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ORIGINAL ARTICLE

Experiencing the death-dying process: a phenomenological analysis of patients with terminal cancer*

Vivenciando o processo morte-morrer: uma análise fenomenológica do paciente com câncer em estágio terminal

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ABSTRACT

The objective of the present study was to understand the suffering emanating from the terminality process and its consequences in the lives of those who experience it. This is a phenomenological study, based on Heideggerian thought, carried out with 11 patients with advanced cancer. The data were obtained through open interviews, conducted from November 2015 to March 2016. Two themes emerged from the results: "Confronting the death-dying process" and "Revealing the suffering from terminality", both of which demonstrate that it is in the confrontation of death that each Being uniquely experiences their individualized way of being-in-the-world. It was concluded that the Being that experiences the terminality of life process reveals, in their own way, their encounter with suffering and the process of acceptance and comprehension of their finitude. This ascribes a crucially holistic and individual eye to nursing, so that the necessities of those experiencing the terminality of life process are contemplated.

Descriptors: Hospice Care; Nursing; Terminally Ill; Death.

RESUMO

Objetivou-se compreender o sofrimento que emana do processo de terminalidade e suas consequências na vida de quem o vivencia. Pesquisa fenomenológica, embasada no pensar heideggeriano realizada com 11 pacientes com câncer em estágio avançado. Os dados foram obtidos por entrevistas abertas, realizadas no período de novembro de 2015 a março de 2016. Como resultado emergiram duas temáticas: "Enfrentando o processo morte-morrer" e "Desvelando o sofrer pela terminalidade", as quais mostram que é no enfrentamento da morte que cada Ser vivencia de forma única e individualizada seu modo de ser-no-mundo. Concluiu-se que o Ser que vivencia o processo de terminalidade da vida descortina de maneira própria, o seu encontro com o sofrimento e o processo de aceitação e compreensão da sua finitude, o que imputa à enfermagem um olhar crucialmente holístico e individual para que as necessidades de quem experiencia o processo de terminalidade da vida sejam contempladas.

Descritores: Cuidados Paliativos na Terminalidade da Vida; Enfermagem; Doente Terminal; Morte.

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INTRODUCTION

Despite the advances of science, at certain point a person with cancer may encounter a terminal prognosis[1]. It is at this time that the patient presumes that the cancer is not going to disappear and that they probably have little time remaining.

With stigmas inherent to its significance, having cancer still alludes to suffering, pain and, above all, death. This interferes in the early search for care, culminating in late detection of the disease. The search for treatment at an advanced stage of the disease collaborates in its exponential incidence of lethality[2].

This sudden, painful contact with the finitude of life, triggered by the worsening of the disease, finds its maximum expression at the moment of awareness of ever closer death. Most people prefer not to think of their death, which makes this a feared encounter that tends to be avoided[3].

In this stage of the disease and of life, it is important to alleviate the suffering that precedes death, offering care that meets the needs that are not always expressed. In this scenario, palliative care seeks to relieve the hardships arising from the disease[4]. However, very few patients benefit from this type of care as they are rarely aware of the real situation of their prognosis[5]. Within this lack of comprehension, many confront the process of finitude without assistance, with no control over their pains and physical symptoms and their psychosocial and spiritual issues neglected.

Thus, given these concerns, it is important to learn about the perception of suffering surrounding the universe of these Beings, to provide not only the opportunity to die without suffering, but also to express their fears in the face of death[6]. In addition, in seeking to understand the patient in their totality, responses are sought together with the patients themselves, considering not only the terminal illness, but also their experiences, to reveal the aspects of suffering that surround them. Thus, the objective of the present study was to understand the suffering emanating from the terminality process, and its consequences in the life of those who experience it.

METHOD

This is a qualitative study, based on the Existential Phenomenology of Martin Heidegger[7]. The possibility of approximation to the experience of patients going through the dying process enables comprehension of the perceptions and necessities involved[8].

The protagonists were advanced cancer patients, treated by a referential non-governmental institution for patients in a vulnerable social situation, situated in a municipality in Northeast Paraná, Brazil. The patients were pre-selected using data collected from medical records made available by the institution, considering the following inclusion criteria: awareness of the current diagnosis, established for over six months, being clear as to the clinical stage of the illness and the prognosis, and having preserved cognitive state (assessed through a mini-exam of mental state).

Fourteen patients were invited to take part, but only 11 effectively participated, as two did not meet the inclusion criteria and one died at the beginning of the study. The data were collected from November 2015 to March 2016, through interviews recorded using digital media, conducted at the institution or in the patients' homes, as per availability. An average of three to four meetings were carried out with each participant, with a mean duration of 40 to 60 minutes, conducted using the following guiding question: "What feelings have appeared while living with the diagnosis of advanced cancer?" Behaviors expressed by the interviewees, such as pauses, alterations in tone of voice, shifts in emotion and interruptions, were recorded in a field diary which composed *the* corpus of the analysis together with what they said.

The interviews were transcribed in their entirety for analysis and enriched with information from the field diary. The transcriptions were read in detail, so that no relevant information was disregarded. The analysis sought out the facts not generally shown to all, as they possess essential meanings and structures that would otherwise remain veiled, enabling comprehension of the phenomenon[7].

Firstly, individual analysis of each interview was carried out to capture the plenitude of feelings expressed by the participants. It began on a path that reveals the ontic, until reaching the ontological dimension of the patients faced with death, stripping away any supposition or opinion that could contravene such perception. Interpretative understanding sought to clarify what remained obscure in the discourse through interpretation of the patient's feelings, that is, the sense of being of each individual faced with the revealed phenomena[7]. After the analyses, ontological themes were established and analyzed according to certain Heideggerian analytical ideas, as well as certain suppositions from oncology and authors versed in said themes.

The research was approved by the Permanent Ethical Review body for Research involving Human Beings of the signatory Institution (CAE no. 1.349.763) and designed in compliance with the requirements of Resolution No. 466/12. In order to preserve anonymity, the participants were identified with names of characters from the book "The Little Prince"[8], in which vast thematic content involving interpersonal relationships, existence and criticism of the importance that people confer on material things can be found.

RESULTS AND DISCUSSION

The 11 participants were aged between 40 and 82 and eight of the patients were female. Ten reported that they had

undergone at least one standard antineoplastic therapy and one reported not having undergone any treatment, due to the aggressiveness of the disease.

Analysis of the material enabled identification of a mixture of feelings experienced before the finitude of life, it being possible to convey the thematic units reflecting their fears and suffering before death while immersed in this reality.

Confronting the death-dying process

The understanding of their situation as a being-in-the-world with advanced cancer leads patients to a level of openness to life and to formalize mechanisms to confront terminality[9]. In his book, Being and Time, Heidegger states that in anticipation of death, the *Dasein* [existence] exists authentically, in its totality. Moreover, in the projection of finitude of life, certain mechanisms are adopted for this confrontation, uncovering the innermost of each being, truly revealing the being-in-the-world at this moment[10].

The reluctance to comprehend the approximation of death causes the patient to take time to process their finitude, despite being irreversibly immersed in it. This scenario reveals their internal disorganization, as they begin to forge resources to understand what is happening to themselves, postponing the possibility of recreating their world[11].

This singularity of the Being was analyzed in the work Being and Time and also later contemplated in the studies of the psychiatrist, and reference on the subject, Elisabeth Kubler-Ross. In the work "On Death and Dying", the researcher goes further to also contemplate the temporality in which suffering is experienced. According to the author, suffering is a source of restructuring for the patient, leading them through five emotional stages: Denial; Anger; Bargaining; Depression and Acceptance[12].

These stages do not constitute a rigorously sequential, linear process, as they may occur in different periods in patients, be it in succession or overlapping, which demands individual accompaniment of the patient to alleviate their suffering[13]. These aspects were demonstrated by the interviewees in the present study.

Denial appears as difficulty in the acceptance of terminality, a psychological defense, causing the individual to deny the reality of their death, or even avoiding speaking about it[14]. In Heideggerian work, negative concession makes one see, it is an opening that reveals itself, thereby taking on a function of purification, acquiring a "productive character"[7]. In the present study, the denial stage was revealed at distinct moments during evolution of the disease: at diagnosis, in the first manifestations of the disease and/or upon worsening.

> *I don't keep thinking about the situation, it's worse, I prefer to believe that everything is ok, that I don't have anything (The Lamplighter).*

> *I don't want to think, I don't think, I want to lead life as if I didn't have anything, people put a lot of fear into us (The Fox).*

When the patient gets angry at the world, they feel wronged and refuse to accept what they are experiencing, there occurs a predominance of anger; be it against relatives or with those surrounding them[14].

In Heideggerian analytics, this disposition, or the opening of the Being rises above the past, when it eventually retreats to its have-been-released[15]. This disposition is characterized in humor or affection, representing the ways people express themselves in their being-in-the-world.

The difficulty in accepting the possibility of death can be expressed through humor, in explosions of anger, accusations and isolation[13].

> *You know what pisses me off, there are so many deadbeats that take the lives of others, they do so much bad in the world and don't die, and there's us that try to help others and keep suffering this way (The Vain Man).*

> *When I found out I had cancer I couldn't believe it, it wasn't fair, I didn't deserve it, I didn't do anything, why did this happen? I'd never drunk a glass of beer, never smoked, nothing fit (The Rose).*

When passing through the bargaining stage, the patient tries to negotiate with the aim of minimizing or putting off their death, they try to make a deal so that things can go back to how they were before. It is a desperate attempt to negotiate through religious promises in exchange for a possible cure[14].

> *I believe I'm going to get better, and if I get well, I will keep my promise of going to Bahia to see Father Cicero (The King).*

> *I really believe that God can do anything, I know He will cure me, because as I am seeking a cure, He is part of the miracle, He won't fail, I have an intimate relationship with God that makes me believe in the cure (The Businessman).*

In confronting the incurability of the disease, the patients themselves and their condition are overcome by (un) certainties and moments that are difficult to be understood and controlled, especially fear, which, in the Heideggerian perception, constitutes a forgetting of oneself. This forgetting of oneself provides a movement of the *Dasein* away from its own possible Being. In forgetting, the patients no longer recognize themselves in the world surrounding them. They do not visualize the possibilities around them, because, in fear, people are disturbed before the world, they cannot silence the heart in the presence of themselves, which makes them distressed and troubled[15].

Upon experiencing the depression stage, patients are immersed in their own internal world and isolate themselves; they no longer visualize horizons that were tangible before. So, at this time it is common to experience feelings of incapability given the situation, such that suddenly, they find themselves absorbed by deep suffering, faced with the impossibility of cure, provoking sadness, guilt and fear[14]. In the present study, guilt is revealed in the loss of vitality and becoming the cause of suffering for relatives.

We had our whole lives ahead of us, then soon something like this appears, which is dangerous, [...] sometimes I would just like to live a little more, to see my grandchildren grow up (The Fox).

I was really shaken, because it's awful, I thought that it would never happen to me. I've suffered a lot, I got really desperate (The Vain Man).

I'm afraid of suffering, I don't want my children to see me like this, I still want to see them grow up, I don't want to have to leave them, but everyone who ends up like this is going to suffer (The Three-Petaled Flower).

In the acceptance stage, the interviewees begin to more consciously understand the limits imposed by their illness and manage to express reality as it really is. As such, they present as more relaxed to speak and express the issues related to death. In this stage, they are confronted with terminality, conceiving it as something irreversible and natural in their lives[14].

What can I do? It is in the hands of God, we can't do anything else, it will be as God wishes. What will be for me to go through another will not, we can't avoid it, it is something of everyone (The Pilot).

God knows what he is doing, it is hard, but with Faith in God we can accept it, because we are all going to die, there's no point being afraid, the day has come, and we are going (The Geographer).

The literature indicates that upon receiving shocking news, or entering a process of loss or grief, the individual tends to permeate through the five stages described by Kubler-Ross[12]. However, being with them in this process of imminence of death, we have found that they experience feelings of *regret* and *hope* more comprehensively.

Regret consigns us to mourning for something we did or failed to do, for something we said or failed to say; or occurs even when we mourn for something that has already happened. When speaking about their experiences, the interviewees seem to look for answers to the situation, and in this yearning for answers many see themselves as co-responsible for the appearance or worsening of the disease. Their experiences provoke feelings of remorse, causing them to place upon themselves an impulsive responsibility of causers of their condition.

I loved my lifestyle, but today I regret to the very last hair on my head all the "cachaçaradas" (drinking sessions)*, the damage I did. I lost not only my health, but also my family (The Pilot).*

I didn't do any tests like everyone else; I wasn't worried about my health; I didn't take care of myself. If I'd been worried like I am today, maybe I wouldn't be talking to you about this (The Rose).

I have many regrets, the biggest is having started smoking. I could have avoided all this. Can I give you some advice son? Never smoke, never put one in your mouth, learn from me, look at my situation in this bed, with this "tube" in my nose (The Snake).

In Heideggerian thought, it is through projecting themselves in the direction of the past that people can catch sight of and accept their being-in-the-world[7]. Moreover, in this projection, the *Dasein* also becomes historical, but the historicity does not reside in the simple fact of the Being-in-the-world being the object or subject of their history, but in having a destination. In this case, history does not mean only what has passed, but also its origin and meaning to the person[8].

Upon revealing their regrets, the participants demonstrate the necessity to leave a warning: "don't smoke", "don't do this", "don't do that". This may be a way for them to confront death and leave a legacy. Furthermore, there is hope of not being forgotten and, through their suffering, prevent, or at least contribute to, other people not going through what they are experiencing.

It can be perceived in the language of the interviewees, who have advanced cancer, that at this moment (*ik-stante* — in-state*)* memories of the past (vigor at having been) are re-awakened, even if the past is presented as a negative load[16]. The feeling of hope was widely grasped in the terminal patients and appears as a positive probability of resilience and should not be discouraged, as it contributes to diminishing reactions of fear and anxiety[17]. Some pretexts of hope are notable in the interviewees, who, despite being aware of the gravity of their prognosis, may glimpse a different future. This keeps them firm in the faith that would provide them a cure or the possibility of at least having the disease stabilized, or even, the hope that they won't suffer in order to die.

Who can guarantee me that these three weeks won't be much more? That the doctor didn't work it out wrong, and that these three weeks could be two, three years? So: Live one day at a time, but really live (emphasis) (The Rose).

I haven't lost hope, I'm going to get well, go back to my wife, I've beaten it once, why can't I beat it again? (The King).

In the scope of Heideggerian analytics, it is glimpsing toward a more proper possibility that the people see and adopt their being-in-the-world[7] This brings to the *Dasein* the capacity to precede oneself and, with hope or even their faith, reencounter the clarity of their finitude, making it possible to feel their life restored, especially their own life force[8].

Faced with everyday situations, we perceive that people tend to anchor their hope on issues that are significant to them, whether external, such as family or spiritual; or internal, when the individual puts their hope in themselves.

Given the importance of feelings of hope in the process of confronting disease, its levels have been explored in the literature in individuals experiencing chronic diseases that will consequently evolve irreversibly into death. This was done so as to verify the impact of this feeling in moments of difficulty[18].

Revealing the suffering from terminality

It is natural to suffer for someone who has a serious disease, even healthcare professionals used to dealing with death face disturbing feelings upon seeing the necessities of patients with a terminal disease. However, when this suffering is personal, the patient comes to experiment a vastness of feelings, including deceptions and fears.

It is understood that "Whether privatively or positively, fearing about something, as being afraid in the face of something, always discloses equiprimordially entities within-the-world and Being-in - the former as threatening and the latter as threatened"[7]. Faced with this thought, we observed in the words of the patients how a simply given entity brings with it, beyond the terrifying threat of death, the deception and fear of suffering.

The doctor said that we should treat it urgently because it was already advancing. Hearing that was a blow, I was really afraid, I looked at my children and was afraid to leave them, but even worse was being afraid of suffering (The Rose).

This (cancer) was much worse than the other one, the fear too, especially when I saw the blood (aggressivity of the disease). This time I can't do anything, not even go out in the sun, I can't walk much, so what's the point? (The King).

It comes as a blow when you hear it, but what can you do? I already knew that sooner or later this would happen. There was something in my head telling me that, but we still don't expect it (The Pilot).

Just having cancer is a cause for suffering. However, having advanced cancer inflames this suffering as it incites a confrontation with one's own finitude, generating fear and guilt. The suffering reported by the interviewees, is also indicated in the literature, and portrayed as biopsychosocial effects of moral suffering, for carrying the prognosis of terminality[19].

In accompanying these patients on their trajectory of terminality of life, aspects were found that enable the conclusion that the suffering transcends fear of death. For them, having cancer and feeling its consequences in their bodies is to experience the arrival of death on a daily basis without the weapons to fight it. This suffering is accentuated with the idea of being dependent on family members, or impotent before the limitations imposed by the disease. This is directed towards family members, because in the patients' mind it is them that will have to deal with this suffering.

This analysis corroborates the literature, when it indicates that the family members of patients confronting this stage of the disease are equally susceptible to the same emotional reactions[20,21], due to the overload of suffering they witness and the difficult decisions they face in everyday life.

Finally, it is important to highlight that many patients neglect their authenticity, confronting the loneliness of the path of terminality in the intimate self, so as to spare their family members the "dark" reality of death. For the patient that is exposed to particularly painful thoughts and situations, being able to manifest their fears and anxieties provides a form of comfort and security, attenuating their suffering.

FINAL CONSIDERATIONS

The results of the present study enable understanding of the suffering that emanates from the process of terminality and its consequences in the lives of those who experience it. The Heideggerian phenomenological analysis revealed the sense of finitude of life and the paths followed by the patients faced with this process, demonstrating that each Being experiences their way of being-in-the-world uniquely, singling out their feelings and suffering in their own time. Thus, we understood that the interviewees experienced a distinct temporality in their process of accepting death, such that each one individually uncovered their encounter with death.

Through this phenomenological view it can be identified that the experience of this stage of the disease is permeated by feelings such as denial, anger, anguish, sadness and desperation. However, embraced by the reflection that this theme imposed upon us and immersed in the experience with these patients, we also perceived that the death-dying process is complex, with biopsychosocial alterations to life, not only for the patients, but also for those surrounding them. This is because, as beings-in-the-world, the patients tend to be surrounded by beings that participate in their lives as promotors of feelings,

sharing expectations in regard to the situations that they could experience in the future before the terminality of life. As such, the discourse revealed the concern of the patients with the beings around them. They demonstrated not only fear of their physical suffering, but, above all, fear of being the motive for suffering or feelings of being overwhelmed for their family members, upon stating that they would prefer to die than to remain dependent on someone.

As a limitation of the present study, the period of data collection can be highlighted as it was permeated by Christmas and New Year festivities, which may have influenced reflections on spirituality and a new start (hope). Even so, the results fill an important gap in the literature, as it is very difficult to approach patients at this stage of life. Furthermore, they demonstrate how necessary it is to offer integral, holistic, multi-professional care to the patient experiencing the process of finitude of life; assistance directed at their necessities, which are often not initially expressed, especially those related to their physical, emotional and spiritual needs.

Therefore, it is necessary for professionals to observe patients, to be willing to carry out a differentiated approach beyond establishing diagnoses and prescriptions; an approach that respects the time of the being-in-the-world and their encounter with suffering as a result of the consciousness/science of their terminality.

We hope that revealing the feelings that emerge in the being before the uncertainties of life serves as a prelude to further studies, with the aim of contributing to the care dispensed to the patient, providing comfort and mitigating their most intimate necessities, their concerns, their fears and uncertainties.

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