

Care of cancer patients in the Family Health Strategy: the user's view



Atenção a pacientes oncológicos na Estratégia Saúde da Família: olhar do usuário
Asistencia a los pacientes con cáncer en la Estrategia de Salud Familiar: el ojo de lo usuario

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ABSTRACT

Objective: understand the experiences of cancer patients regarding the care received and the relationship with Family Health Strategy professionals.

Method: qualitative research based on Heidegger's phenomenology held with ten cancer patients living in the coverage area of three healthcare centers in a city in northwestern Paraná. Data were collected at the patients' homes from November 2012 to February 2013 through open interviews.

Results: some patients were faced with the impersonality of professionals and lack of empathy, interaction, and singling in care whereas others had their expectations met since they experienced a comprehensive care permeated with concern, sharing of feelings, and respect.

Conclusions: the understanding of these experiences raises a reflection on the support that is provided in this instance of care and the importance of overcoming impersonal and inauthentic attitudes in order to transcend to a new level of relationship and care.

Keywords: Family Health Strategy. Neoplasms. Oncology nursing.

RESUMO

Objetivo: compreender as experiências de pacientes com câncer referentes aos cuidados recebidos e a relação com os profissionais da Estratégia Saúde da Família.

Método: pesquisa qualitativa, alicerçada na fenomenologia heideggeriana, realizada com dez pacientes com câncer residentes na área de abrangência de três unidades de saúde de uma cidade no noroeste do Paraná. Os dados foram coletados no domicílio, entre novembro de 2012 a fevereiro de 2013, por meio de entrevistas abertas.

Resultados: alguns pacientes depararam-se com a impessoalidade dos profissionais e ausência de empatia, interação e singularização no cuidado, enquanto outros tiveram suas expectativas atendidas, pois experimentaram um cuidado abrangente e permeado por solicitude, partilha de sentimentos e respeito.

Conclusões: a compreensão destas experiências suscita a reflexão sobre a assistência que é prestada nessa instância de cuidados, e a importância de profissionais superarem atitudes impessoais e inautênticas, a fim de transcender a um novo patamar relacional e assistencial.

Palavras-chave: Estratégia Saúde da Família. Neoplasias. Enfermagem oncológica.

RESUMEN

Objetivo: comprender las experiencias de pacientes de cáncer en relación con la atención recibida y la relación con los profesionales de la Estrategia de Salud Familiar.

Método: investigación cualitativa, basada en la fenomenología de Heidegger, con diez pacientes con cáncer de tres unidades de salud en una ciudad en el noroeste de Paraná. Los datos fueron recolectados en el hogar, desde noviembre 2012 hasta febrero 2013, a través de entrevistas abiertas.

Resultados: algunos pacientes se enfrentan a la impersonalidad de los profesionales y la falta de empatía, interacción y singularidad en la atención, otros tenían sus expectativas superadas, al experimentar una atención integral permeado por la preocupación, compartiendo sentimientos y respeto.

Conclusiones: la comprensión de estas experiencias plantea la reflexión sobre la asistencia que se proporciona en este nivel, y la importancia de superar las actitudes impersonales y no auténtico para transcender a un nuevo nivel asistencial y relacional.

Palabras clave: Estrategia de Salud Familiar. Neoplasias. Enfermería oncológica.

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■ INTRODUCTION

Currently, the health care of people with a chronic degenerative disease, including cancer, is characterized by a tendency to shift some of the responsibility for conducting the treatment to the family. Because of this, nursing through the Family Health Strategy (FHS) has become increasingly present in the home of individuals with cancer by establishing a relationship based on the tie and co-responsibility with the community, striving for comprehensive care for the sick and the family unit⁽¹⁾.

The role of health care professionals at their home becomes essential for patients dealing with neoplasia, providing the multidisciplinary team with opportunities to come together and share the difficulties and anxieties of the home environment with the patients⁽²⁾. Such an attitude facilitates the unveiling of the feelings and concerns that patients keep to themselves.

The literature reveals that the cancer patients view as important in their care attitudes that contribute to intensify their own resources, and that give them the strength to keep the meaning, understanding, and capacity to manage their own life and this way keep strong despite the disease⁽³⁾. For these people, expressions of empathy from health professionals are related, above all, to the informational advice that enable self-control during situations experienced in their daily lives⁽⁴⁾.

However, there are also patients who demonstrate the desire to receive special care where there is room for a relationship based on emotional support, rather than sharing their responsibilities and valuing their autonomy⁽⁵⁾. In view of these considerations, it is understood that the only way to identify what is best for the person with cancer is based on attitudes coming from the health professionals themselves, especially when it comes to trying to listen and getting to know their patients so as to initiate an understanding of what is in fact important for each of them⁽⁶⁾.

These considerations are in harmony with new concerns as to caring for patients with cancer, and this study focuses the following question: How do patients with cancer feel when they receive care from the FHS professionals and as they interact with them in their daily lives? It should be pointed out that this reality of care perceived from the perspective of the patients themselves still deserves more attention in the literature because recent studies have shown that accessibility to FHS services is lower than the professionals realize, not to mention that users believe that the number of professionals assigned to Primary Care is still small for its needs⁽⁷⁾.

Moreover, health care professionals have a key role in coping with cancer because when a diagnosis is given of a

serious and devastating disease, what patients and family members want the most is to have a deeper knowledge about the disease and the possible side effects that the treatment can bring⁽⁸⁾. In this sense, this study can act as an important tool in providing care for patients with cancer because, by becoming aware of the intricacies of everyday care, the needs can be overcome that are presented by the FHS professionals, who often cannot take into account the concerns of the patients when planning the actions and programs for health promotion and recovery.

The objective of this study is therefore to understand the experiences of cancer patients regarding the care received and the relationship with the Family Health Strategy professionals.

■ METHOD

This is a qualitative study based on Heidegger's Existential Phenomenology⁽⁹⁾, which makes it possible to focus on the phenomenon in an attempt to understand others in their facticity, considering them in their singularities—man in his existential totality⁽⁹⁾.

This research is part of a dissertation⁽¹⁰⁾ developed together with cancer patients under the care of the FSH from a municipality in northwestern Paraná. The choice of the Primary Health Care Units (UBS) participants was done from the 69 FHS teams in the city, and it was decided to seek patients in the three UBS that had the largest number of teams according to the National Health Care Facilities Register (CNES).

The participant inclusion criteria were as follows: patients over the age of 18 who lived in the catchment area of the three Health Care Units selected for the study who had been in anticancer treatment for more than six months and who had used some UBS service in the last 30 days prior to data collection. Patients who during the data collection period had been hospitalized were excluded. In each of the UBS selected a survey was conducted with the FHS teams of all the patients who met the previously established inclusion criteria.

After identifying the patients, the first home visits were scheduled together with and/or through the Community Health Agents (CHA) to comply with the ethical rules of confidentiality since the UBS is not authorized to disclose the addresses of patients to third parties without their consent. The other meetings were scheduled without the CHAs, which is when the patients shared their feelings with the researcher. The data were collected from November 2012 to February 2013 with an average of three visits being made to each patient.

A socio-demographic characterization was carried out of the patients for the interviews, as well as data collected about the disease and treatments, followed by the guiding question: "How has been the care you receive from the Family Health Strategy professionals?" The number of participants was determined as the analysis of the reports unfolded since it was done together with data collection. Thus, the sufficiency of meanings capable of meeting the objective of the research⁽⁹⁾ was achieved in the tenth interview, which is when the data collection ended.

The interviews were stored with the aid of a digital recorder and later transcribed in full. Nonverbal behaviors manifested by the participants were recorded in a diary so that they could be a part of the analysis together with their actual words.

To capture the full expression of the subjects, it was opted for the individual analysis of each language from a path that unveils the ontic until reaching the ontological dimension of the experiences and feelings of the patients. To do so, it started with a vague and median understanding when trying to understand the daily facts revealed by the patients, being stripped of any assumption or opinion of the investigator that could violate such a perception. This analytical stage seeks the facts that usually the person shares with everyone since they have meanings and essential structures that are still veiled, which make it possible to understand the phenomenon⁽⁹⁾. In a second stage, called interpretive understanding, the objective is to clarify what was still obscure in the languages from the interpretation of its feelings, which is the sense of being of each individual before the revealed phenomena is interpreted, culminating in Heidegger's hermeneutics⁽⁹⁾. After this stage, ontological themes were established and analyzed in light of some of the ideas of Heidegger's analytics, of some assumptions of oncology, and of authors that deal with such issues.

The anonymity of the participants was ensured by using aliases from the book *The Diary of Anne Frank*, a true story written by a 12-year-old Jewish girl in the form of a diary during the days she stayed with her family and friends in hiding on the occasion of Hitler's persecutions⁽¹¹⁾. Her writings are relevant to patients who have cancer because they came from times when isolation, anguish, sacrifice, and fear of death were part of her daily life and her diary was her only confidante⁽¹¹⁾.

The research project to which this investigation is linked was approved by the Human Research Ethics Committee of the State University of Maringá under Opinion No. 435/2011. All participants signed two copies of the informed consent form.

■ RESULTS AND DISCUSSION

The ten patients who lived with cancer in their homes were between the ages of 35 and 77 years old and seven were women. The location of the cancer ranged from the brain, throat, larynx, breast, lung, intestine, and uterus, and of these, three had metastases. The time of diagnosis ranged from seven months to eight years and all of them were undergoing anticancer treatment such as chemotherapy, radiotherapy, or postoperative recovery at the time of the interview.

The account of patients living with cancer in their existence revealed not only the peculiarities of the everyday care offered by the FHS teams, but also their efforts in search of care that could offer safety and autonomy.

Living with the impersonality of health professionals: from diagnosis to treatment

Being diagnosed with a neoplasia in the life of a person, as well as the search of treatments and alternatives against the disease, cause anxiety and concerns that oscillate according to the needs experienced in their daily therapeutic care⁽¹²⁾. At these times, both the family and the health care team play a key role in the lives of patients since they are resources that are available to offer their help and support⁽³⁾.

Man in his daily life existence interacts with other beings in a predominant way, which he calls impersonal⁽⁹⁾. From this impersonal way of living, man does not show himself as he really is, but according to what others say or do. This condition leads him to remain in a fallen state with the others, which means that his involvement with his loved ones around him becomes superficial and without obligations or responsibilities⁽⁹⁾. It should be pointed out that in certain situations healthcare professionals are concerned that their involvement with cancer patients could have repercussions in their personal life, reflecting the suffering from the disease in their daily lives. Therefore, in order to protect themselves from such a burden, health professionals may take on inauthentic behaviors, demonstrating that in these times, they deviate from their essential task, namely, to be a being of care⁽¹³⁾.

In the same way, FHS professionals often allow themselves to get absorb by the everyday experiences, which take on the form of their world and facing the illness and difficulties of patients as if they were trivial. For this reason, patients view themselves as just another element in the daily work of the health professionals, which reveals the perception of an impersonal relationship with them, as reported in the following testimonial:

I went to them saying, "I think I have a migraine!" And when I took the result, he said, "You don't have a migraine, you have a brain tumor! See right here! You are going to have to go to this doctor or this one. Each one does surgery in a different hospital, you choose." That cold and blunt! I understand that you have to break the news, but not like that [...]. The news itself can be devastating to the person. My wife and I didn't fall over backwards because we were sitting down, but it was very hard to hear those words (Pim).

When I found out that I had cancer, I got very upset. I was so angry that I went berserk. Because you have plans, you have goals, you have dreams. And they come and dump on you a disease like this as if it were nothing [...]. I threw my wallet on the floor, I screamed... Because it is too much to absorb at the same time. To lose your hair, learn how to deal with death, because you have to learn how to deal with death—you don't know what is going to happen. They needed to be more sensitive. It is not easy to find out that you have a tumor (Petronella).

Based on these words from the patients, it can be inferred that as they learn to live with the facticity that they have cancer, because of the consensus of expressions inherent to the activity of the FHS, the individuals expect that the professionals at this level of care would express more esteem and regard with them. However, the health care professionals, as they do their work, may in some situations come across as being closed to considering others, expressing this many times in attitudes of superficiality and indifference, which breaks down the possibility of building authentic relationships as they interact with the people around them or that come to them⁽¹⁴⁾.

From the perspective of the patients, in order to overcome this reality, the act of caring needs to go beyond curative attitudes or actions toward reducing the disease's symptoms. It is essential to receive information that allows them to fully understand the disease, since they desire the opportunity to get to know the anticancer therapeutic process and understand the clinical manifestations that this can cause⁽⁸⁾. However, some patients say that when they went to request clarifications about their disease and treatment they received superficial and fragmented information that did not assuage their concerns regarding the illness.

Everything that I asked the nurses, they didn't know. The only answer that they gave me is that they had messed too much with my head in the hospital and that is why I had the symptoms. They could only say that. When it really gets down to it, I think they need to have this desire to tell us

what is happening because, actually, it is harder to explain everything just right than to simply say that they messed too much with my head and that is it (Pim).

It can be noticed from the words of the participants that the lack of a solid communication on the part of the team gave rise to words from an improper Dasein since when they were asked about something, they could only repeat what had already been said⁽⁹⁾. Notice that during the utterances there is no genuine reference to what is said. The information is simply passed along without commitment with the repercussion of the words uttered. This way of being by human beings causes them to exist in a state of permanent lack of commitment, which deprives them of the possibilities of being with others and to exercise their care, because they are not a part of their world⁽⁹⁾.

On the other hand, the ontological tendency of the communication brings in itself the act of the listener to participate in the message transmitted. To communicate with another requires the involvement of those people, a mutual understanding, the support and facing issues that are difficult to be grasped. It is important for the health team to be open to answer doubts while at the same time be sensible so that, together with the patient, they can understand what are the limits of their understanding and what he/she actually wants to know at this moment⁽¹⁵⁾.

Because of this, for the patient's care to be complete and distinct from the others, doses of active listening and empathy are essential during the care, which requires discernment on the part of the health professionals. It is important to keep in mind that caring for patients with cancer and their family is a an emotionally strenuous task for the health care professional since a holistic plan includes being present, being flexible, responsible, and sympathizing to then be able to become truly close to the sick person and consider access to all their needs and concerns⁽¹⁶⁾.

This reality has not been experienced by Nannie, who reveals in her expression the lack of individualization of the care when she needs help from FHS because she says that they viewed her as just another name on the list for needing care.

There was a day when I went to talk with the nurse and I told her that I was under chemotherapy treatment and was not doing well and that it was already the second time that I had gone there and was not able to schedule a doctor appointment. What did she tell me? That no one was better than anybody else and that there were a lot of people in in worse situations needing a doctor's appointment. I understand that there are people in worse straits than I am. I can understand that, but if you are going through

hard times like these, I think that you should receive preferential treatment! And also, if you can't help, at least don't make things worse. When you are sick, you need to be treated with care and kindness, right? (Nannie).

As demonstrated in these words, the patient expected that when she seeks help from the health team that her complaints should be valued by the professionals, which she believes should meet her expectations of improvement amid the complaints reported. Through this bond, the actions performed by the professionals take on esteem because they are seen as attitudes that value the individual and do not forsake them at any time. The healthcare practice based on subjectivity reveals the grandeur of care, which provides access to the innermost desire of every individual when they become ill.

Following this thinking, user-centered care is a possibility in Primary Health Care as long as it is guided by a constant reflection of the practice and conformations of the services, seeking to break the discontinuity of care⁽¹⁷⁾. In the FHS care model, the being-with-others is favored by the proximity by which the team remains in the reality of life of the patients, which is the key to a care that can be a builder of health and a promoter of wellness as highlighted in the next category.

Meeting with care in its authenticity

The being-with expresses ways of being in your encounter with the other that goes back-and-forth between occupation and concern⁽⁹⁾. In occupation, one allows himself or herself to be guided by disdain and by neglect in dealing with others around them; while, when he cares, the way of correlation is established and becomes a being who cares and understands the others around them, thus becoming a being-with-others⁽¹⁸⁾.

Regarding concern, man can follow two possibilities: to take on the other's care and take his place in occupations as in a dominating substitution, or anticipate his existential possibility to not withdraw care, but return it as such, in which case is ante-position liberating⁽⁹⁾. The second form of care expresses the authentic care because it allows the being receiving care to reestablish his walk and ensures the manifestation of all his possibilities of being⁽¹⁸⁾.

When overcoming the concept of care exposed by Heidegger phenomenology to the reality of care directed to the cancer patient, a similar situation is conceived that calls for holistic and humane care, where there is room for communication of feelings, concerns, and questions about the disease, offering a care beyond one imagined by the

patient⁽¹⁹⁾. In this way the attitude of caring becomes a way of helping the individual to improve his life and learn to walk freely along the journey of his illness.

Along these lines, some respondents expressed the recognition and gratitude to those who had been solicitous when providing care that offers support and autonomy, as shown below:

I was surprised. They came here to visit me at home and then brought the nursing staff, the doctor, cared for me, and gave me medication. And I was very happy because I saw that this is how a health care team should really be. Because I think that when you are sick, independently of what the team is, you have to be aware that some can take more than others (Goldberg).

The care I received from the nurses was very good! I can't complain about them! [...]. They all treated me very well, thank God. And the CHAs, I tell you, every time I need to go to the clinic, they always take good care of me. I have nothing to complain about. Every time I need them, they are always ready to help. If I need anything, I'm sure they will do it (Albert).

You are a nurse, so you should know that I pray for you. In my prayers I thank God and ask Him to bless the health professionals, doctors, and nurses. What you guys do can only be done from the heart because it's not easy to take care of someone (...). So it's a profession where you guys are heroes, you know! And I pray a lot for you guys because I was very well cared for (Simon).

This care permeated by empathy and consideration is because of an authentic concern, which corresponds to the real expression of care from one *Dasein* to another. For the free and reciprocal coexistence of presence and co-presence, a caring that comprises and releases the other to be himself is mandatory, so that through this freedom, the other has the opportunity to show what he really is⁽²⁰⁾.

Guided by this opening, the care offered goes beyond the needs expressed and reaches what was not imagined by the patients, causing a unique admiration for sensible and receiving attitudes. The encouragement of the patients to communicate their feelings and enhance their understanding in this experience facilitates the process of care and professional-family relationship⁽¹⁹⁾.

The account of the patients reveals that, when guided by humanist and warm attitudes, care becomes an attitude of companionship where you recognize the feelings that the other experiences and gives way to respect and sharing of feelings.

When you find out that you have a disease like this, your rug is just pulled out from under you. For me, if it had not been for the doctors and nurses at the health clinic, I wouldn't have been able to bear the news. Because, for example, if you discover that you are going to die in 30 days, how do you want them to tell you? Like someone who comes and says, "You are going to die in 30 days!" (with a grave and serious expression). Or like the other person who says, "Oh no! You are going to die in 30 days." (softly, eyes downcast). Or as those who speak like this, "No, it's not like that. Death is like this, in a month or so, it comes." But they speak with affection, that care about them, you know. And that's how I was treated (Margot).

The concern with which the nurse treated people... In the case of your father and your mother, if you need care, it is one thing. But for you to go to the house of a stranger you've never seen, get into situations that I think you can imagine what I'm talking about, the person only does this if they really care, because it's not easy (Peter).

Thus, the health professional *Dasein* in the FHS, involved in this willingness of opening, reveals his can-be more properly when using forms of dialog that build, which, as a way of caring, offer the patient a safe ground where he can feel support in the face of the difficulties to come.

Similarly, when the health professional is committed to his mission to care in a holistic way, he foresees carrying out practices that receive individuals when they seek them in order to create bonds, valuing subjectivity and attention to the unique needs of each subject⁽¹⁷⁾. The effect of this type of care extends its merits also to the Unified Health System (SUS) as a whole, because the patients understand that, by being the team part of this organization, it also is part of the entire complex that is responsible for its care.

I don't let anyone speak ill of SUS in front of me without me defending them because it is very good. We can get everything at SUS. The appointments are marked and kept...it is very good. Nothing has been missing and still nothing is missing. Sometimes I go there just to get a bandage or something, and they receive us well. They always come to visit me. The doctor and nurses are always around (Sanne).

As for health issues, I can't complain. I don't know if it's because I live near the Clinic and know the people, but for us, the health clinic was essential! There are a lot of people who speak poorly about it. It's hard to understand. That's why I say that health is a lottery (Elli).

It is important to mention that the Primary Health Care provided to any patient requires the reorganization of existing practices in order to strengthen public policies and achieve in fact the integration of actions⁽¹⁷⁾. As for the FHS, providing support that goes beyond its own possibilities, where it is possible to consider the unthinkable and put it into practice, leads to a care that because of its execution, awakens in patients its ontic-ontological condition of being.

■ CONCLUSIONS

Upon receiving FHS care, cancer patients experience different care settings because for them, care is shaped not only by the supply of materials and therapeutic resources, but also by the behavior of the professionals. Therefore, while they value the welfare apparatus, given the fragility of the experience they are going through, they long for a more personalized care. The results show that some patients were faced with the impersonality of professionals and lack of empathy, interaction, and singling in care, while others had their expectations met since they experienced a comprehensive care permeated with concern, sharing of feelings, and respect.

The efforts of cancer patients for finding treatment and better living conditions puts to the test the attitudes of health professional *Dasein*, bringing out his impartiality or subjectivity in care. Circumstances are repeated, but the ways of being of each individual are different, since, within their possibilities, they act according to their willingness to be-with-the-other at the time of illness.

According to this thinking, you cannot generalize care. At every step of his actions, man expresses himself individually, which is the characteristic that should encourage health professionals to get to know their patients before carrying out their care activities. Finding authentic care within the scope of the FHS becomes synonymous with achievement during cancer treatment because, from the fact of being-in-the-world to finding authentic care, there is a tortuous journey permeated with mishaps and anguish.

In view of these considerations, this study contributes to a search in improving the care of patients with cancer in the FHS, since, because they are in this instance of care, these professionals will undoubtedly come across such circumstances of action.

Therefore, the care given to patients with cancer should always be guided by their holistic needs that arise during the therapeutic process. Thus, the transition to a new level of health care that gets beyond impersonal and inauthentic attitudes is impactful to the reality of any patient treated for cancer. And the professionals, as they come to under-

stand the fragilities in this field of knowledge and doing, both in times of diagnosis as in any course of treatment, may be sensitive to a new way to take care of/assist these patients. It is important that further studies be done in this area as this is important to support the offer, not only for nursing but for all members of the FHS, of an authentic and personalized care.

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