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## THE EXPERIENCE OF MAKING THE LIVING WILL WITH SENIOR ACADEMICS FROM THE UNIVERSITY OF MATURITY

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**Abstract:** Death is rarely addressed in our society, and it is necessary to remove it from the taboo status and treat it as part of our existence. The COVID 19 pandemic has emphasized the need to talk about this topic. The elderly identified as risk public since the beginning of the pandemic were greatly affected by social isolation and fear of contamination. From this context, the activity of making the living will - TV was carried out with the elderly from the Universidades da Maturidade (UMA), from the Federal University of Tocantins (UFT). This is an experience report. The method used was the phenomenological, insofar as we tried to rescue the meanings attributed by the subjects to the object studied. UMA is a Nationally recognized and awarded Social Technology – TS. The ST presupposes a set of transformative educational strategies, developed from the specificities of the subjects and built with their active participation, proposing solutions for social inclusion and improving the living conditions of those involved. The assumptions of TS are in line with Paulo Freire’s liberating and emancipatory education. The TV is a document where the person expresses their wishes about the care and treatments they wish to undergo or not if they have a life-threatening illness, respecting the principles of human dignity and autonomy, as well as wishes about farewell rituals and the choosing the person responsible for carrying out its directives. The workshop was divided into four classes, taught by us, a lawyer and a psychologist, as part of a multidisciplinary intervention. The objective was to promote reflections on finitude and desires for the moment of death, with the possibility of making the TV. The intervention is justified by the importance of promoting an education for death. We concluded that the reflections were powerful, shared timidly at first, and from the familiarization with the TV proposal, the

majority participated actively. Students who have been at UMA for more than 2 years showed greater openness and proactively participated in classes, while those who entered less than two years (pandemic period) showed greater resistance. The elderly emphasized the importance of TV to enforce their wishes and guide the family in a delicate moment. Finally, we reinforce the need for an education for death, as part of the life cycle, in all stages of human development and in a transgenerational way.

**Keywords:** Elderly, lifelong education, university of maturity, death, living will, transgenerationality.

## INTRODUCTION

The elderly population has grown exponentially in recent decades in the world. The advancement of medicine, with technologies capable of early diagnosis and offering increasingly sophisticated and effective treatments, has enabled longevity (COUTINHO 2014). In Brazil, IBGE data (2022) indicate that 10.49% of the population is composed of people over 65 years old. And the estimate is that this population will double in 2060. This increase has put old age in the focus of studies and research.

Thus, the 20th century marked major advances in the science of aging, since Metchnikoff (1903) and Nascher (1909) began the systematic study, respectively, of gerontology and geriatrics (FREITAS, et al, 2013).

We can define gerontology “as a multi and interdisciplinary scientific discipline, whose purposes are the study of the elderly, the characteristics of old age as the final stage of the life cycle, the aging process and its biopsychosocial determinants” (FREITAS, et al, 2013), p.69), aims to enable active aging with quality of life. As well as overcoming still existing taboos about old age.

This is because aging is still the focus of prejudice. The social perception of the elderly is still related to retirement, withdrawal from social life, with emphasis on the idea of uselessness/disability and withdrawal or reduction of the protagonist role in relationships, work and community (SOUZA et al, 2002, FREITAS, et al, 2013)). Cities are also not designed for this audience, and there is a lack of efficient public policies that take into account the specificities of the elderly (MIRANDA, MENDES, 2016), all of which negatively impacts their self-esteem, autonomy and quality of life. What made this population act in order to build/rescue an active social identity.

The place conquered and built by contemporary elderly people, by claiming their leading role, autonomy and potential, entering the job market, in physical activities, leisure, arts, continuation of studies, and active participation in the family, intends for societies to take on others. views and perceptions of the elderly. “From this perspective, reflections emerge on what is necessary for the positive experience of old age, considering the vulnerabilities and losses inherent to this process” (TEIXEIRA et al, 2016, p.480). This movement of identity and social empowerment constitutes active aging.

Active aging is based on preventive investment in health strategies, on the constant participation of the elderly in social, economic, cultural, spiritual and civil spaces, allowing well-being and increasing life expectancy (MALLMANN et al 2015). Hence the importance of offering the elderly educational spaces, making lifelong education effective.

Lifelong Education values exactly the theme of “life” as a pillar of education. “Therefore, it understands education not as a formal, bureaucratic, notary process, but essentially linked to everyday life, work,

culture, valuing formal and non-formal processes. It is about education as a process linked to people’s well-being, to citizenship” (GADOTTI 2016, p.07).

This meaningful and dialogic education allows overcoming antagonistic contradictions of traditional education that oppresses and allows a liberating and continued education throughout life, which enables protagonism and autonomy of those involved (FREIRE 1987).

Old age is therefore a complex and important issue, it is a “bio-psycho-sociophysiological and cultural, vital, universal, multi-determined process, which takes place throughout life. It is experienced in a unique, very particular way, as it is processed very differently for each person” (KREUZ, FRANCO, 2017, p.183), with old age being the last of the cycles of our life.

The end confronts us with our mortal condition. Thus, death and old age constitute “phenomena strongly linked to culture, so that an approach to aging seems to demand an understanding and discussion of the grieving process experienced in successive experiences of loss in old age” (COCENTINO & VIANA, 2011, p. 591, p. 591). To better understand this process, it is necessary to invest in research and lifelong education. Such education must encompass the theme of death and the mourning resulting from it, in addition to the mourning resulting from the various physical, social, cognitive losses arising from the process of living/aging (KREUZ, FRANCO, 2017). Part of the interest in contributing to this theme, our initiative to share the lived experience, described throughout the article.

### **LOCUS OF EXPERIENCE**

The University of Maturity, from the Federal University of Tocantins - UMA/UFT is a socio-cultural Extension Program that offers

people over 45 years old an understanding of active aging and seeks to strengthen self-confidence and openness to the job market of its academics, who are mostly over 60 years old. UMA carries out its activities on the premises of the Federal University of Tocantins/UFT in Palmas and has 12 more centers spread across Tocantins, in addition to exporting its technology to other states, acting on a non-profit basis, aiming at the integration of the elderly in society, family and at work (UMA, 2021).

It is a Social Technology - TS, defined as “a set of transforming techniques and methodologies, developed and/or applied in the interaction with the population and appropriated by it, which represent solutions for social inclusion and improvement of living conditions” (ITS, 2007, p. 29). These are strategies built by people, communities and institutions based on their own experiences/experiences and realities in their territories, with the aim of improving the quality of life of those involved.

In this way, UMA offers an innovative and comprehensive education, placing the elderly as the protagonist of the process. It provides subjects connected with the realities and local culture and specificities of academics. The course lasts 2 years, more as the coordinators of UMA say, Dr. Neila Osorio and Dr. Luiz Sinésio, the institution has only a gateway, becoming an extension of the home for the elderly, it is common for academics who have been attending classes for 5, 7, 10 years...

It is important to emphasize that all the methodology used in the UMA are designed to meet the specificities of the elderly, use of a microphone so that everyone can hear well, dynamic methodologies and clear, objective and accessible visual presentations, considering that those who study at the UMA who wish to, not being a prerequisite to be literate, so the group is very heterogeneous.

Knowledge is dynamically shared by teachers, and allows active interaction of the elderly, offering an education that arouses interest and learning that can be used in their daily lives, improving the quality of life of the elderly. In this way, during two years of course, they study topics such as: gerontology, information technology, financial education, rights of the elderly, entrepreneurship, cultural projects, games, thanatology, grief therapies, among others (PPP UMA, 2018). As we can see, one of the themes worked on is death and mourning, offering spaces for education that allow us to demystify and re-signify this process that is natural to our existence.

Another important aspect to consider, given that the workshop took place on the return to classes, after the most critical period of the pandemic, is the multiple effects caused by COVID 19. Studies have revealed that the pandemic, its health impacts and the restrictions necessary to contain it, have impacted mental health, increasing the likelihood of symptoms of stress, anxiety and depression. With regard to terminality, people infected by COVID 19 cannot be accompanied and visited by their family members, and when they die, the farewell rites cannot take place as before, or they do not happen, or they are modified, such as, for example, the -line of wakes, masses/cults/rituals and burials (CREPALDI, 2020, GIAMATTEY et al, 2022), which has had an impact on farewell rites and consequently on the mourning process.

The elderly, identified as public at risk since the beginning of the pandemic, were the most affected by “social isolation and fear of contamination, it is the group that most needs solidarity, as they tend to be more isolated, causing the aggravation of pre-existing problems” and, mainly, triggering or aggravating depression” (CASELLATO, MAZORRA & TINOCO, 2020, p.387).

In addition to offering classes on death and mourning, based on the questions and needs raised by the elderly, taking into account the pandemic context, UMA seeks to build with them ways of clarifying, deliberating or instrumentalizing them based on their demands and needs, making it possible to learning with meaning that propels protagonism and autonomy (FREIRE, 1987).

In this way, it offered a workshop with a lawyer and psychologist, on the living will, “a document in which the person expresses their wishes about the care, treatments and procedures they wish to undergo or not if they have a life-threatening illness” (DADALTO, 2020, p.01), respecting the principles of human dignity and autonomy. The document also includes the person chosen, to ensure that their wishes are respected, and to take the necessary care. It is important to highlight that the demand – the need to speak and understand TV – came from them. Following is the methodology used.

## **THE METHOD**

We will make our analyzes and reflections from the phenomenological method, which according to Holanda (2003), seeks to distinguish the essence of the phenomenon studied, through three fundamental elements: the phenomenological reduction, which seeks to access the perceptions/truths of those surveyed; intersubjectivity, which is the interaction and affectations built between those involved, that is, the researcher-researched relationship; and the third element is the return to the lived experience, in which the researcher – researched takes up their history and affects that cross and transform them based on the lived experience.

Phenomenology is interested in capturing what is experienced, which is not foreseen or defined before it happens, what is experienced in this way is based on relationships,

affectations and interactions (AMATUZZI, 2003).

The article presented is the Experience Report - RE of the workshop. The RE is “the result of an event that passed through the body of its reporter at a given moment. The time of the report marks its diction, it is intertwined with affective conditions, ideologies, and intersubjective aspects with their historical-social meanings” (DALTRO, FARIA, 2019, p. 227). Thus, according to the authors, it is an inexhaustible source of senses and meanings and is not consistent with the search for immutable truths.

We describe the meetings through the field diary, which is “inspired by the work of the first anthropologists who, when studying, carried with them a notebook in which they wrote all their observations, experiences, feelings, etc. to later select the most relevant data” (VÍCTORA, KNAUTH, HASSEN, 2000, p. 73) the notes were taken during and after each meeting and were analyzed later.

## **DISTINCTIONS OF EXPERIENCES ABOUT DYING AND LIVING**

The workshop was divided into four meetings. It arose from the need pointed out by them to better understand the Living Testament - TV, the theme emerged in a class on collective mourning, taught from the commotion in the death of the singer Marília Mendonça and the death of the son of an academic. We emphasize the delicacy of the theme, and the importance of being respectful and welcoming to the diversity of perceptions that could manifest in the meetings. Understanding the natural resistances and difficulties when talking about a topic/taboo.

As we have already said, in TV “the person expresses their wishes about the care, treatments and procedures they want or not to undergo if they have a life-threatening disease, respecting the principles of human dignity



and autonomy.” (DADALTO, 2020, p.01).

Dadalto (2020), a reference author in a living will in Brazil, points out that, while culturally most people are concerned about the death of family members or friends, awareness has grown worldwide about the need to worry about our own death, which has made more and more people seek to make documents such as the living will. This emphasizes the importance of spaces like this, which offer knowledge on the subject.

In the workshop meetings, we formed a circle, so that everyone could see each other and participate equally. The circle method, aims that “the collectives can learn and expand the ability to deal with powers, knowledge and affections, in a more conscious way, since it is assumed that – willingly or not, consciously or not, with protagonism or submission, this deal happens” (CUNHA & CAMPOS 2010, p.38).

We worked from the perspective of death as a natural process of the cycle of Life. Referenced by authors such as Kovács (1992), for her, life and death are not two separate things, they are part of the same process, we begin to die the moment we are born, our cells age and die, small deaths also occur during our existence, to the extent that we lose things along the way to live. So why do we speak with such anguish of the phenomenon of death? Why do people paint death as something scary? The author, in several works and works developed on the subject, emphasizes the need to remove death from the taboo status, and we start to treat it as part of our existential process, as has already occurred in previous periods of our history.

Thus, death awaits all of us, not thinking about it does not delay its arrival even less. Conversely speaking and demystifying it can help us to accept it as an experience as important and valuable as any other in our existence (ARIÈS, 2012).

Some discomforts in talking about death were noticed in the group: “talking about death is a way of calling it”, “I feel discomfort when talking and thinking about death”, “I cannot think about the moment of my death and I have fear of losing someone I love” – at the same time, there were placements of proximity to the theme – “talking about death prepares us for it”, “we do not know the day of death, thinking about it facilitates the way that we and our family members will deal with it when it arrives”, “I was very afraid of death, but I learned here at UMA the importance of talking and preparing for it”, “I had never thought about what I would like when I died, leaving it in writing will help people to deal better with a difficult time”, “like Marília Mendonça, we can die at any moment, thinking like this helps us to do and say what we consider important”.

We emphasized as Kovács (2003), Parkes (1998), Kurble-Ross (1996) and Worden (2013) the importance and need for a cultural change that allows bringing the themes about finitude closer to us. Education for death must occur in our family, school and work routine, it must involve open and frank communication about relationships, losses, limit situations, deaths and bereavements that occur throughout the course of our life. We need to stop running away from that which, as the popular saying goes, ‘is the only certainty we can have, that one day we will die’.

Questioning and reflecting on living and dying enable understanding and self-knowledge, constituting an existential meaning and allowing a meaningful and unique learning about the themes (KOVÁCS, 2003). It was something perceptive in our experience, when we thought about TV information, the perception of death, desires and directives were connected with our histories, cultures, beliefs and values, which allowed us to build, or at least the beginning of

the construction of a relationship of meaning with our finitude.

In the first two meetings, the specifics of the TV were explained collectively and individually to anyone who requested it. There was an initial confusion with the conventional will that defines the desires in terms of the division of material goods. What was clarified, and emphasized that the TV, is about wishes about health care, how would you like to be treated if you get sick, if you lose consciousness, if you would like to have a prolonged life by devices and treatments, who to appoint for take care of the wishes expressed on TV, as I would like the farewell and burial rituals to be.

Currently, patients have been more involved in matters involving their health, including cases of terminal illness. This change arises from greater access to knowledge and health and legal information and also from health professionals, especially physicians, as a result of curricular changes in medicine courses, opening space for patient participation in decisions made about treatment (CHEHUEN et al. al. 2015).

Despite this, the right to die, to be able to choose not to undergo treatments, causes controversy, despite the patient having this right guaranteed, the family and health team often oppose this desire, in order to prolong life, this is often due to these people's lack of knowledge about TV, or the desire to maintain the life of the loved one or patient (CHEHUEN et al. 2015). We emphasize to the group the importance of seeking qualified professionals in this area to help in the best way, appointing trusted people to take care of their directives, seek palliative doctor and lawyer. When preparing the document, let the family know and make copies available to people you trust, in addition to always taking one with you. We also emphasize that the document can be revisited and updated whenever they wish.

The objective of the last two meetings was to offer the elderly the opportunity to prepare their living wills, or at least to germinate this idea, if they wished. A questionnaire was prepared with 9 open questions: 1 – Do you understand what TV is and what is it for? 2 – Would you like to receive more explanations about TV? 3 – Have you talked to people close to you about TV? If yes, indicate these people. 4 – If you cannot express yourself, do you have someone you trust who could help you continue to live with dignity? If yes, who? 5 – If you get sick, and the disease has no cure, would you like to try all possible treatments? Explain your choice. 6 – On the day you die, do you have any special wishes? (A song, prayer, ritual). 7 - If you die, do you want to donate your organs? 8 – If you die, do you have any special wishes that can be fulfilled by family and friends? Which one? 9 – Would you like to register the information provided in this document, so that people have access to your intentions and desires? They were able to take the questionnaire home and bring it back the following week.

The class had about 36 academics, the vast majority, 24 answered the entire questionnaire. Some elderly people expressed difficulties in thinking about these questions, but they were surprised, with the reflections and new ways of looking at their finitude, needs and desires around the dying process. Also, they brought strangeness and surprises regarding the conversation about TV with the families: “they were scared, not understanding the conversation”, “I couldn't talk to anyone”, “they just listened to me and said they will respect my wishes”, “they didn't want to talk about illness and death”, “I don't have anyone I trust”, “we had already talked about death, so it was easier to talk about TV”, “they had doubts about TV, they would like to talk to you”, “my daughter thought it was very important, she said she will do her TV too”, “we lost my

husband, who was in the ICU for 2 months, we didn't know what to do, my children liked the TV idea", "I felt light when thinking and writing my wishes for my family, I felt that they stayed too".

We make ourselves available to talk with the families, and also with them, in case new questions arise. We welcome and respect everyone who was unable to make the TV, we even emphasize in the group that each one has their own time, rhythm and way of dealing with things and that the different singularities need to be respected.

There were detailed descriptions of funeral rituals, wishes that could be fulfilled by family and friends after death, objects with sentimental value that would be destined for loved ones, expressed a desire to be cremated, to donate the body to the UFT medical course, of not prolonging life and having a natural death, of using all the resources of medicine to prolong life, of donating their organs and not donating. A diversity of desires and affections, consistent with our human singularities.

As the phenomenological method presupposes, we researchers, also learned and were affected by everything that was shared, we leaned together with them on our directives and desires. We live in the skin the antagonism of wanting to talk about finitude and thinking about our TV and the anxieties and fears arising from talking about a taboo topic in our society. Undoubtedly, the gains were much greater than the discomforts felt. As we talk and reflect, we naturalize the theme, and in this way we experience a possibility of education for death. We highlight the pioneering spirit of UMA, in working in a transversal and transdisciplinary way death and mourning and the themes arising from them such as TV.

We evaluated the experience of education for death as very rich, as it contributed to

the demystification of the dying process, experienced in an academic space for the elderly. Because it was a transdisciplinary experience, where the law brought knowledge about TV, specifics and implications of its making and psychology acted by welcoming and helping the participants in the confrontation and resignification in their relationship with death and dying, which as we have already said is directly related to life and living.

The UMA methodology, which proposes knowledge based on the demands and specificities of its audience, promotes an emancipatory education that propels the protagonism and autonomy of those involved, as Paulo Freire (1987) points out.

Another important distinction is that the elderly who have been in the UMA for a longer time (two years or more), who have already had contact with the topic, were mostly able to prepare their TV, inversely those who had entered the last two years (pandemic period), they had greater resistance in approaching the subject, considering it still a taboo. This attests to the effectiveness of education for death. Finally, we highlight the need for more research and sharing of successful experiences, which can inspire and materialize the paradigm shift around death – from taboo to a natural process and part of our existence.



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