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Life history and meanings: end of life in an intensive and semi-intensive care unit

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Abstract *This study addressed the end-of-life experience of a patient admitted to an intensive and semi-intensive care unit based on the accounts of a family member who accompanied her therapeutic journey. The study sought to understand how healthcare teams consider patients' life histories and how this influences care strategies. We also sought to identify the interaction between healthcare teams and patient family members when patients are no longer able to communicate. Immersion in an intensive and semi-intensive care unit enabled an ethnographic approach involving participant observation, in-depth interviews and monitoring of bedside visits. The results show that, despite not being considered by the care team in the case presented in this article, understanding a patient's life story, even when narrated by family members, is important for ensuring humanized care and developing effective care plans for these individuals.*

Key words *End of life, Culturally appropriate technology, Comprehensiveness in health care*

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Introduction

End of life experiences force individuals to confront the fundamental dilemmas of human existence[1,2]. Whether in hospital or at home, individuals facing end of life find themselves compelled to make sense of how they have lived, the decisions they have made and the way they have built their relationships, taking stock of their life story[3,4]. End of life is an important moment in human experience that requires special attention so that it can be lived with dignity.

In this article we present Joana's experience (participants data was anonymized to meet ethical requirements) of living her last days in an intensive and semi-intensive care unit accompanied by her daughter, Elis. Joana was hospitalized due to the worsening of an autoimmune disease that she developed in her last year of life.

Joana's story invites us to think about a range of issues that cut across the theme of terminality, including: the place of cultural determinants in therapeutic processes[5-9], the power exercised by biomedicine over the body in the context of intensive care[10], respect for the autonomy of individuals who are no longer able to express themselves[11-13], the role of care team-family interactions[14-17] and attention to individuals' wishes[14,18]. This story allows us to explore themes and issues that are central to the care process. This study takes a novel approach, applying a social science perspective on health after ethnographic data collection based on the authors and issues mentioned above.

The result is an article in which the underlying sociocultural dimensions of care come into focus, revealing the obstacles people face in ensuring that their dignity is preserved in certain care settings.

Methods

This article is the result of a study entitled "Critical/Intensive Care from the Perspective of Family Members of Individuals Admitted to the Transitional Care Ward of the Hospital das Clínicas of the State University of Campinas", approved by the research ethics committee of the institution where the research was conducted (reference code CAAE 82731317.8.0000.5404). We conducted a qualitative[19,20] ethnographic study[21-24] using the set of techniques[25] mentioned below. The data were collected on Mondays to Fridays from 7:00 am to 2:00 pm over a period of four months (March to June). During this time, cases involving dozens of patients undergoing care at the unit were reviewed. Of these, three end-of-life patients were selected. The process included interviews with the patients' family/companions and conversations with the resident doctors responsible for the cases.

One of the data collection techniques used was participant observation (PO)[26,27], divided into two moments: 7:00 to 10:00 am, when the medical team made bedside monitoring visits and met to discuss each case, defining procedures and reviewing any incidents that had occurred the previous day; 10:00 am to 2:00 pm, when we continued to monitor ICU routines, observing care practices and talking with the patients' families and care team.

Part of the medical team were permanent ICU staff, including coordinating physicians and a third-year resident (R3). The other members worked in the ICU on a rotational basis for periods ranging from two weeks to one month.

In-depth interviews[19,20] were also conducted with the family members and/or companions of the end-of-life patients who consented to participate. In all cases the patients were not physically and/or cognitively capable of engaging in long conversations. The interviews were conducted in a large well-lit and well-ventilated common room on the fourth floor opposite the ICU, ensuring the protection of interviewee privacy. The interviews were recorded after obtaining written consent and lasted between one and two hours. In most cases, interviews were conducted on more than one occasion.

The guiding thread of the interviews was the life story (LS)[28] of the person the interviewee was visiting. Despite this focus, there was a noticeable desire on the part of interviewees to recount the process of the illness that led to hospitalization. We chose to interrupt the accounts as little as possible to encourage a continuous free flow of reflection by the interviewees.

After data collection, the cases were screened to select those that contained elements that would allow us to explore the research topic. After transcribing the interviews and organizing the field notebook data, Joana's case was chosen for this article due to the breadth of the themes running through her LH, her therapeutic journey and the willingness of her companion to participate in the research when invited. Although presenting an overview of all the patients' stories and therapeutic trajectories may be useful for identifying similarities and differences between the cases, while writing the LSs we realized that presenting the data in the form of a single case

study[29] would provide a depth that would enable an important methodological leap by demonstrating what is left behind when an individual's LS, values and desires are treated as secondary.

For the purposes of this case study, we accompanied bedside visits for ten days. Three semi-structured interviews lasting between two and three hours were conducted using a pre-prepared interview guide. The first interview was conducted in person and recorded. The second interview was conducted by telephone, with the informant requesting that it not be recorded, although she had previously authorized the use of any information mentioned. The third interview was conducted via videoconference and recorded. The audios were transcribed, and the field notebook was systematized to also serve as a data source. We then wrote the single case study included in the final research report and this article.

The story presented below is the result of this methodological process.

Results

Joana's case

We had been monitoring the progression of Joana's clinical condition for just over a week when we realized that she was a potential case study. She was seeking alternative treatment for the disease that she had developed over the last year: a rare autoimmune disease that severely damages the skin and mucous membranes.

The case required special care from the health team. Joana was not responding to treatment with corticosteroids and skin damage had affected almost 90% of her body. Since she had had the disease for over a year, painkillers had little effect on the pain caused by the wounds. She was placed in the only isolated room in the unit during her stay to reduce the risk of infection and provide a less invasive and more welcoming and comfortable environment. Full body dressings were applied on a daily basis. Murilo, her doctor, reported that bed baths lasted up to three hours due to the technical difficulty of the procedure.

One of the things that drew our attention in this case was the involvement of Joana's companion in the care process. According to Murilo, her daughter mediated dialogue with Joana and helped dress her wounds and bathe her.

We decided to learn about Joana's LS when the team began to speculate about the limitations of the cure strategies. The immune parameters were responding poorly and there was a suspected infection that meant the treatment of the underlying disease would have to be interrupted due to the contraindication of an antibiotic.

About Joana

Aged 41, Joana was, among many other things, the epitome of Brazilians who leave their hometown in search of a dignified life in the country's big cities. Up to her early teens, she had lived in a town in inland Pernambuco, working with her husband doing whatever job she could provide a livelihood for her family.

The second daughter of a family of nine, her mother sewed, washed and cleaned for others and Joana was chiefly responsible for caring for her younger siblings. Her mother put her in charge of caring for her siblings, providing part of the family's livelihood and performing household chores. Elis's account suggests that her mother and grandmother had a troubled relationship.

The difficulties of family life coincided with Joana meeting Lázaro, the man who would become her husband, and Elis' father. They married after a short courtship and moved into a rented house in their hometown.

After three attempts to get pregnant followed by miscarriages, Joana gave birth to her first daughter in the seventh month of pregnancy. Joana had three more pregnancies that also ended in miscarriage. Six in total throughout her life.

They moved to São Paulo due to job insecurity in their hometown, settling first in the city of São Paulo and moving to an inland town a few years later.

The place of work in Joana's experience

After moving to the city, an opportunity arose to open a snack bar. Opening this business seemed to have a mixed effect, because while marking financial progress it also led to an increased work load, affecting family and marital harmony.

Elis recounted a series of arguments between her parents resulting from an excessive workload. For her father, though contradictory, the solution to the family crises was more work. However, Joana did not seem satisfied with the idea of reducing life to work.

It was in this context that Joana's illness began to show its first signs.

The process of illness

Elis talked about the process of illness always from two perspectives. On the one hand, she made it clear that she was aware of her mother's medical history. On the other, she pointed out that the cause of the illness was not purely biological, but rather the result of the complex relationship between her mother's history, social and family relationships and a religious element, which was emphasized in the account.

The first clinical sign was a lesion on her scalp, which Joana attributed to a reaction to a hair treatment. Due to the discomfort caused by the lesion, she went to several doctors (a general practitioner, dermatologist and infectious disease specialist), but the strategies were ineffective.

Despite the pain, Joana maintained her daily routine until blisters began to appear on different parts of her body. Difficulty swallowing, the pain and the delay in finding a solution to the problem began to affect Joana psychologically.

According to Elis, given the complexity of the condition, coupled with diagnosis difficulties and the ineffectiveness of the treatment strategies, her mother began to consider religious solutions as an alternative.

Spirituality as a therapeutic approach

Joana was Christian but never had any reservations about having other religious experiences, leading her to go to a faith healer. Elis went with her, and at the end of the session the healer said, in Elis's words, "[...] Look, daughter, everything is fine with you [referring to Elis], but there is something wrong with your mother".

Despite an explanation that made sense to Elis, the spiritual consultation and therapy recommended by the healer had no practical effect on the disease, which continued to progress. Joana's disappointment with the strategy had a negative impact on her mood. Her condition deteriorated, leading Joana to seek treatment at a hospital in the city where she lived, when, for the first time since the beginning of her search for a diagnosis, a doctor considered the disease that we would later come to know as a possible diagnosis.

Based on this hypothesis, Joana was admitted to hospital for a week, during which time her condition improved. The hospital team decided to continue treatment at home due to the risk of hospital infection. Despite this decision, there was still no certainty about the diagnosis.

Elis reported that the return home produced an immediate negative response, raising suspicion once again that the illness may have been caused by some kind of spiritual interference, which is when Joana decided to seek guidance a second time with another therapist.

According to Elis, the second therapist confirmed that "something has been done to your mother", but that she was unable to treat something of that nature, telling her that her mother had "[...] something very strong" and referred her to someone with more experience. They went to a third therapist, who confirmed the other two versions:

[...] they did something to you that is difficult to undo, because they did it to kill you. You will go through a phase in which you will do many tests, you will see many doctors, but they will not be able to tell you what it is because it is beyond their ability to understand [...] your worsening condition is spiritual, so you will not see any improvement and your tests will not reveal anything.

Joana had undergone a process of extreme weight loss. When her malnutrition reached a critical level, Joana needed to be admitted to hospital again. A series of tests was then carried out to investigate the condition further. Elis talked about the test results with a tone of surprise:

As incredible as it may seem, a bunch of tests came back and there was nothing. Nothing had changed. Blood, urine, this and that, nothing. I was perplexed, you know? Then the guy [the third therapist] *came to mind [...].*

At that point, it became clear that we should explore Joana's relationship with the spiritual and religious dimension in more detail, so we asked Elis to talk about how her mother viewed the spiritual diagnosis that the third therapist had given, to which she replied:

When you find yourself going to every hospital, every doctor, every specialist, and no one tells you anything, no one improves your case, a battery of tests and everything comes back negative, you open yourself up to other options.

It is worth highlighting one of the elements in Elis's account. She told us that during the consultation the therapist demonstrated an ability to investigate the complex nature of Joana's process, finding a place for both spiritual rationality and medical knowledge, saying:

Spiritually, I'll see what I can do for you, but don't stop going to the doctor, because it's manifesting itself as an illness in your life. You have to treat it. Neither spiritually nor the doctors alone will be able to help. It'll be a combination of both.

One of the recommendations made by the third therapist was to wear a protection necklace he offered to Joana to protect her from negative energy that could further compromise her situation. According to Elis, wearing the necklace had a practical effect, with Joana's clinical condition beginning to show signs of improvement and the diagnosis becoming clearer.

However, due to the exhaustion of therapeutic possibilities at the hospital where she was receiving treatment, Joana was transferred to another facility that provided more complex care in a neighboring city. The care team at the new hospital asked her to remove the necklace, in compliance with the facility's health protocols. Elis said that they did not oppose the protocol, even though she believed that this may have contributed to her condition worsening again.

[...] when they did the test she had to take the necklace off. As soon as she took it off, overnight, she stopped eating, she stopped doing anything. Then they despaired, saying they had never seen an illness like that before [...].

While Elis was emphatic about the effectiveness of the spiritual alternative, the delay in diagnosis, which, after months of going to specialists had still not been confirmed, caused a sense of urgency, leading her once again to anchor herself in biomedical treatment possibilities. This shift in approach coincided with the exhaustion of therapeutic possibilities at the second hospital where she was being treated.

The third hospital

From that moment on, we were able to closely monitor Joana's clinical condition, which was critical. When we became aware of her condition, none of the information presented here had been gathered: her family relationships, her spirituality, the therapeutic path that had led Joana to that situation. The team was concerned with reducing the suffering caused by the procedures, but there seemed to be no room for Joana's LS.

At the third hospital, which provided a higher level of complex care than the other two facilities, the diagnosis was quick. As it is a rare disease, its name is not mentioned here to preserve Joana's privacy.

The disease continued to progress despite the diagnosis. The pain, loss of independence, disconnection from her daily life, separation from her work and marital life and difficulty finding a treatment had a profound impact on Joana. At that moment, after realizing that we had managed to establish a relationship of trust with the informant, it was possible to explore some of the conversations Elis had been having with her mother, considering the possibility of an irreversible deterioration of the condition that could lead to her death.

The end-of-life process

Interviewer: *Joana's prognosis could evolve into very different positive or negative clinical conditions. One of these possibilities is the risk that the situation could become complicated, and she could die. Does your mother understand the gravity of the situation?*

Elis: *At bath time she might even prefer it.*

This is the part of the interview in which Elis tells us about how her mother views the possibility of death. Elis goes on to make it clear that, contrary to what this passage may suggest, her mother does not see death as the only way to end her suffering. According to her daughter, this wish comes to the fore in moments of severe pain.

When answering the question of how her mother copes with the possibility of death, Elis tells us that her mother would rather die than prolong her suffering during the procedure. However, when the pain subsides, she says her mother fears death and makes plans.

While on the topic, we ask Elis if her mother is aware of her overall clinical condition. She tells us that she is, "because of the pain". She goes on to say that Murilo is always clear about the stage of the disease.

Elis says that Joana often mentions her desire to die at home if she can no longer be cured at the hospital:

She [Joana] says to me: "If I'm going to die suffering, take me home. I don't know if you can authorize that, whether I have to sign something, but if I'm going to die suffering like this, take me home, so I can die in my own environment [...]". But the thing is, I [Elis], I don't have a diagnosis saying: "look, your mum's going to die". She may die, but it's not her reality at the moment [...] I feel that if I did that to ease her pain, I'd be the one killing her. [...] If the doctor said to me: "look, there's not much else we can do", I'd decide whether I want her to stay here or to take her home. So, yeah, I'd go with whatever she thinks is best for her.

In the last few days that we accompanied the medical team, we knew that Joana's prognosis was end of life; however, neither Elis nor her mother were informed.

Joana was sedated most of the time because of the pain, making it impossible for her to talk to the care team and express her end-of-life

wishes. It is important to highlight that everyone involved – the care team, Joana and Elis – regarded sedation as an effective comfort measure, given the severity of the pain. When Joana was lucid and alert, the only person who talked to her was Elis, who also seemed to be the only person who was aware of her mother's wishes.

Three days after our last conversation with Elis, on a Saturday morning, we received the news that Joana had passed away as a result of the sudden onset of a hospital infection. As Elis later said, Joana had "rested".

Discussion

Anthropology, in its widest sense as a discipline[21,22,30] or through its intersection with the field of health[9,23], challenges us to take what our research subjects have to say about the questions we ask them seriously. When we asked our interviewee about her mother's LH, the following emerged: i) recurrent mentions of the knowledge and strategies employed by the family to manage her mother's illness; and ii) mentions of her mother's her end-of-life wishes.

In both cases, to consider the subject's subjectivity in a care context it is necessary to be willing to listen to what the patient has to say and, even more so, to pay attention to the involuntary communication produced from this interaction and the extent to which the care environment makes the subject feel at ease to express their knowledge and desires[8,14,18].

The place of the other's knowledge

An example to reflect on related to the theme that is the subtitle of this section is the situation involving wearing/not wearing the necklace in Joana's story.

Elis cast doubt on the strategy of using the necklace as a therapeutic resource. From the first time we spoke, she seemed clear that she was dealing with people within an institution that represents scientific rationality. This observation is important because it reveals how scientific knowledge is understood socially: a state of truth that says who can speak and what can or cannot be said[31]. In Joana's case, despite the necklace's effectiveness, Elis reported that she never informed the staff that the necklace served a therapeutic purpose because she understood the hospital's health protocols.

During data collection, as the hospital environment became more apparent it became clear that the way cases were handled did not give companions the opportunity to explain details of the care strategies adopted to care staff prior to hospital admission. Case discussions are based on clinical and biomedical parameters, combining feeling and clinical experience; however, this sensitivity did not seem to include the religious therapeutic strategies adopted by Joana.

The findings of this study demonstrate an inclination on the part of the health team towards hard and soft-hard technologies[32], while at the same time failing to recognize or undervaluing central elements of care processes linked to soft technologies built around communication, dialogue, listening and welcoming[33].

Spirituality and health

The academic debate on the role and/or effectiveness of spiritual care as a therapeutic approach is by no means recent and brings together significant contributions from authors from the global North and South[34-38]. Although interest in this topic has produced a wide body of academic literature, the way in which the care team treats this spiritual component reveals that they assign it a low level of legitimacy. It is important to highlight that the care team's lack of awareness of Joana's investment in both biomedical and spiritual treatments, and the effectiveness of the latter, illustrates that combining clinical strategies, knowledge and insights from other epistemic matrices remains a challenge.

Despite this challenge, studies such as Bezerra's[39] point to a significant increase in clinical approaches aimed at addressing spirituality in patients receiving palliative care. Thus, despite resistance from certain medical specialties and fields, the literature points to increased attention to the spiritual component in end-of-life care planning.

Finally, drawing on the reflections proposed by Akerman[37], it is worth highlighting that, as a therapeutic resource, spirituality can be thought of in terms of what (inspired by the theory of salutogenesis[40]) the authors call health assets: "health assets can operate on the person, group, community and/or population levels as protective (or promoting) factors to cushion daily stress" (pg. 2). This approach is key to understanding that, even in the context of end of life, certain practices and ways of life have the potential to produce health and comfort, regardless of the health outcome.

Communication and the place of wishes and meanings

Following the care team, having access to discussions and understanding how the case was managed provided access to information that made us realize that the maturation of the clinical practice of professionals providing end-of-life care leads these professionals to develop a technical sensitivity that allows them to identify when these individuals are longer be able to express their wishes and to set limits for attempting to reverse the clinical situation. This is what we call practical wisdom[41], repeatedly referred to by one of the physicians coordinating the sector where data collection took place when prognoses begin to become more evident.

Despite this sensitivity, the case in question seems to demonstrate a lack of communication, directly with Joana – whose expression of wishes and choices suggest autonomous participation in the care process – and with Elis, when Joana was unable to express herself due to her clinical condition.

The field experience showed us that few doctors, residents and students feel comfortable communicating bad news, and that this difficulty, or lack of willingness, can directly interfere with ensuring that the end-of-life experience is as close as possible to the wishes of those receiving care.

In this case, not only Joana's participation in the care process but also her knowledge about the prognosis were taken away from her, as if the approach of death can be reduced to the moment when care ends, despite what is known about the importance of death in the human experience[1-4].

Joana was therefore deprived of the opportunity to signify, re-signify and assign meaning to this moment of her life, which usually occurs when death approaches, as Elis's experience seems to show.

Despite the anguish recounted by Elis at various moments of our conversation, she offered some important reflections on her experience with her mother's illness, hospitalization and care, which suggest that the experiences she had throughout the therapeutic process were necessary for her to resignify a series of issues in her life. As she said:

I wouldn't say that it's a bad experience, I'd say that those who don't understand the meaning of life should have the experience of living as I live here [...] If she dies [...] she'll have achieved one thing: she'll have transformed a lot of things.

It is also interesting to note the place she gives to God in her life and in her expectations for relief from her mother's suffering. The emphasis she places on this issue shows that it was a recurring theme in the way she dealt with this process:

Sometimes, I try to imagine that God doesn't have much to do with her suffering, with what's happening [...] he has [more] *to do with life, with outlook on life, with destiny, so I imagine that maybe He didn't want to change her life through her death, or through her suffering. Maybe it was her time to go; it was to change my father, me, to make me stronger. I've become a different person, more responsible, with a different mindset, you know? So maybe that's all there is to it [...].*

Elis's comments go beyond the objective fact of death as the end; she includes a subjective fact using her imagination, which expresses a symbolic dimension that is constitutive of human beings, as pointed out by Morin[2]. Becoming a different person as the result of someone else's death in this case corresponds to a version of the myth of death and rebirth, which, together with the myth of the double, was present in all the cultures studied by this author.

The possibility of her mother's death is embedded in a narrative that seeks to deconstruct the idea that death is an experience that carries only suffering. For Elis, it is not a divine desire or punishment. Her comments highlight the contingency and uncertainties surrounding the process of intensifying her mother's suffering, which has nothing to do with a trial. The proximity of her mother's death provided the opportunity for a process of positive signification, which served to transform her and her father's lives.

With this experience, Elis teaches us that Joana was deprived of a process of signification that could have produced a death that was more connected to her life.

Final considerations

The analysis of this sole case draws attention to the singularity of the processes of signification that can contribute to ensuring an approach to public health that is closer to contemporary social demands focused on epistemological plurality and the diversity of ways of being, living and dying.

At the end of life it is common for individuals to resort to different types of knowledge to produce meanings and senses in the elabo-

ration of lived experiences[1,2]. However, as Fernandez[8] points out, hegemonic medical knowledge based on an ontological approach to the health-disease process tends to disregard this process of signification in its clinical reasoning, obscuring strategies adopted by individuals based on other epistemologies. This is no different in the case of the end-of-life experiences, as Joana's case teaches us.

The management of the clinical condition we described here did not allow Joana to build or express a meaning for her end of life due to this common situation in health services of this nature. While we were not able to learn further about the plurality of meanings of dying from Joana, her daughter's account illustrates, as we believe, the importance of considering these meanings to ensure the development of a more inclusive medical practice for individuals receiving end-of-life care.

Collaborations

AD Silva participated in the conception and design, data collection and analysis, interpretation, writing, and revision of the version to be published. JCA Fernandez participated in the conception and design, data analysis, interpretation, writing, and critical revision of the version to be published.

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Data availability statement

The data sources adopted in the research are indicated in the article's body.

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