EXPERIENCE OF A PERSON WITH ADVANCED CANCER: A PERSPECTIVE FROM MERLEAU-PONTY’S POINT OF VIEW

ABSTRACT

This phenomenological study is based on Maurice Merleau-Ponty’s philosophy. It aims at describing the experience of a person with advanced cancer. Data was obtained in the first half of 2009 through open nondirective interview with guiding themes. It then underwent analytical ambivalence, a technique based on Edmund Husserl’s phenomenological eidetic reduction and resulted in the definition of two categories: certainty of death and certainty of life; fear of dying and the courage to commit suicide. The results show the feelings’ ambiguity of a patient suffering from cancer as well as the need for special care and assistance at this stage of the disease, considering the conflicts inherent to physical suffering and the social stigma involved.

Keywords: Philosophy, Nursing; Neoplasia; Chronic Disease; Therapeutics; Oncologic Nursing.

RESUMO

Estudo fenomenológico sob a perspectiva de Maurice Merleau-Ponty, com o objetivo de descrever as vivências de uma pessoa com câncer em estágio avançado. A descrição foi obtida no primeiro semestre de 2009, por meio de entrevista aberta não diretiva guiada por um roteiro com temas norteadores. Em seguida, foi submetida à analítica da ambiguidade, técnica fundamentada na redução fenomenológica eidética de Edmund Husserl, o que resultou na definição de duas categorias, que respondem ao objetivo proposto: convicção de morte e certeza de vida; medo de morrer e coragem de suicidar-se. Os resultados mostram a ambiguidade dos sentimentos do ser com câncer e permitem a reflexão sobre a necessidade de cuidado e atenção especiais à pessoa nessa fase da doença, considerando os conflitos que envolvem o sofrimento físico e o estigma social a que o ser com câncer está submetido.

Palavras-chave: Filosofia em Enfermagem; Neoplasias; Doença Crônica; Terapêutica; Enfermagem Oncológica.

RESUMEN

Estudio fenomenológico desde la perspectiva de Maurice Merleau-Ponty, con el objetivo de describir la experiencia de una persona con cáncer avanzado. La descripción se obtuvo en el primer semestre de 2009, a través de una entrevista abierta, no directiva, conducida por un guión con temas de orientación que luego fue sometida a la analítica de la ambigüedad, técnica basada en la reducción fenomenológica eidética de Edmundo Husserl, que se tradujo en la definición de dos categorías, que corresponden a la finalidad: la convicción de muerte y la certeza de vida; miedo a la muerte y el coraje para suicidarse. Los resultados muestran la ambigüedad de los sentimientos del ser con cáncer y permiten una reflexión sobre la necesidad de cuidado y atención especial a la persona en esa etapa de la enfermedad, teniendo en cuenta los conflictos que involucran el sufrimiento físico y el estigma social a las cuales está sometida la persona con cáncer.

Palabras clave: Filosofía en Enfermería; Neoplasias; Enfermedad Crónica; Terapéutica; Enfermería Oncológica.
INTRODUCTION

A cancer diagnosis is usually associated with great anxiety and feelings of emptiness and abandonment. Patients review moral values and reflect on the meaning of life. Denial is often the first reaction to the disease since patients find it hard to believe they are going through such experience once they suppose it will only happen to others. It is the certainty of a terrible and often incurable disease.

The relationship between cancer and pain, suffering, physical deterioration and the sense of finitude emphasises the importance of care, which must provide emotional support to cope with conflicts and difficulties. Such feelings involve fear of future suffering, of dying, of leaving the loved ones, of forsaking projects, of depending on others, of invasive treatments and their consequences.1,2

In an advanced stage of a serious illness death becomes imminent. At this moment, the main objective is to help patients feel more comfortable and minimize suffering instead of seeking cure and treatments that prolong life.

Cancer is the second most common cause of death in Brazil behind cardiovascular disease, and its incidence is increasing. It is a chronic degenerative disease which may progress slowly or quickly lead to death. Early diagnosis and immediate treatment can slow its evolution or even cure some of its types. Health promotion through individual initiatives and socio-political actions is essential.3,5

Coping with cancer requires health education measures addressed to all population groups. People must be aware of the fact that there is no specific prevention for cancer; therefore regular check-up is essential to early diagnosis. Thus, there must be support and encouragement to the formulation of laws that determine the expansion of the possibilities of monitoring the occurrence of cases, conducting therapeutic actions necessary for the complete cure of the disease, control and attempt to prolong the life of the person, while facilitating the treatment centres to adopt alleviating measures for the associated symptoms.4

The cure of several types of cancer is possible thanks to technical and scientific developments such as surgical procedures, chemotherapy and radiotherapy, especially in early-diagnosed cases. On the other hand, prognosis depends on the stage of the disease, most of all on morphological and structural aspects of the tissue of origin, on the presence of lymph node involvement, and on the degree of involvement of surrounding and distant tissues.5

People usually link cancer to suffering and death, generating stress that can trigger somatic, psychological and social imbalances.

In view of such considerations, researchers sought to identify how people with advanced cancer live the process of existential finitude. The following question guided the present study: what are the feelings of people with terminal cancer?

This article aims at describing the experience of someone with advanced cancer, in order to contribute to planning and implementing health actions addressed to patients at this stage of the disease.

METHOD

Researchers employed the theoretical and methodological phenomenology of Maurice Merleau-Ponty’s philosophy to understand the feelings and perceptions of a patient with advanced cancer. From this point of view, phenomenology is “a philosophy which sustains that the world is always ‘there’ before reflection as an inalienable presence”. The philosopher’s effort would be “to rediscover that naive contact with the world” to grant it “philosophical status.” The author considers phenomenology as the “ambition of a philosophy that aims to be an exact science, but is also a space for exhibition, time and world experiences.” It is, therefore, the resumption of temporal experiences continuously related to the world of perception and, depending on the inter-subjectivity, immanent experiences become trans-scalar and sensitive experiences become objectivity.2

The present study was carried out with a 54 year old white retired Catholic literate married man, nicknamed Mr. Magnesium, born in Bahia (Brazil) and specialized in auto mechanics. His socio-anthropological profile was consistent with the object of study, i.e. suffering from a chronic degenerative disease in advanced stage, requiring constant and direct care of a family caregiver.

The phenomenological approach enables studies with a small number of subjects, even only one person, as in this case. The study’s merit lies in the deep discussion of the subject according to the fundamental principles of phenomenology, especially Merleau-Ponty’s philosophy. This philosopher’s maximum precept is the description of intentional perceived experiences expressed as present feelings carrying a past horizon (temporality) and projecting towards a future one.6

Merleau-Ponty believed that feelings are never individual, but shared as an intercorporeal generality. Fear, sadness, embarrassment and anxiety affect the sensitive nature common to all human beings; therefore, the perception of an individual is also the perception of the others. In this context, the study of Mr. Magnesium’s feelings unveiled a perceptual experience that is not individual but inherent to any human being with advanced cancer.

Mr. Magnesium’s experience was recorded via open-end ed nondirective interview4 with guiding themes. The study observed the National Health Council ethical and scientific requirements (Resolution No 196/1996) regarding human research and was approved by the Ethics and Research Committee of the State University of Southwest Bahia, under protocol No 049/2008. The participant signed the Statement of Free
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and Prior Consent. The interview took place at his residence where he was bedridden, under his wife’s care.

The interview was carefully recorded and transcribed. The interviewers observed non-verbal signals (gestures, intonations, physiognomy, silence, pauses, body movements, information underlying the discourse and affective states and moods). Such elements should not be ignored since they provide important information.

Mr. Magnesium’s experience was described according to the analytics of ambivalence. This method was created for data analysis in phenomenological studies, especially those based on Merleau-Ponty’s philosophy. Its theoretical background is Edmund Husserl’s eidetic reduction which tries to reach the essence through the suspension of objectivist ideas. According to Merleau-Ponty, since essences are perceptions and they reflect a profile of what was experienced (phenomenon) even though never in its entirety, then perception is always ambiguous. The analytics of ambivalence consists in describing the ambiguities revealed by what is perceived.

RESULTS AND DISCUSSION

Mr. Magnesium’s narrative unveiled the incidence of several ambiguities, once it comes from a perceptual experience. However, since academic texts require objectives, two categories were established: “certainty of death and certainty of life” and “fear of death and courage to commit suicide.”

CERTAINTY OF DEATH AND CERTAINTY OF LIFE

The perception that cancer is a disease that if not early treated can interrupt life, reflects the understanding (according to the philosophy of experience) that advanced cancer means the end of the possibility to become another self, i.e. the experience of one’s own body. The body refers to a perceptual experience to itself and to the “I can” experience. Therefore, the idea of the own body is connected to the perception that leads to the experience of “my other self”. In Merleau-Ponty’s philosophy perception is seen from the point of view of the person who experiences it, since the only conclusion is that it is an ambiguous experience with two natures: an impersonal one (feelings), and a personal one (language, thoughts). Mr. Magnesium’s speech demonstrates this ambivalence: while he recognizes the disease as an impossibility to continue living he believes in the chance of being alive keeping his life projects:

[…] this disease is terrible because it is incurable, but I hope to be cured […] I live with it, I fight against it, I hope to live; […] now I want to live, I don’t have those thoughts anymore, I want to live, to work, I am retired, aren’t I? But I want to earn some money, mainly because I want to live in society […]

Sensor-motor systems enable the experience of “the other”. The mutilation of one or both lower limbs limits the possibility of going to and fro, which means, according to Merleau-Ponty, a way of interrupting “the other’s” experience. It explains why Mr. Magnesium’s refuses to have one of his legs amputated: he would rather carry on with the affected limb, allowing social relationships and the experience of becoming “another one”, which is the essential function of perception (one’s own body).

Experiencing one’s own body (perceptual experience) involves five dimensions: the habitual body, the perceptive body, the speaking body, the sexed body; and the other’s body. The notion of habitual body refers to the understanding that the representations and concepts that people create about things are never adequate to define what they really are. Things always appear in profile but this has a background, also called past horizon which encompasses many other profiles. This notion is a paradox of the body, which is similar to the paradox of the world.

The notion of habitual body allows us to understand Mr. Magnesium’s story: he conditions the possibility of carrying on his life projects with the wholeness of his material body. He says: “[…] the doctor wanted to amputate my leg, but I didn’t […] I think if you do so, you are useless for the rest of your life […]” – this means he returned to a body system he may not have been previously aware of. Although we have the whole material body, we never think in its single parts or functions, but when one of these parts is affected, all our attention turns to it. Usually when we grab something with one hand, we do not think about its articulation to the forearm, arm and shoulder. Nevertheless such parts do not perish. This is the idea of the term “phenomenon”, i.e. something that is shown in profile, but drags all others with it.

Thus, although Mr. Magnesium is convinced that his health problem can lead to death, his habitual body tells him to go ahead, which allows him to visualize life prospects: “[…] nowadays I only think about healing and walking, I want to walk again. I still haven’t done everything I want […] I want to work, touch the cows, touch the ground […]”.

Launching oneself into the future guided by the habitual body corresponds to the notion of perceptual body. In other words, it is like moving in two perspectives: on one hand, the body looks for something from an anonymous past, since “all perception takes place in an atmosphere of generality and is given to us as anonymous;” on the other hand, not knowing what the body wants, it transcends to the future, as if launching itself beyond, towards the possibilities.

In this sense, in the updating process, we look for something in the past and if it is not yet formulated, we look for it in the future (where we are not now). This is Merleau-Ponty’s
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Pain is a major cause of human suffering; it threatens quality of life and reflects on people’s physical and psychosocial condition. Since nurses are so close to the patients, they have the opportunity to comfort, relieve pain and improve the quality of life of those in need.11

All nursing professionals should be offered training because the profession demands a more caring stance towards cancer patients. Such care should not be restricted to technological aspects, i.e. it is necessary to see the person who is suffering and not only the suffering.62 This humanizing perspective considers care globally, as an ontological structure of the being.

A deeper understanding of the ambiguity of Mr. Magnesium’s experience leads to assessing the trajectory of the “other’s body” who lives with advanced cancer. There are several moments in which the person with cancer becomes “another self”. Among them experiences of resilience, optimism and spirituality, treatment and metastasis, abstinence, finiteness, pain, suicide attempt, loss of autonomy and independence could be mentioned:

[…] when I received the diagnosis it was very difficult, I cried [...], I cried a lot, I felt very sad, I thought I would hang myself [...], then I got used to it, and started seeing it as any other disease; [...] I hope to be cured, I’ll live with it, I’ll fight against it, I hope I can live; at the beginning I felt very sad, I cried, now I don’t cry anymore; [...] now I don’t feel anything, I put everything in God’s hands! I don’t know how to explain it [...] God knows! [Resilience, spirituality and optimism], [...] I was afraid when one part of the body was treated and it appeared in another part; [...] I had chemotherapy and radiotherapy in my head, in the guts, in the knee [...] it was normal, I suffered when they lost a vein [...] once there were no veins anymore[...] the radiotherapy was quick, it took only five minutes [...] the leg was the most difficult part [...], I had to undergo surgery, it went wrong and I had to be operated again; [...] I need an haemorrhoids surgery, I am suffering a lot [...] if the cancer spread to another place it would be terrible, I would have to go through it all again! [Treatment and metastasis], [...] everything changed, [...] my life changed, it is all different [...] I miss things, except cigarettes and alcohol; [Abstinence], [...] I used to cry because I was afraid of leaving my family, so sad [...] , I was afraid of dying, everybody is afraid of dying [...] when the doctor said I had only a few days of life, I was afraid of leaving my father, my mother, my children, my family; [Finitude]. [...] after surgery I felt pain [...] I called for the nurse but she would take a long time to come, I would cry and think I was going to die [...].

We were considerably touched by this intersubjective experience. According to Merleau-Ponty’s phenomenology the pain of someone whom we interact with is also ours since pain is a common feeling and all humans are susceptible to it.

In Mr. Magnesium’s case, the nurse took a long time to come when demanded. This could indicate he had already received his dose of painkiller. We should highlight that nurses are expected to provide comfort, care and psychological support in order to alleviate the patient’s painful condition.

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The things, the world and us. In describing this experience, Merleau-Ponty indicates the existence of two “rival totalities” that congregate in speech, in an attempt to articulate a notion of the other’s body: a private totality and a social totality. The private totality refers to the pre-objective world; what, in a perceptual experience, is inflicted upon us as a phenomenon. The private deals with the body’s own experience (perception), something that Husserl characterized as a lived experience or temporality and Merleau-Ponty calls “sensitive flesh,” which mirrors the “glorious flesh”. This, in turn, characterizes the social totality, which refers to the cultural or social coexistence.

The “private totality” or “sensitive flesh” is the intentional experience, the feelings, what we re-start at every moment of our lives, regardless of our wishes, and from which we formulate ideas and thoughts. The glorious flesh is the reflective experience articulated with the guidance of the sensitive flesh. This process is always ambiguous and conflicting, because it refers to the intersubjectivity that involves the impersonal (feelings) and the personhood (social demands).

Therefore, the other’s body is not explained, but understood. It manifests itself in a prodigious manner, because everything we value as human beings takes place in our own field, “appearing in the balance of my experience, coming into my world!”. So what was invisible, almost imperceptible and even indeterminate for Mr. Magnesium, became objectively visible after his participation in this study.

FEAR OF DYING AND COURAGE TO COMMIT SUICIDE

Mr. Magnesium’s testimony reveals the ambiguity experienced in one’s own body. On one hand, fear of finitude (fear of dying), which in Merleau-Ponty’s theory constitutes the other’s most radical experience, since it interrupts the exercise of the “I can” and the experience of sexuality – an opening to the other-self. On the other hand, there is an attempt to hasten death which implies an interruption of the other’s experience. So, the ambiguity is unveiled: he is afraid of dying but has the courage to commit suicide. Fear of death leads to anxiety that encourages suicide:

[...] when the doctor said I had only a few days of life, I was afraid of leaving my father, my mother, my children, my family [...]; I thought about hanging myself [...] I looked for wires so as to put my finger in a socket to kill myself [...] I took a blanket and tied it to the bed and started to pull [...] in those moments I only thought about hanging myself.

The fear of dying experienced by Mr. Magnesium makes us see that a person with cancer loses the ability to be opened to the other, in the sense of experiencing sexuality and being opened to coexistence, which is different from genitality. In this study it involved several aspects, among them the awareness of survival and chronicity, the possibility of dying, the intense physical pain, the treatment and its implications, the gradual loss of autonomy/ independence and the restriction to individual freedom.

Fear of dying was exposed as a two-way suffering: physical death due to advanced cancer and emotional death related to the loss of sexuality. Similarly, its chronicity (lengthy and permanent evolution) affects a person in many different ways: deficit in self-concept, loss of independence, changes in roles, social relationships and sexuality. Chronic illnesses lead to successive losses of autonomy and control that generate sorrow, anxiety, sadness, anger and fear.

Learning to live with a chronic illness depends on individual features: on how it is accepted and on what we expect from life. Each person has different demands, and the adaptation to the effects of a prolonged chronic illness is the main demand. Changes in lifestyle and leisure activities are highlighted as one of the difficulties of living with cancer.

[...] I can’t do anything anymore; I go from bed to chair and from chair to bed in other people’s arms [...] before the disease I enjoyed drinking, I smoked a lot [...] I used to hunt[...] it was my favourite job, as well as fishing[...] now everything has changed. I don’t fish anymore [...] my life has changed, the disease changed everything [...]

Changes affect the whole process of living and intensify feelings of anxiety and uncertainty about the possibilities as a human being. These feelings are related to the human condition, “to be released” into the world, a way of referring to their own existential possibilities. According to this author, Dasein (“the way the entity is structured and performs as being-in-the-world and being-with-others”) encompasses various modes of being; one of them is the condition of being released into the world, which is susceptible to death.

In terms of Dasein’s basic state death is conceived as being-towards-the-end. It is an ontological possibility that Dasein must assume, as the possibility of no longer being present. In this light, the phenomenon of death is no longer a mere ending or disappearance but assumes its existential human qualities.

When coping with a disease the attempts to regain health emerge. According to Heidegger the sense of the being is time,
Therefore, the contingency of illness updates a command that comes from the past, is casted into the future and aims at continuing a healthy existence14. In this context, we can understand the ambiguous relation between health and disease.

Imagine an individual before the advent of an illness, living his temporality from profile to profile, i.e. “leading a normal life.” Suddenly, the diagnosis of cancer interrupts that person’s projects. In this circumstance, according to the philosophy of the own body, the person halts sexuality (the opening to the other) and creates an adjustment strategy to deal with the situation. In some cases, this strategy consists in episodes of anxiety, depression, irritability, social isolation and, finally, a discontinuity in life projects.15

Suffering caused by the disease and loss of independence were highlighted by Mr. Magnesium as situations that trigger feelings of insufficiency and inferiority: “[…] when I think about the disease I feel despised, I feel despised because I can’t do anything; I go from bed to chair and from chair to bed in other people’s arms […]”.

The difficult adjustment to disability triggers not only physical changes, but also psychosocial ones. Manifestations of fear due to economic uncertainties and social / professional approval emerge.2

Fear of death is experienced at diagnosis and follows the patient with cancer throughout his fight against the disease. Death is the most frightening event of life, which no one can control or predict. In the present study, the fear of dying was also related to drifting apart from the family:

[...] at the beginning I felt very sad, I used to cry a lot […] I cried because I was afraid of leaving my family, so sad […] I was worried about leaving my family, I was afraid of dying […] I was afraid of leaving my father, my mother, my children, my family.

It is appropriate here to recall Merleau-Ponty’s words67:

It is as essential to me to have a body as it is essential to the future to be future of a certain present. Scientific thematization and objective thought cannot find a single function strictly independent of the structures of existence nor a single “spiritual” act not laying in a corporeal infrastructure. Even more: not only is it essential to me to have a body, but to have one, this one, here.

Being close to the interviewee enabled us to understand the disease’s impact on a patient’s whole life and not only on the patient’s body. We also realized that the experience of fear and suffering becomes part of the human existence and that losses caused by the disease become more frequent and disabling over time.

Physical pain is one of the biggest fears and difficulties faced by someone with cancer and its persistence can generate anxiety, anguish, stress, as well as cardiovascular and respiratory disorders.6 It will eventually be present, either due to painful treatments or due to the disease itself. The sense and fear of pain, fear of death, decreased self-esteem, hopelessness, anxiety and despair are psychological variables that contribute to the suffering. Pain is recalled by the patient as excessive physical suffering that can also cause extreme psychological disorder, even leading to suicide:

[...] I thought about hanging myself […] I looked for wires so as to put my finger in a socket to kill myself[...] my children stopped me, I wanted to die because I was in extreme pain, I wasn’t sad but the pain in my belly was intense […] when that happened I could only think about hanging myself, the devils wanted me to hang myself, I thought of nothing else, it was too much pain!

Suicide attempts reveal the being’s incapacity to bear the burden of living with a serious and disabling health condition. In Heidegger’s perspective, it is Dasein’s desire to be no longer there, in the world, and this awareness could mean the path to reconstruction and resizing of existential perspectives.

The main cause of suicide is depression: 70% of people that commit suicide have depressive symptoms; however, the severity of symptoms does not constitute an additional risk factor7. A comparative study of hospitalized patients demonstrated that the prevalence of depression was higher among cancer patients than among other inpatients.8 In classical psychology, depression is an event in which the person cannot keep a stance of inner acceptance; new psychology would call it a “conflict in intersubjective processes”, considering that there is no perceptual experience inside the material body, but in the relationship, and this is completely external.6

As cancer is a completely external phenomenon (i.e. clinical signs) the person is forced to recognize it. This is an episode that tends to block inter-subjectivity. It reduces the sense of personal worth and favours depression, which may appear early in the disease or after surgery and other treatments, requiring patient’s constant adjustments.

Cancer is one of the most feared diseases primarily because it promotes feelings of fear, anguish and despair. Despite science and technology advances may stop the progress of the disease in its early stages, cancer is still seen as an irreversible process and, in the popular imaginary, its diagnosis means a death sentence. It is linked to extreme pain, suffering and physical and psychological mutilation.19

The stigma attached to the disease tells the world about the reality of a condition that interferes with productive capac-
chronic disease requires a constant struggle to cope with serious, depressive, hostile, anxious, and insecure.21 The drama of experiencing a chronic disease requires a constant struggle to cope with several difficulties such as discriminatory and judgmental reactions, which often lead to self-imposed isolation, making the patient suspicious, depressive, hostile, anxious, and insecure.21

**FINAL CONSIDERATIONS**

The present study provided the opportunity for a reflection on human nature as ambiguous being and on the need for special care and attention to those who live the experience of advanced cancer. The patient’s awareness of his progressive degeneration, of the incurability and the social stigma attached to the disease affects profoundly the sensitive dimension of the person. Therefore, this construct has significant relevance to health, especially for nursing, as it is a science whose root is assistance in any field of activity of the profession, whether in primary care, in home care or in hospital treatment.

Since nurses seek to develop care from the perspective of completeness, in order to understand the person in his biopsychosocial dimensions, they are essential professionals in an interdisciplinary health care team. Nurses are able of producing care for people with advanced cancer, in order to understand their sociocultural background and moral values. Therefore, listening and sharing the patients’ experiences, opinions and ideas in an attempt to comprehend and attend to their demands of care. This means displaying a professional and humanizing attitude that characterizes nursing as science and art.

The results of the study provide evidence that could support the overall assistance to people suffering from advanced cancer, noting that health care in this context should not be directed only to the disease but also to the conflicts that the patients are experiencing, both because of the suffering as a result of treatment or because of the stigma of social discrimination. Thus, it is essential to enable the creation of self-help groups among people with cancer aimed at promoting inter-subjectivity. Such groups could help them raise their self-esteem so - among people with cancer aimed at promoting inter-subjectivity. They could help them raise their self-esteem so that they can cope with the disease. Noteworthy is also the need to sensitize health professionals and managers to adopt effective public policies, based on what is most essential to human beings, the perceptual experiences. The challenge is to systematize these experiences in the pursuit of knowledge in order to incorporate respect for life in its entirety.

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