causing further damage, and, in spite of perceiving some financial pressures, none of them had problems due to the lack of beds, drugs or equipment in their routines. However, all of them emphasize that this is not the Brazilian reality (even though the majority of them never worked in a public hospital) that, in their opinions, is marked by the poor's hardship to access the health resources.

When it comes to the patient and the people in their closer relationship circle, the Latin-American context appears again. Many of my interviewees try to explain the patient's and family's behavior resorting to regional characteristics that would lead to different outcomes if the research had taken place in another country. Sentimentality, the sons' and daughters' duty to take care of their aging parents, religious devotion, and a tendency to favor comfort over technology are considered the Brazilian way of dealing with the end of life.

However, these characteristics, combined with other socio-economic aspects, are also used to dismiss alternative treatments or to justify the lack of understanding or resistance to the diagnosis. When this happens, the doctors entrench themselves behind the supposed sensible base of scientific evidence. This attempt to purify the knowledge and set boundaries between expert and lay knowledge puts the intensivists back at the center of the decision-making process.

Albeit I had not interviewed patients and family members, in the talks with the doctors, I could, to some extent, approach the ways the medical and health technological culture shapes their expectations on health and aging. Nowadays, the expectations related to technology and Medicine are higher, and it is hard to accept that a person will age and die at home or that one disease is really irreversible. Since there are so many possibilities, the end of life does not seem natural. Rather, death is something to be avoided, and the hope is that Medicine will always develop to raise life expectancy and offer fixes suitable even to the most fragile patient.

7. Conclusion

This Master's Thesis had the aim to investigate the care practices, assumptions, and rhetorical claims employed by Brazilian intensivists to manage the elderly's end of life situations.

Guided by the research question: *How do doctors navigate through different obstacles and scenarios in Brazilian health care setting to address the terminally ill older patient?*, I listed four primary points to approach in the interviews.

First, I started with the legal situation, in which the Penal Code does not offer directions to handle a terminal case in the context of an aging population and several technological resources. Belonging to a community that is powerful and respected in Brazil, the doctors feel protected and oriented by their professional council and do not worry about the legal consequences of their decisions. What is clearly forbidden is not performed, i.e., euthanasia, but the intensivists do not feel paralyzed by the lack of clarity in the law. Medical authority, scientific basis, and the understanding that life will eventually come to an end make them feel comfortable with the decision to not extend the patients lives.

Second, in this private network, financial pressures and the lack of resources do not concern the doctors. The economic context, nonetheless, influences their assessments. Cost-benefit analysis is an important topic when defining the therapeutic conduct for the elderly patient. ICU coordinators that keep a closer relationship with administrative and financial departments are slowly perceiving a movement to limit the medical freedom to intervene at the end of life and to increase doctors' accountability for the costs. Besides, the doctors recognize that the costs to keep a patient alive that does not has a chance to recover his functions are too high, both to the healthcare system as to society.

Third, technology and the evolution of knowledge in Medicine transformed the experience of death into a winding road, demanding the patient to travel backward and forward to the hospital. Doctors and families share the hope that Medicine will continuously evolve to keep death at bay and that new fixes will be developed to tackle the conditions that put the older patient at risk of dying. On the other hand, all the actors are cautious of the side-effects caused by the use of technology. The fear of iatrogenesis and dysthanasia permeates all the interviews and is the most persuasive argument to convince the families and patients to give up further treatment.

Fourth, the decision-making process at the end of life incorporates social and personal perceptions of aging. Instead of de-contextualizing the patient and trying to provide a diagnosis based only on biological marks and scientific evidence, the doctors affirm they consider many factors and share the decision with other players, both to define a terminal case as to decide the path to follow after this conclusion. The way of living, the role of the patient in his/her family, the children's, spouse's, and relative concerns are taking into account. What is more, inside these ICUs, no decision is made before discussing the case with a multidisciplinary team and the referring physician.

7.1. An STS perspective on aging and terminality

Anthropology, Social Sciences, and STS studies point to the social construction of Medicine as well as the establishment of a society ruled by medical and technoscientific developments (Clarke, 2003, 2009, Lock & Nguyen, 2018, Samson, 1999). In my research, these perspectives appear in the way doctors see their responsibilities also outside the hospital. The "continuous pressure" of having a life in their hands (Dr. Roberto) and the "burnout" caused by futile treatments, that raise the costs and give back to society a person that has no conditions to live a fulfilling life anymore (Dr. Francisco) are some examples of the embeddedness of social life in care practices. Looking from a different side, the possibilities brought by technology changed people's hopes regarding death. Dying at home became inadmissible (Dr. Francisco), and now it is hard to accept a diagnosis of terminality.

The conceptualization of the patient, his/her body, and diseases also shape expectations and discourses at the end of life. The body is like a machine, that requires maintenance and, to a certain point, can have its worn-out parts substitute or fixed by doctors. What is more, these fixes could happen at any age (Kaufmann et al. 2004, Samson, 1999). The intensivists show excitement with a minimally invasive procedure to correct aortic stenosis, recommended even for patients above 80 (Dr. Vera, Dr. Plínio). For them, this kind of technology can raise life expectancy and turn age into just a number. However, they do acknowledge the body as a complex system, in which fixing one problem can lead to unintended consequences in different parts.

The medical gaze (Foucault, 1977) is not so evident in these ICUs. Instead, at the end of life, the patient's context matters. More than that, it dominates the doctors' discourses, both to explain the patient's current health conditions as to negotiate the level of the intervention in his/her final days. Self-governance, self-assessment, risk avoidance, and the following of health recommendations are the expected behaviors from a patient (Brown & Webster, 2004, Conrad, 2007, Dumit, 2012, Foucault, 1978, Lupton, 1999). For them, an untreated disease (Dr. Francisco) or bad habits, such as smoking (Dr. Antonio and Dr.

Roberto), are responsible for the fragilization of the body and the consequent limitations in therapeutic options.

All these conceptualizations seem logical in Brazilian biomedicalized society, that follows, mostly, Western Medicine (Clarke, 2003, 2009). It is prevalent, in my interviewees' answers, the focus on prevention to refrain chronic diseases of becoming acute, the challenge imposed by polypharmacy, the evolution of knowledge and technology in intensive care, and the identification of the patient by his condition, not his age. On the economic aspect, the intensivists point to the increase in the proportion of ICU beds in hospitals. These news beds are open to assist a different kind of patient. Instead of trauma and acute cases, ICUs now work mostly with patients above 60, to stabilize de-compensated conditions of chronic diseases.

Moreover, bio/medicalization also puts the older patient in a passive, almost childish position, and, as an expression of love, the family members might push for further treatment. (Conrad, 2007, Côrrea et al., 2016, Floriano et al., 2012, Santos & Almeida, 2002, Gandolpho & Ferrari, 2006). Doctors tell me that family members tie aging with the loss of abilities to decide and many times try to hide the diagnosis from the patient or to make the decision for him/her. In a desperate last act, particularly when the family member has a good economic condition and was absent during the elderly's final years, the push for “heroic measures” becomes stronger (Dr. Antonio, Dr. Roberto, Dr. Plínio).

Nonetheless, even inside the medical community, resistance to medicalization starts to emerge. These intensivists affirm that dysthanasia is the worst harm they could cause to a patient, and they count on palliative care to manage the patient's discomfort and let death follow its “natural” course. This viewpoint is shared with the patients, that mostly report the angst of suffering in a terminal case and want technology to be employed selectively (Benjamin, 2016, Joyce & Loe, 2010). Notwithstanding, this attempt to make death more “natural” can also be considered a way of keeping the social control of Medicine, while addressing the patient's concerns with the loss of autonomy (Zola, 1972, Salter, 2004). In the end, the patient still has to comply with the doctor's recommendations and hospital guidelines and does not leave medical care, but is only submitted to less invasive procedures.

Describing their care practices, the doctors tell me that technology supports their assessments, but does not cover for the complexity of the real life (Berg, 1997, Brown & Webster, 2004). They follow guidelines and protocols to evaluate the patient and define the best way to address his/her condition but have to rely on tacit knowledge to compensate for the lack of literature in this age range. The employment of tacit knowledge, nevertheless, clashes with people's trust in numbers and science to provide reliable information for decision-making. Information about health and diseases, truthful or not, is abundant and easily accessible online (Conrad, 2007, Brown & Webster, 2004). Therefore, it is hard for the expert patient and his/her family members to believe that what Dr. Google suggested does not apply in their situation. Instead of an ally, Dr. Google becomes a competitor, challenging the human intensivists and bringing mistrust to the doctor-patient relationship.

Another facet of medicalization that was often approached by my interviewees is the notion of risk. The fear of iatrogenesis is often a justification to avoid the use of technology, and common sense is that even the safer procedures carry risks. Unintended consequences, the lack of knowledge to understand the reactions of a body that bears several comorbidities and a look at the future, to predict how much or for how long a patient would benefit from new technology are part of the clinical assessment (Beck, 1999, Lupton, 1999). The omnipresence of risk and mistrust, characteristics of risk societies (Beck, 1999) have two main impacts, according to my interviews. One, it leads people to look for alternatives by themselves to challenge the diagnosis they received in ICUs, ranging from experimental treatments to religious rituals. Second, it makes doctors shut down controversies by claiming they only adopt evidence-based practices, even though, in reality, they have to tinker with medical knowledge to respond adequately to the multiple contexts they find in their workplaces (Brown & Webster, 2004, Mol, 2002).

My sensitizing concepts helped me to see how the doctors employ rhetorical tools and enact the objects involved at the end of life to reach what they consider a good death. Multiplicity is intrinsic to care practices. My contribution to Mol's concept (2002) is to show the role of intensivists in coordinating the multiple meanings of death, aging, and the adequate levels of intervention within the families and multidisciplinary team in ICUs. Multiplicity is not in the background of their practices. Instead, my interviews are aware of it and assume the role of negotiators to build the reality they see fit for the situation. They incorporate concerns and meanings, offer some things while denying others (e.g., providing respiratory support, but not antibiotics, as Dr. Plínio explained) and anticipate scenarios to frame their discourses and convince the actors of what they believe is the best conduct for the patient. As one last move, the cultural entanglements of Latin-America and Brazil to medical practice are used to justify a particular way of caring for the patient (Prasad, 2014).

Finally, applying multiplicity, logics of care and care practices, and cultures of technosciences (and, by extension, Medicine) to my analysis allowed me to see what is behind the doctors' commitment to the first command of the Hippocratic oath. To "do no harm", first the doctors have to embrace several tasks, and develop diverse skills that do not fit the categories of medical work. They have to connect to the environment inside and outside the hospital, develop the political ability to make strong arguments and concede on a few topics to implement their ideas of goodness, manage conflicts, and offer emotional support to the actors involved with terminality. Instead of the image, reported in the interviews, that they are not doing anything for the terminally ill patient, these intensivists have to go beyond their job descriptions and master techniques that are not taught in medical schools. Thus, enacting the elderly's end of life in Brazilian ICUs requires a lot of effort, that might not be recognized by patients and families and go unnoticed in the hospital routines.

In this Master Thesis, I offered a contribution to anthropological and sociological Brazilian studies focused on the elderly and the health care system. This STS perspective on the configurations of the Brazilian health care system, the lack of legislation to deal with terminality, biomedicalization, and imaginaries regarding the elderly enhances the understanding of aging and death in hospital settings in the country.

With a distinct look to the aging population in the biggest and most populous country of Latin America and a focus on the healthcare professionals, this research, then, puts the decision-makers at the center of the investigation while also addressing new situations created by a change in the demographic profile of the population.

7.2. Further research

The medicalization of aging and death will continue to be relevant topics for STS scholars and sociologists, in the face of an aging population and the spread of technologies that make interventions feasible even in weakened bodies. New foci of research on this subject will enhance the discussions about a life worth living versus the possibilities to extend it, as well as the consequences of delegating the end of life to the realm of Medicine.

In this study, I chose to focus on intensive care units and intensivist doctors, which allowed me to look only at a specific set of practices and representations of the aging patient, the ill body, and the meanings attributed to care practices.

An investigation with the patients would provide access to the opinions of the most affected part in this process. Despite being the subjects of interventions and living with the consequences of the decisions made to save them or to prevent them from suffering, these actors are often silenced, and their agency can be lost in the hospital routines. Likewise, interviews with family members could provide an account on how they perceive the dying process of a beloved one in hospital settings and on the way doctors, in fact, deal with terminality in older patients. Among physicians, a cohort of emergency doctors might lead to distinct views of the older patient, terminality, harm, and technology employment.

My research took place in Brazil and was informed by the countries idiosyncrasies. I intended to research public and private institutions to check the impact of the country's inequality on medical assistance in terminal cases. Albeit I could not accomplish this goal, emphasis on this characteristic remain relevant. Further proposals include comparing regional differences and public hospitals in poorer cities or neighborhoods versus private luxury hospitals in the capitals. On a higher level, it would also be interesting to investigate how different Latin-American societies frame the elderly's end of life.

Beyond offering multifaceted overviews on terminal cases, these opportunities for future studies would increase the Southern participation in STS and call attention to voices that are often not heard in the global scientific community. Moreover, acknowledging different practices and contingencies in medical assistance is a way to counteract hegemonic approaches imported from the Global North. Validating non-Western methods and perspectives in Medicine would enable the construction of local solutions to regional problems and, hopefully, reduce the inequality in the access to health services.

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Abstract - English

With a growing aging population, Brazil is facing the task to rethink the way it deals with the elderly in medical settings. While the demographic profile and medical technology are changing fast, the law is still not responding to the challenges that emerged in this scenario, especially in terminal cases. Moreover, families, doctors, and patients are learning how to manage expectations and decide what is worth at the end of life in the face of all the possibilities offered by Medicine.

This research takes place in a hospital network in Sao Paulo and considers the physicians the focal point in the decision-making process in Intensive Care Units. The aim is to investigate their roles in the enactment of the multiple meanings, actors, and situations that construct terminality. Analyzing their perceptions of aging, agency of the elderly in health decision-making, and the social and juridic contexts that influence their decisions, this thesis argues that beyond technical skills, doctors assume a crucial role as negotiators of the end of life. They enjoy a dominant position in this bio/medicalized society (Clarke et al., 2003, Conrad, 2007, Foucault, 1978, Samson, 1999, Zola, 1972) and use it to shape the definitions of aging and a good death. Moreover, under the light of the concepts of multiplicity (Mol, 2002) and cultures of technoscience (Prasad, 2014), the intensivists come out as builders of a reality that reflects their own beliefs of what is appropriate care at old ages.

Abstract - Deutsch

Angesichts der zunehmenden Alterung der Bevölkerung steht Brasilien vor der Aufgabe, den Umgang mit älteren Menschen in medizinischen Einrichtungen zu überdenken. Während sich das demografische Profil und die Medizintechnik schnell ändern, reagiert das Gesetz immer noch nicht auf die Herausforderungen, die sich in diesem Szenario ergeben haben, insbesondere in aussichtslosen Fällen. Darüber hinaus lernen Familien, Ärzte und Patienten, mit Erwartungen umzugehen und zu entscheiden was sich am Ende des Lebens lohnt, angesichts aller Möglichkeiten, die die Medizin bietet.

Diese Forschung findet in einem Krankenhausverbund in Sao Paulo statt und stellt die Ärzte ins Zentrum des Entscheidungsprozesses auf Intensivstationen. Ziel ist es, ihre Rolle bei der Inszenierung der vielfältigen Bedeutungen, Akteure und Situationen zu untersuchen, die die Endgültigkeit konstruieren. Diese Abschlussarbeit analysiert die Wahrnehmung des Alterns, die Einflussnahme älterer Menschen auf die Entscheidungsfindung im Gesundheitsbereich und die sozialen und juristischen Kontexte, die ihre Entscheidungen beeinflussen, und argumentiert, dass Ärzte über die technischen Fähigkeiten hinaus eine entscheidende Rolle als Verhandlungsführer bezüglich des Lebensendes einnehmen. Sie haben eine beherrschende Stellung in dieser bio-medizinisierten Gesellschaft (Clarke et al., 2003, Conrad, 2007, Foucault, 1978, Samson, 1999, Zola, 1972) und bestimmen damit die Definitionen von Altern und gutem Tod. Im Lichte der Konzepte der Multiziplität (Mol, 2002) und der Kulturen der Technowissenschaften (Prasad, 2014) erweisen sich die Intensivmediziner darüber hinaus als Erbauer einer Realität, die ihre eigenen Vorstellungen von angemessener Pflege im Alter widerspiegelt.

Resumo - Português

Com o crescente envelhecimento da população, o Brasil está enfrentando a tarefa de repensar os meios com que lida com os idosos em estabelecimentos médicos. Enquanto o perfil demográfico e a tecnologia médica mudam velozmente, a lei ainda não é capaz de responder aos desafios que emergem nesse cenário, especialmente em casos terminais. Mais do que isso, familiares, médicos e pacientes estão aprendendo a gerir suas expectativas e decidir o que vale a pena no fim da vida face às possibilidades oferecidas pela Medicina.

Essa pesquisa situa-se em uma rede de hospitais em São Paulo e considera os médicos como ponto focal no processo de tomada de decisão em Unidades de Terapia Intensiva. O objetivo é Investigar seus papéis na encenação de múltiplos significados, atores e situações que constroem a terminalidade. Analisando suas percepções sobre envelhecimento, agência dos idosos na tomada de decisão médica e os contextos sociais e jurídicos que influenciam suas decisões, essa tese defende que, para além das habilidades técnicas, os médicos assumem um papel crucial como negociadores do fim da vida. Eles desfrutam de uma posição dominante nessa sociedade bio/medicalizada (Clarke et al., 2003, Conrad, 2007, Foucault, 1978, Samson, 1999, Zola, 1972) e fazem uso dela para moldar as definições de envelhecimento e boa morte. Além disso, à luz dos conceitos de multiplicidade (Mol, 2002) e culturas tecno-científicas (Prasad, 2014), os intensivistas emergem como construtores de uma realidade que reflete suas próprias convicções sobre o que é uma assistência apropriada em idades mais avançadas.

Appendix 1 - Guiding Questions for the Interviews

The questions for the interviews were organized around the elements that appeared in the situational map I drew for the Exposé's State of the Art (below) and followed my research questions. I opened the interviews with a general inquiry, to see what the doctors prioritize in their answers.

1. For how long have you been working as an intensive care doctor? How long in this hospital?
2. What are the main changes in intensive care, specifically when it comes to older patients, that you observed during your career?
3. How are terminal cases defined? Is it an individual or collective definition?
4. How do you communicate this diagnosis to the patient and to the family members? What are the options after this diagnosis?
5. What do you consider when a terminal patient refuses further treatments and interventions (through Advanced Healthcare Directives or, when it's possible, simply saying that to you)?

After that, I started to tackle the sub-questions. I have tried to organize them in topics related to the elements presented in the map and I came up with several questions, that worked as a checklist.

Subquestion 1: How does the current legal situation, where the Penal Code and the orientations of the Federal Medicine Council seem to be in conflict, affect the decision-making process?

This subquestion leads to the uncertainty aspect related to the Legislation/Regulation element. To answer it, these topics should be addressed:

- Legal loophole:

1. What prevails during the decision-making process: the Federal Medicine Council guidelines or the Penal Code?
2. How do the doctors position themselves in the debate between orthothanasia and dysthanasia?
3. How do they try to preserve the patient's autonomy, a topic in the Elderly Statute, in face of the legal restrictions?
4. Which one presents more legal risks?
5. What do they do to protect themselves from these risks?

6. Do they need to formally justify their conducts?

- Doctors perceptions on the Advanced Healthcare Directives:

1. Do they provide information about this document and inform the patient of their choices regarding interventions at the end of life?
2. What is the legal orientation provided by the hospital when the doctor is faced with a document that asks for no interventions to extend life?
3. What do they do when the patient's wishes expressed in the document are in conflict with the family's wishes?
4. When a proxy is appointed, do the doctor's only refer to this person's directives or there is an effort to understand and combine the proxy's and the patient's wishes?

Subquestion 2: How does the increasing availability of technologies and knowledge to intervene in end-of-life cases shape the medical conduct regarding the elderly?

This subquestion points to the conundrum among the availability of technology, the uncertain outcomes of its employment and patient's and family's hopes. Also, the framing of aging will be addressed with these topics:

- Availability of technology x Refusal of interventions:

1. Knowing that knowledge and technology evolved to make interventions safer even in older ages, how do the doctors deal with the patient that refuses these procedures?
2. How do they deal with the families questioning therapeutic options and asking for interventions to extend the patients lives, even when this is not the patients wish?
3. How do they position themselves between the imperative to treat and not acting in end of life cases?
4. How do they access harm in this situation?
5. And how do they access priorities (effectiveness, quality of life, ability to make the patient recover his/her functions)?

- Aging as a problem/disease:

1. What is considered a "natural" evolution of the case and what can be fixed?
2. How do you evaluate and handle comorbidities at old age (treat only the most complicated, think about interactions, etc.)? Does age makes a difference in this case?

Subquestion 3: How do doctors deal with financial pressures and class differences when caring for the elderly with terminal illnesses?

This subquestion tries to address the biopolitical aspect of the biomedicalization, as listed by Clarke, Shim, Mamo, Fosket & Fishiman (2009), considering that economy and financial aspects influence biomedical practices, as well as economy, models of payment and availability of resources are shaped by the new biomedical practices:

- Biomedical practices influencing and being influenced by the healthcare sector economy

1. How does the assessment of technology use for elderly patients at the end of life work?
2. How are procedures substituted when a new knowledge / technology emerges?

- Financial pressures:

1. Do you feel any kind of pressure to use or avoid certain costly procedures when assessing the best conduct in this scenario?
2. In the case of doctors working in public hospitals, do you feel pressured to prioritize a certain kind of patient when there is a lack of intensive care beds?

- Social Contexts:

1. Do you think social class makes a difference in the way the patient deals with the end of life?
2. When you explain to the patient and the family the therapeutic options and the possible outcomes, is there a difference in the understanding/perception of the best way of dealing with the situation? If yes, how do you cope with it?

Subquestion 4: How do doctors', patients', families' and society's perceptions of aging influence the assessment of health conditions and the decision-making process at the end of life?

This is possibly the broader and most important subquestion to highlight the intertwining of science, technology and society. The following topics have tried to lay out the different actors and elements presented in the map and to show where they connect:

- Doctors' perceptions:

1. What are your bigger challenges when dealing with elderly patients?
2. Can you explain the decision-making process in this situation?
3. Questions like the recovery of social function or life expectancy make a difference when you evaluate the therapeutic options?

- Patients' perceptions:

1. What kind of last wishes are prevalent (to withhold treatment, to use all technology available to extend the life or to accept some interventions, but not others)?
2. What are the most important factors, reported by the patients, when choosing what kind of the interventions they want to be submitted to/avoid?
3. What is the weight of the patient's opinion in the final decision?

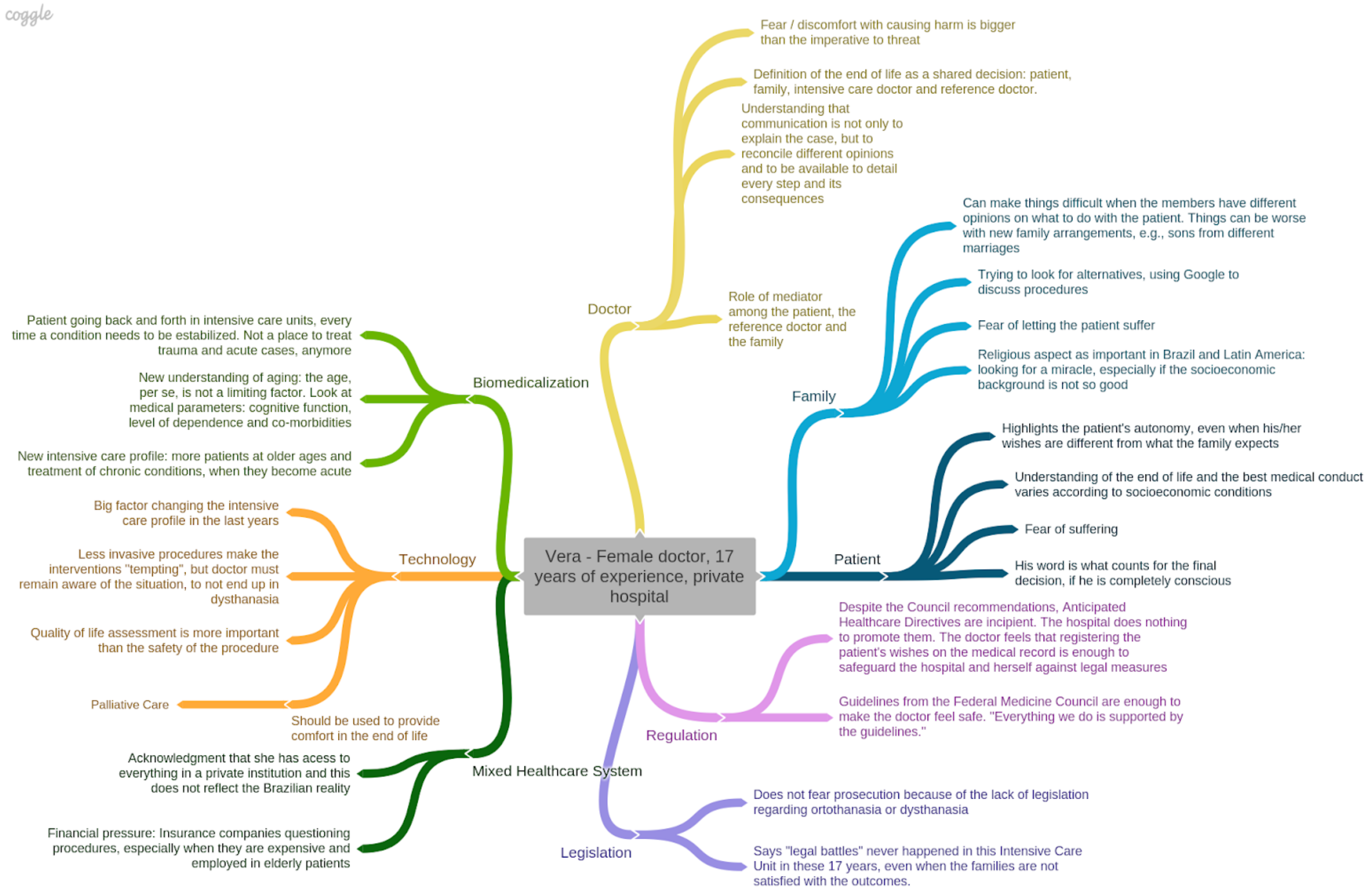
- Society’s and family’s perceptions of aging/biomedicalization - Here, my intention was to start with a general overview of the society’s perceptions, proceed with the family’s perceptions and end with the doctor’s own perceptions and values when faced with this situation:

1. In your opinion, what are the main society’s values and perceptions embedded in the understanding of aging and the end of life [here, I expected the doctors to hint at the role of religion in attributing meaning to the way the patient dies, the role of the family, older people as a burden to society x aging as a benefit (vs. dying young), the acknowledgement of inequalities in the access of resources (differences between aging poor or rich), ideas of quality of life, etc.]?
2. Regarding the families and these values, what are their main worries and expectations?
3. And what are the values you attribute to aging and to the end of life process (doctors’ personal understandings)?
4. Nowadays, what would you consider a good death for these patients?

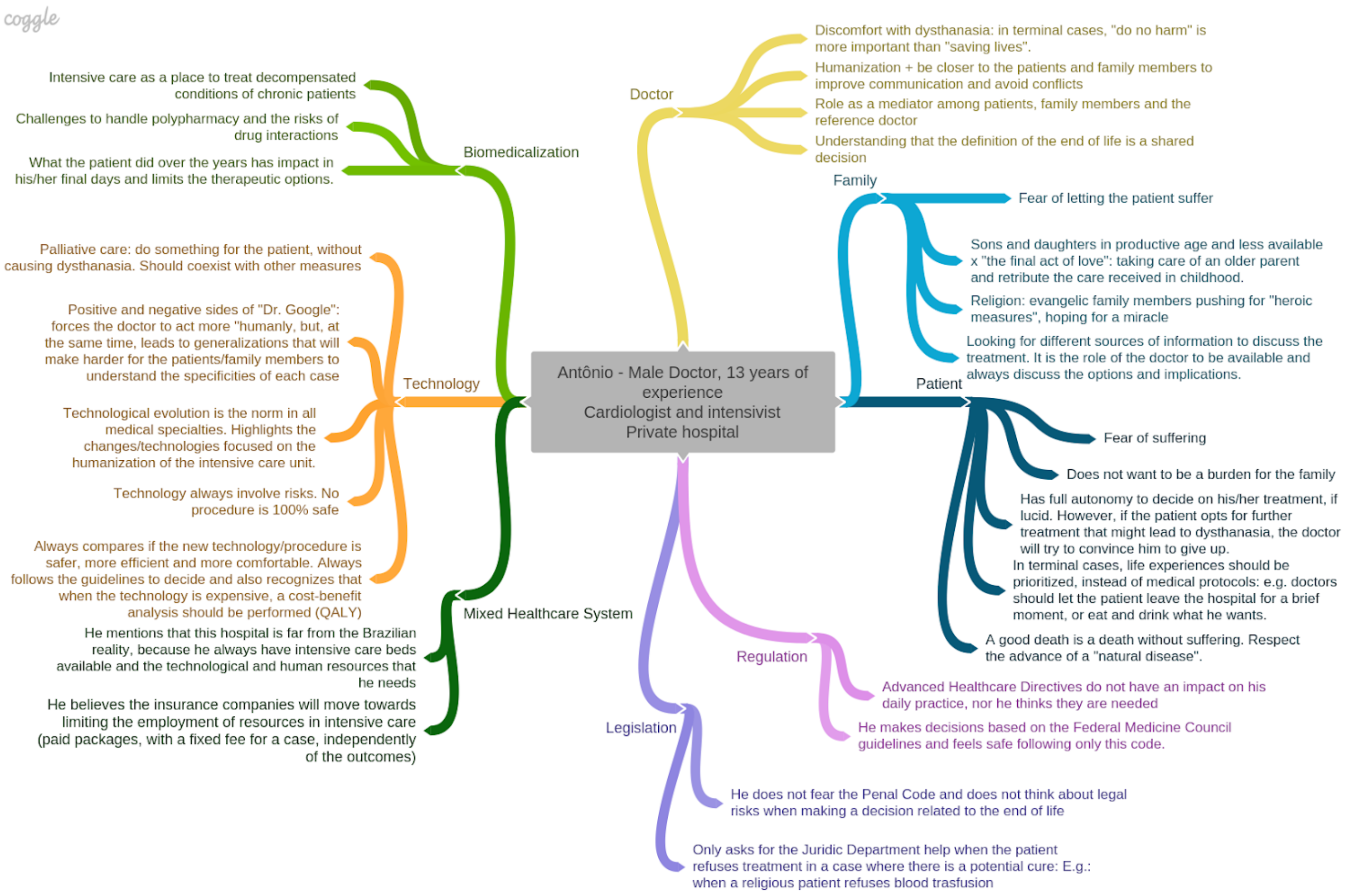
Appendix 2 - Situational Map: Topics for the Interviews

Appendix 3 - Situational Maps: Data Analysis

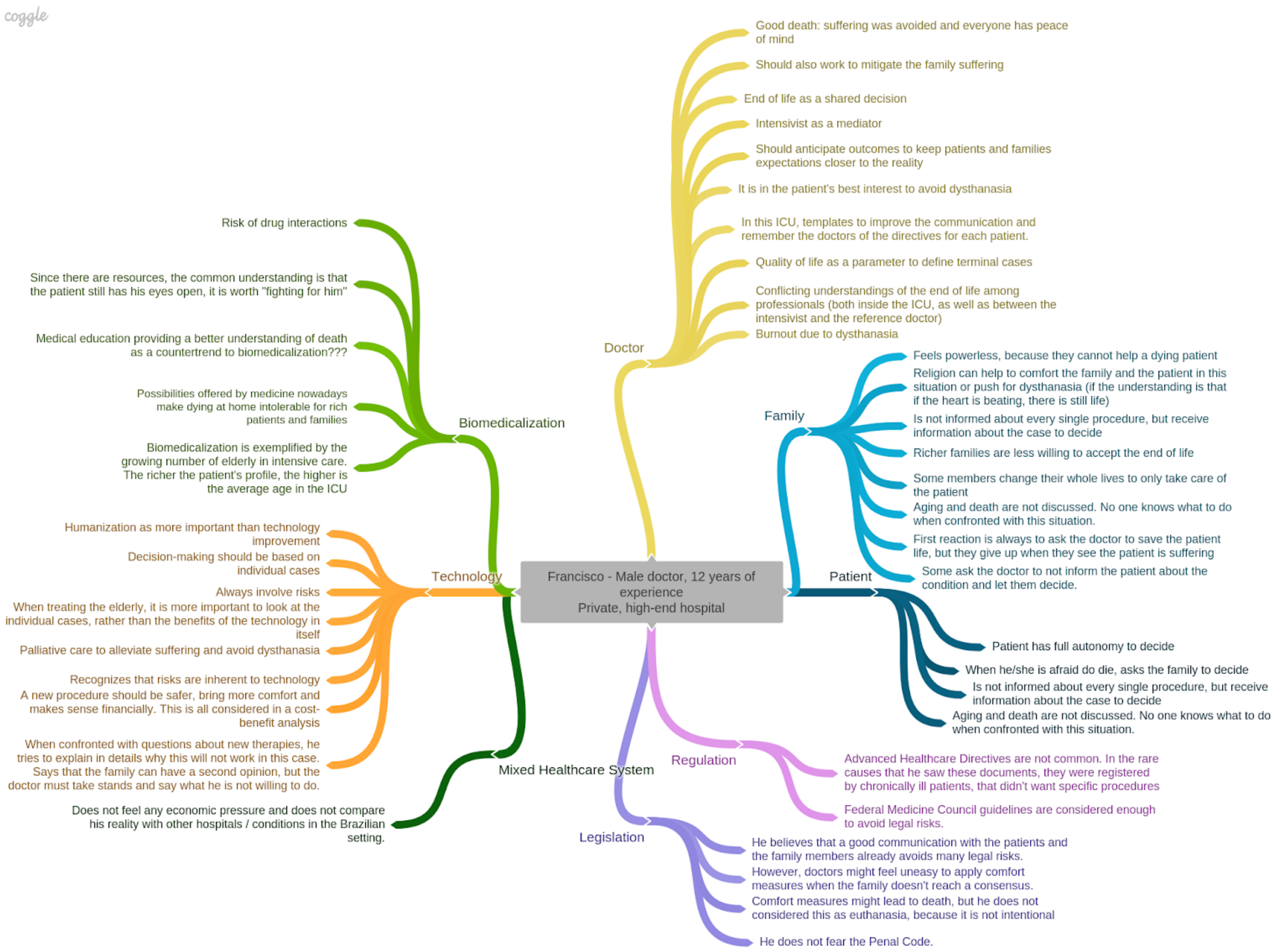
Map 1 - Interview 1: Dr. Vera



Map 2 - Interview 2: Dr. Antônio



Map 3 - Interview 3: Dr. Francisco



Francisco - Male doctor, 12 years of experience
Private, high-end hospital

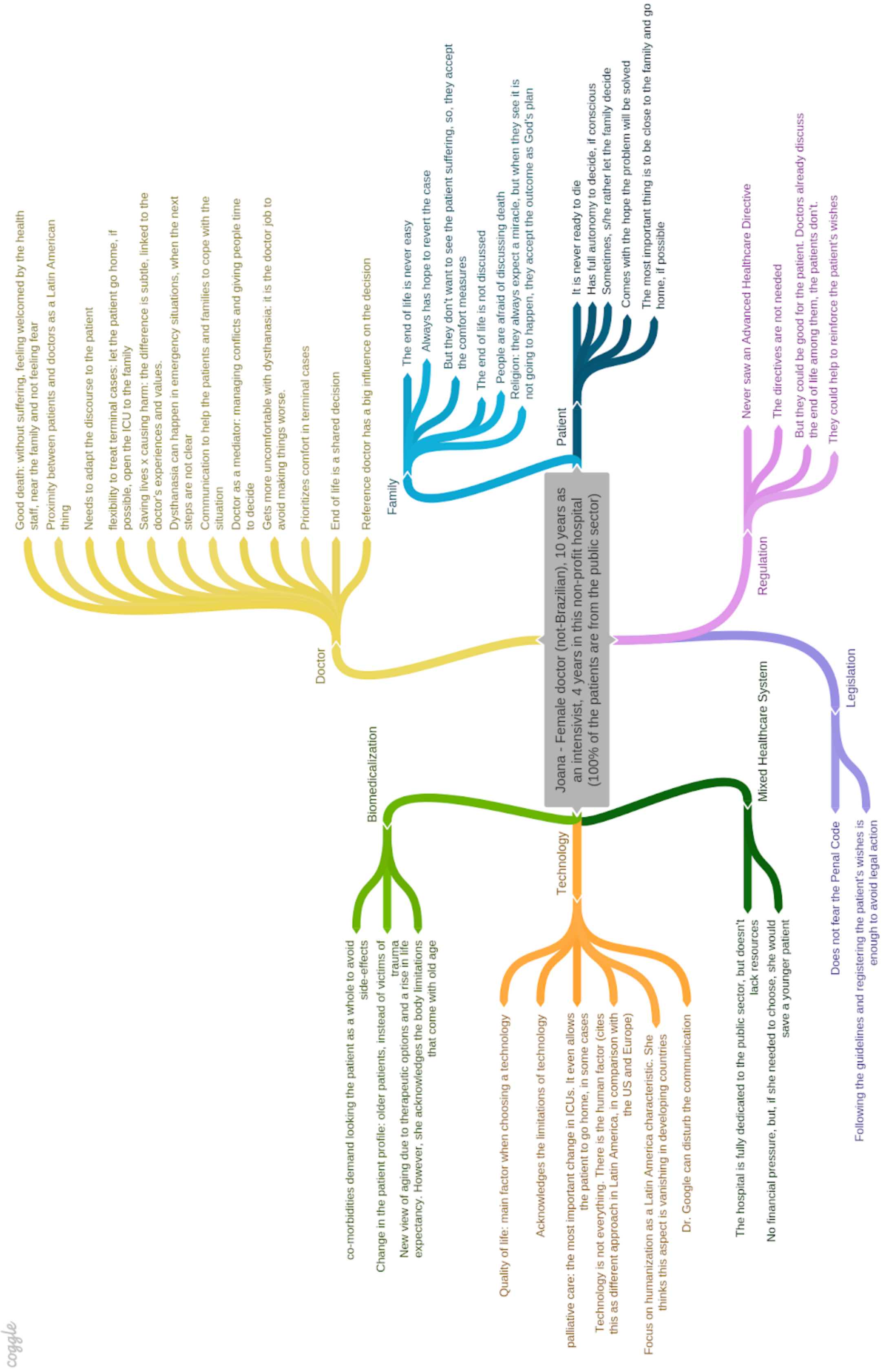
- Doctor
  - Good death: suffering was avoided and everyone has peace of mind
  - Should also work to mitigate the family suffering
  - End of life as a shared decision
  - Intensivist as a mediator
  - Should anticipate outcomes to keep patients and families expectations closer to the reality
  - It is in the patient's best interest to avoid dysthanasia
  - In this ICU, templates to improve the communication and remember the doctors of the directives for each patient.
  - Quality of life as a parameter to define terminal cases
  - Conflicting understandings of the end of life among professionals (both inside the ICU, as well as between the intensivist and the reference doctor)
  - Burnout due to dysthanasia
- Patient
  - Family
    - Feels powerless, because they cannot help a dying patient
    - Religion can help to comfort the family and the patient in this situation or push for dysthanasia (if the understanding is that if the heart is beating, there is still life)
    - Is not informed about every single procedure, but receive information about the case to decide
    - Richer families are less willing to accept the end of life
    - Some members change their whole lives to only take care of the patient
    - Aging and death are not discussed. No one knows what to do when confronted with this situation.
    - First reaction is always to ask the doctor to save the patient life, but they give up when they see the patient is suffering
    - Some ask the doctor to not inform the patient about the condition and let them decide.
  - Patient has full autonomy to decide
  - When he/she is afraid do die, asks the family to decide
  - Is not informed about every single procedure, but receive information about the case to decide
  - Aging and death are not discussed. No one knows what to do when confronted with this situation.
- Regulation
  - Advanced Healthcare Directives are not common. In the rare causes that he saw these documents, they were registered by chronically ill patients, that didn't want specific procedures
  - Federal Medicine Council guidelines are considered enough to avoid legal risks.
- Legislation
  - He believes that a good communication with the patients and the family members already avoids many legal risks.
  - However, doctors might feel uneasy to apply comfort measures when the family doesn't reach a consensus.
  - Comfort measures might lead to death, but he does not considered this as euthanasia, because it is not intentional
  - He does not fear the Penal Code.
- Mixed Healthcare System
  - Does not feel any economic pressure and does not compare his reality with other hospitals / conditions in the Brazilian setting.
- Technology
  - Humanization as more important than technology improvement
  - Decision-making should be based on individual cases
  - Always involve risks
  - When treating the elderly, it is more important to look at the individual cases, rather than the benefits of the technology in itself
  - Palliative care to alleviate suffering and avoid dysthanasia
  - Recognizes that risks are inherent to technology
  - A new procedure should be safer, bring more comfort and makes sense financially. This is all considered in a cost-benefit analysis
  - When confronted with questions about new therapies, he tries to explain in details why this will not work in this case. Says that the family can have a second opinion, but the doctor must take stands and say what he is not willing to do.
- Biomedicalization
  - Risk of drug interactions
  - Since there are resources, the common understanding is that the patient still has his eyes open, it is worth "fighting for him"
  - Medical education providing a better understanding of death as a countertrend to biomedicalization???
  - Possibilities offered by medicine nowadays make dying at home intolerable for rich patients and families
  - Biomedicalization is exemplified by the growing number of elderly in intensive care. The richer the patient's profile, the higher is the average age in the ICU

Map 4 - interview 4: Dr. Plínio

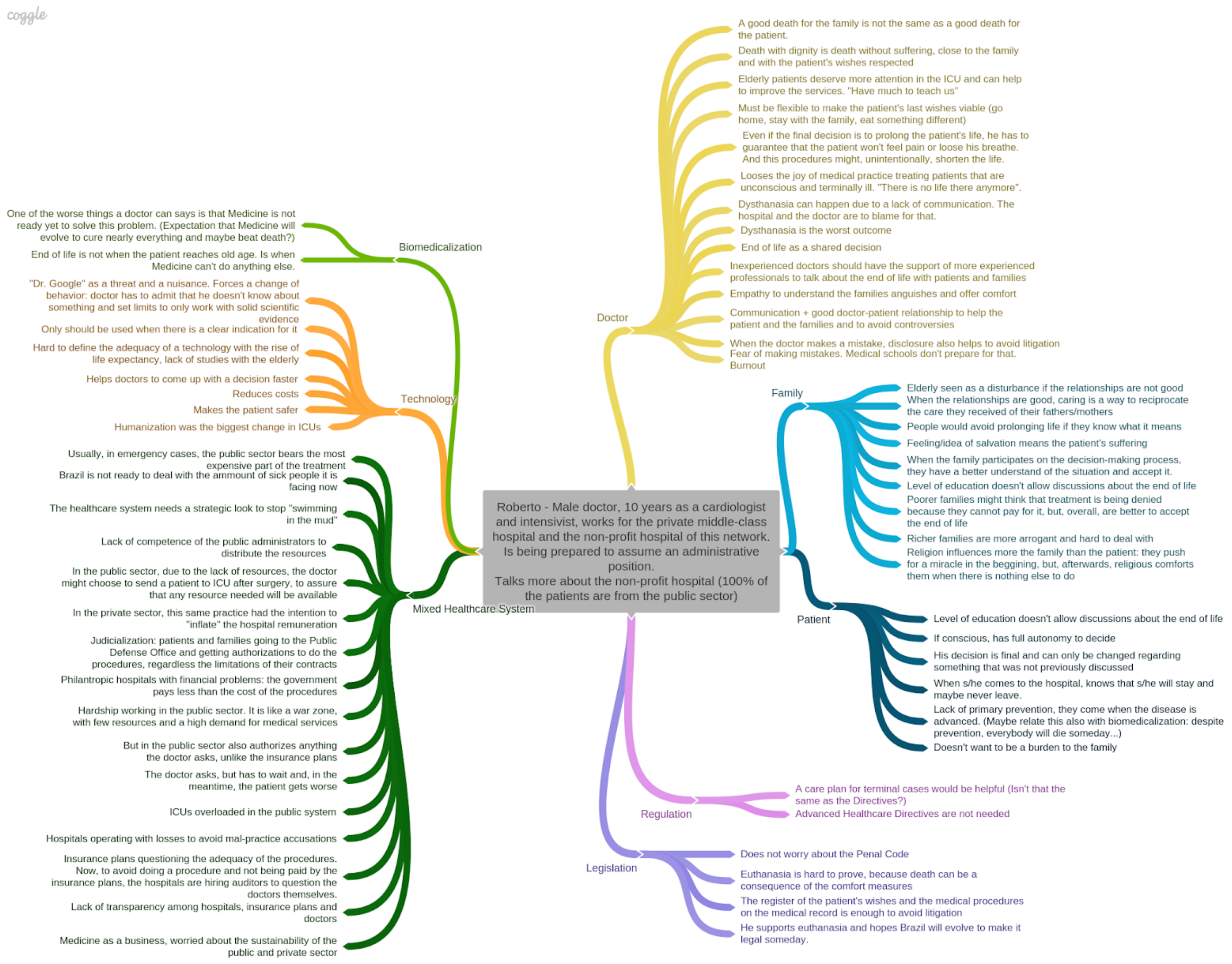
Plínio - Male doctor, private high-class hospital, five years of experience, one year in this hospital. Also works in a public hospital, but in a clinical setting

- Doctor
  - Must be sure that patients, doctors and family members are aligned, to avoid miscommunication. Can have the help of other health professionals to improve communication (psychologists, social assistants)
  - Doctor must be available and anticipate outcomes to avoid a conflict between expectations x reality
  - Negotiates levels of intervention with the patient and the families
  - Troubled with dysthanasia, tries to change people's mind when they opt for a procedure that might lead to it.
  - Quality of life is the main factor when defining a terminal case
  - Has the role to anticipate outcomes and help the families expectations meet reality
  - Intensivist as a mediator
  - End of life is a collective decision
  - A good death is when suffering is avoided
- Patient
  - Family
    - Higher income makes family members resistant to an end of life diagnosis
    - Too much information makes families think that there is always a way to save the patient
    - Lower income families tend to accept the situation, because they are closer to the patient and see the suffering
    - Families that are absent during age try to "compensate" in the patient's final days, often disturbing instead of helping
    - Religious people are better at accepting the end of life
    - Might decide against the patient's wishes when the patient cannot decide by him/herself. Doctor gets frustrated, but has to accept it.
  - Has full autonomy to decide, even against the family's wishes
  - Fear of dying when s/he is affected by a sudden disease
  - When suffering for a long time, s/he asks for comfort measures
  - Doctor has to always keep a conversation with the patient, to "feel" the situation and support his/her decision
- Regulation
  - Advanced Directives are not needed, but they would help the families to plan and get used to the idea of terminality
- Legislation
  - He does not worry about the Penal Code, but he registers everything in the medical record to avoid contestations in the future
- Biomedicalization
  - Changes in medical education: older doctors are resistant to palliative care, whereas the younger ones have a more "natural" relation with palliative care and terminal cases (would this be a countertrend to biomedicalization?)
  - Life expectancy it is related to the evolution of medicine. That is why there are so many older patients in ICU's
  - Age becomes only a number, the patient is seen through his health conditions
  - Treating co-morbidities is challenging, because one treatment influence the other. When trying to estabilize the patient, the doctor must also be aware to not cause harm due to drug interactions, for example
- Technology
  - Experimental technologies are refused
  - Better access to information (Dr. Google) is demanding a change in the doctor's behavior. They have to be open to discuss diagnosis and treatments
  - Quality of life is assessed before changing a procedure or employing a new technology
  - Palliative care to avoid dysthanasia (countertrend to biomedicalization?)
  - Less-invasive procedures make interventions safer at older ages
  - Makes the doctor want to do everything that is possible to save a life, but only if the patient has real chances of recovery his functions (Could this lead to bad outcomes/overtreatment?)
  - Less-invasive technologies, not the most up to date, are welcomed, because they cause less harm
- Mixed Healthcare System
  - If he had to make a choice, due to lack of resources, he would give a bed to a patient with better chances to live.
  - Financial pressure is bigger for new technologies/procedures
  - When the insurance plan does not want to pay, judicialization happens

Map 5 - Interview 5: Dr. Joana



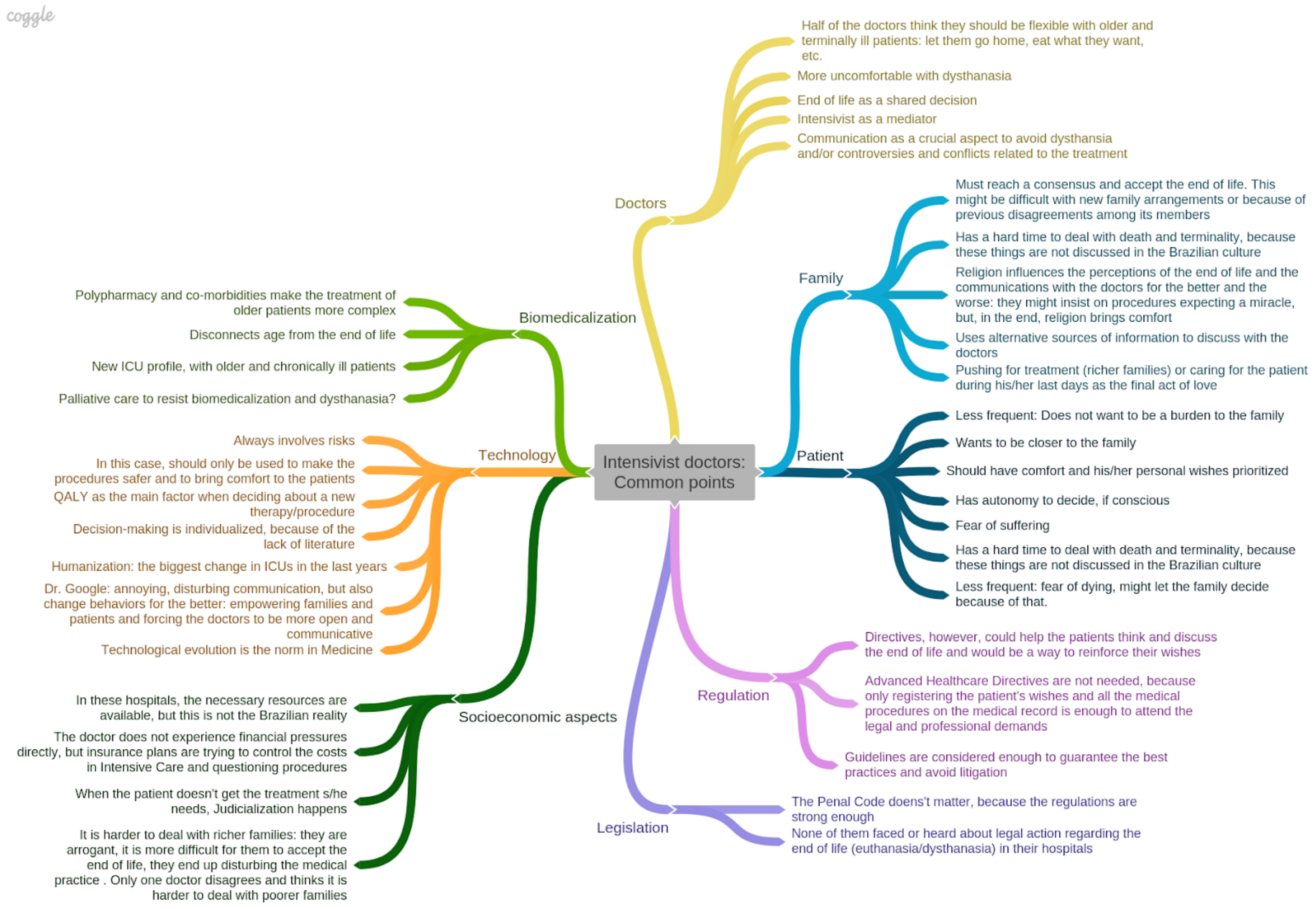
Map 6 - Interview 6: Dr. Roberto



Roberto - Male doctor, 10 years as a cardiologist and intensivist, works for the private middle-class hospital and the non-profit hospital of this network. Is being prepared to assume an administrative position.
Talks more about the non-profit hospital (100% of the patients are from the public sector)

- Doctor
  - A good death for the family is not the same as a good death for the patient.
  - Death with dignity is death without suffering, close to the family and with the patient's wishes respected
  - Elderly patients deserve more attention in the ICU and can help to improve the services. "Have much to teach us"
  - Must be flexible to make the patient's last wishes viable (go home, stay with the family, eat something different)
  - Even if the final decision is to prolong the patient's life, he has to guarantee that the patient won't feel pain or loose his breathe. And this procedures might, unintentionally, shorten the life.
  - Looses the joy of medical practice treating patients that are unconscious and terminally ill. "There is no life there anymore".
  - Dysthanasia can happen due to a lack of communication. The hospital and the doctor are to blame for that.
  - Dysthanasia is the worst outcome
  - End of life as a shared decision
  - Inexperienced doctors should have the support of more experienced professionals to talk about the end of life with patients and families
  - Empathy to understand the families anguishes and offer comfort
  - Communication + good doctor-patient relationship to help the patient and the families and to avoid controversies
  - When the doctor makes a mistake, disclosure also helps to avoid litigation
  - Fear of making mistakes. Medical schools don't prepare for that.
  - Burnout
- Family
  - Elderly seen as a disturbance if the relationships are not good
  - When the relationships are good, caring is a way to reciprocate the care they received of their fathers/mothers
  - People would avoid prolonging life if they know what it means
  - Feeling/idea of salvation means the patient's suffering
  - When the family participates on the decision-making process, they have a better understand of the situation and accept it.
  - Level of education doesn't allow discussions about the end of life
  - Poorer families might think that treatment is being denied because they cannot pay for it, but, overall, are better to accept the end of life
  - Richer families are more arrogant and hard to deal with
  - Religion influences more the family than the patient: they push for a miracle in the beggining, but, afterwards, religious comforts them when there is nothing else to do
- Patient
  - Level of education doesn't allow discussions about the end of life
  - If conscious, has full autonomy to decide
  - His decision is final and can only be changed regarding something that was not previously discussed
  - When s/he comes to the hospital, knows that s/he will stay and maybe never leave.
  - Lack of primary prevention, they come when the disease is advanced. (Maybe relate this also with biomedicalization: despite prevention, everybody will die someday...)
  - Doesn't want to be a burden to the family
- Regulation
  - A care plan for terminal cases would be helpful (Isn't that the same as the Directives?)
  - Advanced Healthcare Directives are not needed
- Legislation
  - Does not worry about the Penal Code
  - Euthanasia is hard to prove, because death can be a consequence of the comfort measures
  - The register of the patient's wishes and the medical procedures on the medical record is enough to avoid litigation
  - He supports euthanasia and hopes Brazil will evolve to make it legal someday.
- Biomedicalization
  - One of the worse things a doctor can says is that Medicine is not ready yet to solve this problem. (Expectation that Medicine will evolve to cure nearly everything and maybe beat death?)
  - End of life is not when the patient reaches old age. Is when Medicine can't do anything else.
- Technology
  - "Dr. Google" as a threat and a nuisance. Forces a change of behavior: doctor has to admit that he doesn't know about something and set limits to only work with solid scientific evidence
  - Only should be used when there is a clear indication for it
  - Hard to define the adequacy of a technology with the rise of life expectancy, lack of studies with the elderly
  - Helps doctors to come up with a decision faster
  - Reduces costs
  - Makes the patient safer
  - Humanization was the biggest change in ICUs
- Mixed Healthcare System
  - Usually, in emergency cases, the public sector bears the most expensive part of the treatment
  - Brazil is not ready to deal with the ammount of sick people it is facing now
  - The healthcare system needs a strategic look to stop "swimming in the mud"
  - Lack of competence of the public administrators to distribute the resources
  - In the public sector, due to the lack of resources, the doctor might choose to send a patient to ICU after surgery, to assure that any resource needed will be available
  - In the private sector, this same practice had the intention to "inflate" the hospital remuneration
  - Judicialization: patients and families going to the Public Defense Office and getting authorizations to do the procedures, regardless the limitations of their contracts
  - Philantropic hospitals with financial problems: the government pays less than the cost of the procedures
  - Hardship working in the public sector. It is like a war zone, with few resources and a high demand for medical services
  - But in the public sector also authorizes anything the doctor asks, unlike the insurance plans
  - The doctor asks, but has to wait and, in the meantime, the patient gets worse
  - ICUs overloaded in the public system
  - Hospitals operating with losses to avoid mal-practice accusations
  - Insurance plans questioning the adequacy of the procedures. Now, to avoid doing a procedure and not being paid by the insurance plans, the hospitals are hiring auditors to question the doctors themselves.
  - Lack of transparency among hospitals, insurance plans and doctors
  - Medicine as a business, worried about the sustainability of the public and private sector

Map 7 - Interviews' Common Points



Appendix 4 - Original Quotes in Portuguese

All the interviews were performed in Portuguese and freely translated to English in the Data Analysis section (chapter 6). For clarification purposes, some quotes were also edited. Here I list the original quotes, in order of appearance.

6.1. Legal and regulatory aspects

O Código Penal é a menor das nossas preocupações. Tudo que a gente faz é baseado em literatura. Em nenhum momento a gente aumenta droga ou qualquer outra coisa para abreviar a vida, mas sempre para aliviar os sintomas. (Dr. Roberto)

O que eu priorizo sempre é a vontade do paciente e o que eu posso fazer para deixá-lo mais confortável, sem que eu esteja comprometendo ou trazendo algum sofrimento para ele. Quando eu levo isso em consideração, eu não me preocupo com a parte jurídica. Óbvio, eu sempre escrevo tudo no prontuário, para caso algum familiar logo depois venha a procurar saber o que aconteceu, deixo bem explícito, tudo direitinho, mas nunca tive problema com essas condutas. (Dr. Plínio)

Se está em acordo com o paciente de priorizar conforto, de ligar um sedativo para ele dormir, eu acho que isso não acaba sendo eutanásia, é mais uma medida de conforto. E a gente tem o duplo efeito da medicação, vai abreviar a vida, mas eu estou garantindo que o paciente não tenha sofrimento. (Dr. Francisco)

Entre nós, como médicos, falamos sim. Por exemplo, vou fazer isso, porque quero aquilo, se tivermos uma doença terminal. Mas isso não é comum na população. (Dr. Joana)

Agora, eutanásia assistida, como em outros países, aí já é um país muito evoluído, com renda per capita muito alta, um grau de instrução muito alto. Quem sabe que meus bisnetos um dia consigam ver que o Brasil evolua para esse nível. Acho que é um direito do paciente. (...) Acho que a pessoa tem o livre-arbítrio de decidir se quer viver ou morrer num caso terminal. (Dr. Roberto)

6.2. Interchangeable meanings and variety of practices

A melhor forma para definir o grau de investimento e até onde nós vamos é sempre ser uma coisa compartilhada, com o médico assistente, com a família, inclusive com o paciente se ele estiver lúcido. Até que ponto a gente vai? Eu acho que isso não pode ser unilateral. Por mais embasado que a gente esteja cientificamente, ela não pode ser unilateral, de um médico só. (Dr. Antonio)

A terminalidade é uma questão difícil e mesmo entre diferentes médicos a percepção é diferente. (...) Quando a gente vai ver a literatura, mesmo o consenso americano de recomendações de terminalidade, ele diz que a terminalidade deve ser discutida até antes do diagnóstico. Devemos expor para ele: então a sua doença pode evoluir dessa forma. Qual vai ser o seu desejo quando você estiver nisso? O problema é como as pessoas interpretam isso. Tem médico que às vezes, mesmo na UTI, o paciente tem um suporte de todos os órgãos, ventilador, diálise, suporte artificial, hemodinâmica e precisa de transfusão diária, ainda não consegue assumir essa definição. (Dr. Francisco)

Aí resolve sentando, conversando, tirando a capa aqui para a pessoa ver que eu sou uma outra pessoa qualquer… Buscando uma certa proximidade. Isso não é ser falso, não é ser ator, mas de alguma forma você compartilhar aquele momento. (Dr. Antonio)

Neste momento tem que estar muito à disposição da família, porque, para dar um passo para trás, é muito fácil. Você tem que estar à disposição. Não pode ser “já falei hoje na hora da visita, só amanhã vou falar de novo.” Aí é péssimo. Sempre estar disponível para tirar dúvida. Tentar alinhar as expectativas da família e tentar, eu sei que não é fácil, se antecipar àquela situação. E às vezes até dentro de uma mesma família, isso é muito complicado. Você fala com um que aceita super bem, tem outro que não aceita. Tive uma situação assim no final do ano passado, uma situação de terminalidade com duas filhas, uma aceitava super bem e a outra não. E além de tudo elas eram brigadas e não se conversavam. Tivemos que dividir o horário para elas não se encontrarem. É muito difícil, tentar juntar com toda essa confusão. (Dr. Vera)

Liberei uma das minhas pacientes para o aniversário de 15 anos da neta. Tecnicamente, ela não tinha condição de sair do hospital, mas falando com o médico dela, decidimos deixar ela ir. Foi para o aniversário, voltou para o hospital depois da festa e morreu dois dias depois. Eu acho que a gente deve deixar o paciente viver seus últimos prazeres. Em qualquer caso terminal, para mim, eu acho que tudo é válido. (Dr. Antônio)

Uma ex-funcionária minha foi internada. Uma senhora de 70 e poucos anos, com uma doença cardíaca em fase final. Já sabíamos que se viesse [para o hospital] não iria voltar. Conversei com as filhas, conversei com a paciente. Falei infelizmente a medicina aqui encerra os seus esforços porque a partir do momento que eu fizer isso, a senhora vai ter sofrimento. As solicitações dela: ver os cachorros, comer canja e panetone… Queria comer sal, porque já estava há tantos anos sem comer comida com sal. Eu deixei ela fazer tudo. Até que um dia ela foi piorando, piorando e faleceu. Mas morreu com dignidade. Ela teve dignidade, teve respeito, teve local, teve apoio da família e teve a vontade respeitada. (Dr. Roberto)

Aqui neste continente, América Latina, ainda prima a parte humanizada. Que em outros lugares tem diminuído bastante. Não sei se eles são mais práticos ou nós somos mais sentimentais e ainda temos toda aquela carga emocional por trás. (Dr. Joana)

Acho que distanásia é um dano maior, porque não tem como eu mensurar se aquele cidadão está sedado. Existem monitorizações não invasivas para a gente ver que nível de sedação o paciente está, mas mesmo assim, tem coisas que são imensuráveis: o que o paciente está ouvindo, o que ele está raciocinando? (...) Do mesmo jeito, não sei o que ele está sentindo quando eu estou enfiando um dreno no tórax dele. Então é muito complexo, isso. Eu realmente acho que a distanásia é matar duas vezes. Isso para mim é muito ruim. Aqui a gente tem uma realidade completamente diferente do Brasil porque eu tenho leito, tem mais de 200 leitos de UTI aqui nesse hospital. Então não tem problema de faltar leito da UTI. Eu não preciso brigar para que o paliativo atue para resolver logo o meu problema, porque não me falta leito. É mais o ponto de vista humano. O que a gente está fazendo com esse paciente? (Dr. Antonio)

Para mim, com certeza, [o pior é] um procedimento mal-indicado para estender a vida com as suas consequências. A gente vê diariamente pacientes em situações… Por exemplo, para a gente manipular e dar banho tem que fazer medicação para ele aguentar a dor. Para que eu vou fazer alguma coisa que eu nem sei se vai trazer benefício só para ver se ele vai viver mais um pouco? Isso me deixa muito mais preocupado e incomoda muito mais do que a situação contrária. (Dr. Plínio)

É uma situação muito difícil, a gente fica muito incomodado. A gente tenta expor da melhor maneira, tenta convencer, mas quando a gente vê que não vai ser possível, a gente acaba acatando o que o familiar com poder legal designou. (Dr. Plínio)

A maior parte dos profissionais fica apreensivo em limitar o suporte porque sabe que uma pessoa pode vir a questionar. (Dr. Francisco)

Fiz o que tinha que fazer: entubar. Quando ele chegou, expliquei que ela não iria mais sair do tubo, que já não tem condição, que sua doença chegou numa fase final, e que agora seria esperar [que ela morresse]. (Dr. Joana)

A gente tem que abordar a família antes que isso aconteça, não na hora que está acontecendo. Na hora que está acontecendo, é damage control. Vai fazer porque senão ele vai morrer. Mas erramos ali, de não ter abordado no começo que isso poderia acontecer. (Dr. Roberto)

6.2.1 Visions of aging and Medicine

A gente está com um perfil de idoso um pouco diferente. Até uns anos atrás, o paciente de 60 anos já não trabalhava, ficava em casa, e tal. Hoje, chega aqui paciente de 80 anos que trabalha, é funcional. Então, antes de definir, da idade por si só, tenho que ver quanto ele é independente funcional ou dependente. Se ele for independente, não vou olhar idade. Se for dependente, em que grau? Aí vou estabelecer prioridade. Mas a idade por si só hoje…. Tive paciente aqui de 102 anos que teve alta. Lúcida, consciente, orientada… (Dr. Vera)

Está mudando a expectativa de vida, estão mudando os padrões culturais das pessoas. Essas pessoas estão chegando idosas, porém super lúcidas e independentes. Quantos FHC existem no nosso dia-a-dia? Eu estava hoje com um paciente de 82 anos, historiador, tenor lírico. Fiquei uma hora conversando. (Dr. Vera)

A gente lida com muito paciente acima de 80, 90 anos e muitas vezes a gente vê que a idade é só um número, né, a gente não pode levar em consideração. A gente tem paciente na UTI de 90 anos que leva uma vida como se tivesse 60, totalmente hígido, totalmente funcional. (Dr. Plínio)

O que mudou principalmente: incorporação de tecnologia e envelhecimento populacional. Então, assim, o perfil ao longo do tempo mudou muito, então cada vez a gente vê mais pacientes idosos incorporando tecnologia. (Dr. Vera)

Temos um paciente aqui que vai ter alta agora. Ele não tem mais opção terapêutica. Ele tem um tumor que já é irressecável, se iniciou a quimioterapia para tentar diminuir o tumor e ser operado, porém, entrou no grupo dos poucos pacientes que evoluíram tão mal a uma sessão de quimioterapia, que quase morreu aqui por causa das infecções. Nós conseguimos tirá-lo dessa fase. Ele está num momento bem, clinicamente, ele já sabe que não vai ser feito mais nada. Estamos controlando a dor, que é o principal dele, alimentar com sonda, já tudo está explicado e ele quer ir para casa. Então, é o momento para isso. Sabemos que em algum momento ele vai voltar, com alguma complicação. Vai ser uma infecção pulmonar, porque ele bronco-aspira, mas, essa é a vontade dele. E, para nós, é o correto. Quando necessitar voltar, ele vai voltar. (Dr. Joana)

Tem idoso que fica uma semana em casa, dois meses no hospital. E entende que ele é idoso, está no fim de vida, mas enquanto está com os olhos abertos, vamos tentar. Mudou não num sentido bom, como tem mais suporte, mantém-se, independente de ter qualidade de vida ou não. (Dr. Francisco)

No idoso, a gente sempre vai buscar o que for menos invasivo para o paciente, nem sempre o que é mais tecnológico, de última geração, mas o que é menos invasivo. A gente vai tentar trazer o menos possível de dano no que a gente for fazer. Por exemplo, cateter venoso central. Antigamente, para dar a droga, tinha que pegar o acesso no pescoço ou uma veia de grosso calibre. Hoje em dia, a gente tem o cateter de inserção periférica que é passado no braço e vai até lá, então, assim, muito menos invasivo puncionar o braço do que o pescoço. Esse tipo de tecnologia é muito bem-vinda e a gente vai priorizar para o paciente idoso. Temos que sempre tentar fazer o que for menos invasivo e que possa trazer menos riscos para um paciente que já é cheio de co-morbidades. (Dr. Plínio)

Todo paciente que interna e tem co-morbidade, nós avaliamos o quadro e fazemos reconciliação dos medicamentos que estão em uso. Nós temos que trabalhar com uma equipe multiprofissional para ver qual é a doença que ele tem agora e quanto essa co-morbidade influenciou para ele desenvolver a doença, ou que vai influenciar o tratamento. Então, internou com uma infecção, tem um antecedente de pressão alta, a gente vai ter que tirar o remédio da pressão nesse momento porque ele tem risco de estar em choque…Ou parkinsoniano, por exemplo. Teve que entubar, passar uma sonda, aí a gente já sabe que a absorção de remédios de Parkinson com a sonda é prejudicada, então vai ter que planejar a dieta, pausar a dieta para dar o remédio. É bem complexo e precisa ter esse olhar multiprofissional para essas co-morbidades. (Dr. Francisco)

O grande desafio é a polifarmácia, as co-morbidades e os efeitos colaterais das drogas e dos dispositivos que nós temos como lançar mão. Por vezes, o idoso não tolera um determinado antibiótico ou uma determinada droga que a gente utilizaria no paciente mais jovem, por causa da insuficiência renal, de quadros pulmonares prévios relacionados a cigarro e até quadros oncológicos. Geralmente é o maior limitador. Ou seja, você ter uma pneumonia grave, entubada, em diálise e tal, a probabilidade sua de morte é de 3%. Agora se pegar um paciente com 80 anos, mesmo que não tenha nenhum antecedente, só o fato de ter 80 anos, uma pneumonia que foi entubada, nem está em diálise, a mortalidade dele é 10 vezes maior que a sua. (Dr. Antonio)

Dr. Osler falava que o paciente não morre pela doença que tem agora, ele morre pelo que ele carrega. Por exemplo, uma doença pulmonária anterior causada pelo cigarro. É esperar isso. O que o paciente carrega no seu passado faz com que ele morra muito mais, então, as limitações em cima do idoso são bem maiores. (Dr. Antonio)

A maior parte dos pacientes que está no UTI são idosos, sem dúvida nenhuma. No privado, talvez os pacientes de UTI sejam mais idosos, porque têm condições de vida melhores que os de um hospital público, em que, na transição do adulto para o idoso, já houve uma doença que não foi cuidada. (Dr. Francisco)

Sabemos que ele vai voltar eventualmente. Mas já está tudo explicado, todos estão cientes. (...) Quando esse momento chegar, propomos conforto; abordamos a necessidade de o paciente se sentir acompanhado com a família. Que é melhor ficar na enfermaria, com seus familiares, filhos, mulher, etc. Do que morrer sozinho em uma UTI gelada. (Dr. Joana)

Na minha época, não, mas hoje o intensivista tem a disciplina de cuidados paliativos na residência. A abordagem dos conceitos, desde o básico, distanásia, eutanásia, ortotanásia, até a abordagem de fim de vida. Apesar de ter aumentado o suporte tecnológico, acho que o intensivista hoje tem oportunidade de ter o conhecimento necessário para oferecer uma morte digna, de não estar causando mais uma distanásia, um prolongamento artificial [da vida]. (Dr. Francisco)

Começamos a falar de cuidados paliativos, de uma forma mais estruturada, de três anos para cá. Com participação de profissionais especializados, uma equipe multidisciplinar... Mas acho que ainda tem muito a evoluir. Acho que a gente está caminhando ainda lentamente em relação a isso, a gente tem muito o que aprender. (Dr. Vera)

Tanto com a família, quanto com o médico assistente e a operadora, às vezes eles não compreendem. Acha que você não vai fazer mais nada. Mas isso não significa que o paciente nunca mais vai sair do hospital. Significa que o tratamento vai ter mais foco no conforto, não na doença. Eu não vou deixar o paciente para morrer. O que for possível para eu corrigir, para inclusive tirar o paciente da UTI e ir para o quarto, ou ele morrer na UTI com conforto, o que eu puder dar e os exames me ajudarem, eu vou fazer. Então, o cuidado paliativo não é só dar sedação, oxigênio e comida. Isso daí é a terminalidade. Quando está no finzinho da vida, só. (Dr. Antônio)

6.2.2 Competing meanings of technology

Facilitou a gente ver as coisas, a gente chega numa decisão mais rápido. Mas a tecnologia, por outro lado, fez a gente fazer a pessoa viver mais e fez a gente não estar preparado para isso. Então, por exemplo, já tive pessoa de 102 anos na UTI, o que foge totalmente da nossa curva de atendimento. Lógico que quando você tem uma idade que você nunca trabalhou, e aí? Isso é esperado para a idade? Tem que se atualizar. Nossa expectativa de vida está em 7p, 80 anos, e as pessoas estão vivendo quase 100 anos. Então tem um gap: coisas que a gente não sabia que podiam acontecer, acontecem. (Dr. Roberto)

Às vezes, o uso de tecnologia está levando a gente à distanásia, de querer utilizar demais e achar que, já que é menos invasivo, eu vou fazer e não entender a questão da terminalidade. (...) Ah, mas essa questão de é tão pequeno, não precisa cortar, é só uma punção... Não faz sentido fazer, mesmo sendo fácil. (Dr. Vera)

Com certeza isso dá uma expectativa de vida muito maior para o doente. Ele recupera as funções mais rápido, o trauma é muito menor. (...) Muitas vezes era contra-indicada a cirurgia porque o paciente não teria status para aguentar. Agora, fazemos esse procedimento super tranquilo, sem grandes problemas no pós-operatório. (Dr. Plínio)

É seguro entre aspas. Eu já vi paciente morrer depois da cirurgia de implante de marcapasso com 50 anos de idade. Mesmo os procedimentos minimamente invasivos seja até um cateterismo cardíaco, acontece de o paciente morrer num exame eletivo. Ele vem de casa e morre durante exame. Aconteceu uma vez isso comigo e é a pior sensação para o médico. (...) Também tem contra-indicação por causa do custo. Agora, você não vai colocar um CDI num paciente que tem câncer pulmonar, com metástase cerebral, metástase no intestino… E que tem expectativa de vida extremamente baixa, porque aí o custo do aparelho é muito alto. Isso está embasado dentro dos protocolos por esse tipo de tratamento. (Dr. Antonio)

O médico vivem sob pressão 24 horas por dia. Estou com uma vida na minha mão. Se eu errar, se eu não pensar, vai acontecer alguma coisa. É por isso que muitos médicos têm depressão, usam medicamentos para ficarem acordados ou para controlar a ansiedade. E a faculdade não nos prepara para isso. Nós temos que aprender na prática. (Dr. Roberto)

Tudo tem limite. Claro que o primeiro impulso é salvar vida, mas a gente tem que ser muito racional de falar, até onde que vai o limite de salvar a vida, até onde vai o limite que eu estou levando a um dano. Eu acho que tem limites definidos, mas não é uma receita de bolo. E quanto mais você vai vendo o paciente crítico, mais você vai ficando seguro para definir isso. No começo você sente muito medo de tudo. Até medo de ser processado. O tempo te dá mais segurança. (Dr. Vera)

O Dr. Google nos afronta todos os dias. Ele tem todas as informações, sabe de tudo, nunca dorme e está sempre atualizado. (Dr. Roberto)

No começo, todo médico é conhecido por não querer falar, achar que sabe de tudo, que está certo. No começo acaba sendo um negócio... Puxa vai me contestar? Aí você acaba acostumando e vendo que é uma realidade hoje em dia. Todo o mundo tem acesso a informação e quer saber o que está acontecendo, o que é melhor. Hoje para mim é algo totalmente normal, do dia a dia e esperado, mas no começo eu achei um pouco estranho, desconfortável. (Dr. Plínio)

Acho que você tem que ser aberto, transparente e mostrar. Ele googlou, o que é real, o que tem embasamento de literatura, o que é charlatanismo. Isso acontece muito, principalmente nessa questão de vida. A gente teve um exemplo clássico quando aquele cara de Ribeirão Preto trouxe as pílulas para o câncer. Tinha paciente aqui em terminalidade que trouxe a medicação. Está aprovado pela Anvisa? Tem evidência de literatura? Não, então não vai usar. (...) Tem que estar muito alinhado com a política da instituição. Ser transparente e avaliar: é ético? Tem literatura? Tem respaldo? Tem que ser transparente, é um momento difícil para a família. Você tem que ser seguro e dócil ao mesmo tempo para não criar uma confusão. (Dr. Vera)

Eu acho que esse é o papel fundamental de um coordenador de serviço hospitalar de uma unidade. Ele pode não saber a informação do momento, mas tem que ser honesto e dizer: eu não vi esse estudo, me dá uns dois ou três dias para ler e eu vou posicionar prós e contras. (...) Vamos conversar, eu não sou contra nada, mas trabalho baseado em dados científicos. É conversar e conquistar [convencer o paciente]. Tem que escutar o que ela está falando, porque ela está no desespero. Acho que você tem que ser apto e desenvolver a relação médico-paciente. (Dr. Roberto)

Acho que tem um lado positivo, até para as pessoas se inteirarem daquilo que está acontecendo. Eu acho que isso de alguma forma obriga também que as pessoas sejam mais humanas no sentido de passar todas as informações, as limitações terapêuticas. Mas o lado negativo é que, como posso te explicar, aquilo que a pessoa está lendo não é uma coisa muito preparada para que o leigo consiga entender. Então às vezes a cobrança em cima do tratamento para a doença X, mas peraí, nesse paciente não vai resolver. Isso não vem com manual, né, então essa é parte ruim desse livre acesso das informações. E aí a gente tem que ir construindo isso no relacionamento com o paciente. (Dr. Antonio)

Com base científica eu não discuto. Se eu ver que tem base científica, vai ser submetido a isso. (Dr. Roberto)

Acontece. Tento sentar e explicar o contexto, porque não funciona nesse caso. Tento esclarecer as dúvidas e se ele forçar, eu falo: eu não faço isso, se você quiser pedir uma segunda opinião, fique à vontade. Mas eu tento esclarecer de forma mais profissional possível, porque é feito ou não desse jeito. (Dr. Francisco)

6.3 Socio-economic aspects

A gente abre o ano fiscal sabendo que vai ter perda (perda presumida). Se não trabalhar com no mínimo R$ 200, 300 mil reais por mês de perda presumível, seu hospital não gira. Isso é para dar respaldo para a instituição não ser processada e fazer a boa prática. (Dr. Roberto)

Acho que esta é uma das principais causas de burnout em intensivista é o quanto de dano a gente causa e o quanto a gente investe num paciente que não vai ter qualidade de vida, que a gente vai devolver para a sociedade numa situação pior, que vai gerar mais custo.(...) O que a gente está fazendo? Está fazendo ele sofrer, encarecendo o sistema, gerando um custo altíssimo para a sociedade e não vai trazer benefício nenhum. (Dr. Francisco)

Hoje, as operadoras de saúde têm levado muito em consideração custo-efetividade. Estão muito em cima da gente. Não adianta eu falar que vai chegar uma tecnologia aqui que vai custar R$ 250 mil para um paciente. Quais os critérios, qual a literatura, qual o embasamento? Nunca é uma decisão só do médico e nunca é fácil. Mas é uma realidade cada vez maior. (Dr. Vera)

Os juízes não são técnicos [em Medicina]. Eles não sabem que que tem que segurar custo. Não é não oferecer, é questionar o tratamento. (Dr. Roberto)

Principalmente aqui, a família talvez por um poder aquisitivo maior, serem mais informados das coisas dentro da medicina, eles exigem mais e são um pouquinho mais difíceis de aceitar os cuidados proporcionados ou até paliativos. Não sei, talvez até por muita informação, eles acabam achando que sempre vai ter um jeito de resolver o problema. (Dr. Plínio)

Eu gosto mais de tratar o público sem remuneração [ao hospital], do que o público que tem convênio. Que é um público que acha que tem direito, é o cara que joga na tua cara que paga o teu salário. Acho que renda influencia negativamente na pressão sobre o médico. A população de baixa renda, por incrível que pareça, entende melhor que a população com uma renda mais estabilizada ou uma renda alta, porque ele acha que pode pagar os melhores tratamentos. E a população de baixa renda sabe até onde é o limite porque já viu, escutou, participou. (Dr. Roberto)

Tem pacientes que são bem mais humildes e conseguem compreender muito mais que pessoas extremamente ricas do ponto de vista financeiro, mas que são extremamente pobres do ponto de vista intelectual, ético, moral, para compreender algo complexo relacionado a terminalidade de vida de um paciente, por exemplo. Tem mais a ver com personalidade. (Dr. Antônio)

O que eu percebo aqui é que a imensa maioria dos pacientes não quer dar trabalho para os filhos deles. Eles estão conscientes que tudo tem limite e que este limite está chegando perto e que eles não querem ser um vegetal dentro da casa dos filhos. Eles querem, sim, que seja priorizado o conforto e não a manutenção de uma vida que não tem sentido. (Dr. Antônio)

Acho que a maior parte não tem uma especificação clara de qual é seu desejo. Até quanto ele toleraria perder a qualidade de vida por um determinado tratamento? Esse tipo de discussão só acontece com a agudização da doença. (Dr. Francisco)

Falamos diretamente com o paciente também, de uma forma muito clara. Eles reagem de um jeito… Surpresos, né? Ninguém está preparado [para morrer]. Às vezes eles não nos respondem, só começam a chorar. Geralmente, o paciente idoso, não sei, talvez pela própria fragilidade, deixa que os outros decidam. Que os filhos decida, que a mulher ou o marido decida. (Dr. Joana)

Ok, eu farei [insistir no tratamento], mas não vou deixar ter dor, não vou deixar sentir falta de ar. Vou dar remédio para dor, vai entrar em coma profundo, vou botar o aparelho para respirar, do aparelho vai poder ter várias infecções de repetição… Quando você começa a abrir o leque, a pessoa não acha que é pura e simplesmente dar um remedinho para salvar. A sensação de salvamento dela é o sofrimento para o paciente. Aos poucos ela vai mudando de opinião. É o jeito que você conversa. (Dr. Roberto)

Nós tentamos explicar de maneira bem genérica, não todas as opções, porque senão vira feira. Obviamente que se ele quiser a distanásia, a gente vai tentar não fazer. Mas isso eu nunca presenciei. (Dr. Antônio)

Às vezes, o idoso diz que se sente mais confortável no ambiente de UTI do que ficando em casa, dando trabalho para a família. (Dr. Roberto)

6.4.1 The role of the family

Justamente pela família ter aquela ideia de que é a responsável por ele agora, mesmo que ele esteja totalmente lúcido e orientado para tomar decisões, a família é o mais difícil de lidar. (Dr. Plínio)

Você tem família que é muito dominadora e não aceita a decisão dele [do paciente]. A gente chama a família e explica que ele precisa participar da decisão. A família não tem o direito, quem tem autonomia é ele. É claro que se o paciente já está debilitado, confuso, sonolento, não teria nenhum valor discutir com ele. Mas sempre que ele é consciente, a gente deixa claro que a decisão é dele. (Dr. Francisco)

Na minha opinião, a palavra do paciente é a final, se ele está consciente. Mas às vezes até o médico titular é contra o que o paciente quer. É a gente tentar entrar em consenso. Cada hora é de um jeito. Como coordenadora da UTI eu tenho que lidar com diferentes egos e personalidades. Cada um eu trato de um jeito. Aí é o jeitinho para conciliar. É o paciente que tem que ter papel determinante, ele tem isso garantido pela nossa Constituição. (Dr. Vera)

Essa é a situação mais complexa. A gente entende, é claro, que a prioridade é sempre garantir o desejo do paciente. Acho que nossa missão é sempre em primeiro lugar garantir o conforto do paciente, mas mediar esse conflito e tentar ao máximo mitigar o sofrimento da família também. O familiar vai ficar com uma culpa o resto da vida, um sentimento de que às vezes não foi feito tudo que era possível. (Dr. Francisco)

O que eu vejo, especialmente quando o familiar toma um soco de realidade, é que ele se sente num paradoxo. Vem um paradoxo na cabeça dele que está embutido, pelo menos entre nós, brasileiros, que nossos pais foram feitos para cuidar da gente e que quando eles envelhecerem, a gente cuida deles. Uma troca de funções. Aí ele sente que na hora que chega a função dele, chega alguém para frear essa função. Que aí eu estou interrompendo o fato dele cuidar do pai dele. Inicialmente existe essa questão cultural, que não é maldosa, e sim uma coisa até relacionada ao amor, mesmo. Acho que esse é o fator predominante. A imensa maioria é a coisa do amor, a necessidade de retribuir aquilo que foi feito. Do mesmo jeito que o pai trocava a fralda, ele acha que tem que fazer isso pelo pai dele. Inicialmente, no primeiro contato, quando a gente vai falar de terminalidade, ele entende isso: não posso contribuir para a morte do meu pai. (Dr. Antonio)

Ele está numa situação de que está vendo um ente querido sofrer e vai se despedir. Ele se sente impotente, porque não consegue efetivamente ajudar. (Dr. Francisco)

Ficam o dia inteiro no hospital cuidando do pai ou da mãe de 90 anos, que não trabalha, que modifica toda a vida em função do cuidado dos pais. (Dr. Francisco)

Existem casos aqui que não em que a gente tenta conversar diariamente, abordar, explicar, mas é difícil, é difícil. Normalmente tem isso quando os familiares ficaram ausentes nesse momento de velhice. Acho que talvez, de alguma maneira, eles sentem que não fizeram o que podiam fazer e que agora vão poder ajudar.Mas às vezes acaba mais atrapalhando do que ajudando. (Dr. Plínio)

Aqui no Brasil, América Latina como um todo, a gente tem uma visão um pouco diferente de Europa, Estados Unidos, tal, que é a questão religiosa muito forte. Que às vezes isso é uma barreira muito difícil. Determinadas religiões, e aqui não estou fazendo nenhum juízo de valor e nenhuma crítica a nenhuma religião, mas a gente sabe que determinadas religiões têm muita dificuldade de aceitar. (...) Começam a vir N situações de cura por milagre, a pílula, o óleo, o lenço. Isso se torna muito forte. É muito contexto latino. (Dr. Vera)

A família bota muito mais fé que a religião vai reverter [a doença]. Eu não discuto e algumas coisas eu sou muito a favor. A fé é dele e ele vai recorrer a fé para dar conforto a ele. Ou esperar o milagre. A gente vê a família intervindo [na tomada de decisão]. Querem trazer gente de fora para rezar, organizam corrente de oração… (Dr. Roberto)

Cada família é diferente. As expectativas sempre se mantêm, a esperança sempre se mantêm. Optamos primeiro por conversar com quem cuida diretamente desse paciente. Quando essa pessoa não tem a capacidade, como te diria, preferimos conversar com alguém muito mais tranquilo, por exemplo, filhos. Em geral, em grupo, explicamos que seu pai / sua mãe, chegou a um momento da sua doença que já se considera, não que nós consideramos, que já se considera uma etapa final. Que nós propomos, que nosso principal objetivo é lhe dar conforto, evitar que sofra e que continue sofrendo. Praticamente todos, eles aceitam, porque ninguém quer que eles sofram. Nós damos tempo para aquele que não aceita [nossa recomendação] se adaptar a ideia de que vai acontecer. (Dr. Joana)

Às vezes a gente tem que barganhar, fazer acordos, né. Se tiver uma piora não vai entrar com antibiótico de novo, expõe o que pode acontecer e o que a gente pode fazer para controlar o caso ou priorizar outras medidas de conforto. (Dr. Plínio)

É resiliência e manejo de conflito. Deixar a equipe inteira multidisciplinar preparada que a gente vai enfrentar conflito com essa família. Precisa lembrar a família que isso vai acontecer assim. "A gente falou que quando entrasse em insuficiência respiratória não ia entubar, até acertar a dose da medicação, ele pode ficar um pouco desconfortável…" E antecipar, talvez. Assim: está acontecendo isso e os próximos passos que provavelmente vão acontecer são esses: frequência do coração vai baixar, vai ficar mais sonolento. Tentar mostrar o que está acontecendo e dar segurança de que o paciente recebeu o melhor tratamento. (Dr. Francisco)

Nós temos que ter esse olhar visado mais para o cuidado paliativo e conversar com a família, ver as angústias, o que eles têm pendente. Por exemplo, o cara era o pilar da família, eu estou quebrando o pilar. Quem é o próximo que vai estar no meio? Quem vai receber essa informação, o que vai acontecer? (Dr. Roberto)

6.5 What is a good death?

É natural que você fale em terminalidade em um paciente mais idoso. Não é meu foco de trabalho, mas falar de terminalidade de um bebezinho de dois meses é extremamente complexo. Aí a gente está pegando os extremos. No paciente de 40 anos, quando ele tem pai, mãe, também não é muito simples, e aí tem filho, e você está lidando com duas gerações relacionadas com esse paciente, é um pouco difícil também. O mais fácil é o paciente idoso, porque a gente, de alguma forma, está preparado para enterrar nossos pais, né? A gente não está preparado para o oposto. (Dr. Antônio)

Entre um idoso e um jovem, não na questão de tratamento, o tratamento que ele necessita será feito, porém, o paciente jovem, que tem possibilidade de se recuperar, voltar a uma vida ativa, produtiva, eu tento mais. Sem desmerecer o outro, claro, fazendo tudo necessário, mas eu tento mais. (Dr. Joana)

Meu objetivo é garantir que o paciente não tenha nenhum tipo de sofrimento: que não tenha dor, que não sinta falta de ar, que ele não fique agitado, que ele sofra o menos possível. Tanto para o médico, quanto para o paciente e para o familiar, acho que é o que seria uma morte digna: não ter sofrimento. (Dr. Plínio)

Para mim, é deixar o paciente viver seus últimos prazeres. Em qualquer caso terminal, para mim, eu acho que tudo é válido. Tudo o que for bem explicado e conversado, tudo é válido. O paciente fala: quero tomar um litro de cachaça. Por que não? Se depender de mim, você vai tomar. (Dr. Antônio)

É quando a família e o médico têm segurança de que o que tinha que ser oferecido, no momento certo, foi oferecido. Que não houve nenhum excesso de terapia oferecida e que o paciente, principalmente, se garantiu que ele não tivesse sofrimento. Que todos tenham certeza de que tudo que podia ser feito, foi feito, sem prolongar o sofrimento. (Dr. Francisco)

Que o paciente não sofra, que se sinta acolhido por todo o pessoal do hospital. Para mim, médica, não quero ser entubada, ressuscitada e nem mantida por aparelhos. Para mim, digna é me sedar, tranquila, com a minha família, para não me sentir sozinha e com medo. (Dr. Joana)

Uma boa morte é quando o paciente morre com dignidade. Aceita uma doença que não foi ele que causou e infelizmente a gente não sabe ainda como tratar. Quando tem dignidade, respeito, local, teve apoio da família e teve a vontade respeitada. Dignidade é dar o maior conforto que puder, realizar os desejos que quiser, independente do esforço que se precise fazer. (Dr. Roberto)