

Performance of the Family Health Strategy from the perspective of users with cancer

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ABSTRACT

The objective of the study was to understand how users with cancer perceive the performance of professionals of the Family Health Strategy teams (the family health program of the Brazilian Ministry of Health). A descriptive study of a qualitative nature was conducted in a city in the northwest of the state of Paraná. The data were collected by means of semi-structured interviews with nine users with cancer registered with the Family Health Strategy. Two categories emerged from the thematic content analysis, which showed that, from the perception of the participants in the study, the care received is based on the supply of materials and inputs, in addition to clinical procedures, that are considered essential for care. However, the participants resented the lack of attention and interaction with the team. In conclusion, although the participants recognized that the care received includes necessary devices for the follow-up of their disease, they perceived a distancing in the relationship with some members of the healthcare team and the consequent lack of attention to their emotional needs and subjectivities.

Descriptors: Neoplasms; Primary Health Care; Patient Satisfaction; Nursing Care.

INTRODUCTION

The presence of cancer in homes and families is becoming a gradual and evident reality in the world and in the Brazilian scenario. In developing countries, the impact of cancer on the population is estimated to reach 80% among the 20 million new cases expected by 2015⁽¹⁾, making its status as a public health problem unquestionable⁽²⁾.

The current scenario of cancer control has changed, with great emphasis on promoting the prevention

of the disease, early diagnosis, and the experience lived by patients during and after treatment⁽³⁾. In addition, Brazilian Primary Health Care (PHC) has received emphasis by leaders and funding worldwide, and it was accepted as the best alternative for most cases of health promotion and care, both for stabilizing costs and for providing care for users close to their homes⁽³⁾.

In Brazil, with the purpose of ensuring access for users with cancer to all levels of care in the Brazilian Unified Health System, the Brazilian Cancer Control Policy was established to ensure support by health teams for their needs during the whole course of the disease⁽⁴⁾. Primary health care, especially the Family Health Strategy (FHS) is, among other demands, responsible for actions directed to users with cancer and their families, and it must be present at all stages of the disease⁽⁵⁾. Although there is no systematization of the comprehensive care to users with cancer at this level of care, the follow-up of these individuals and their families is performed by PHC by means of home visits (HV), support for caregivers, technical procedures, medical appointments, and emotional care provided to users, among others⁽⁵⁾.

The importance of PHC in the care provided to users with cancer is reaffirmed in a study conducted in the Netherlands, in which it was found that women with breast cancer had sought primary care services twice as often as before, aiming at solving problems associated with the treatment (side effects from therapies) and obtaining psychological care⁽⁶⁾.

It is worth mentioning that the interaction among services of different care institutions is still poor, especially regarding communication for counter-reference^(5,7-8). A study conducted in Denmark found that when patients with cancer start their treatment, they often lose contact with the primary healthcare team, which affects communication between the general and the specialized teams⁽⁷⁾. In addition, continuity of care is often hampered by the inexperience of the primary healthcare team concerning the approach to cancer, resulting in its non-involvement in care⁽⁸⁾.

Therefore, FHS professionals need to establish a relationship based on a bond and co-responsibility with the human being under their care⁽⁹⁾, always taking into account the needs and demands of users and families who live within the FHS coverage area. Consequently, the users' point of view concerning the quality of care received is an essential aspect for the evaluation of services, because it reflects the bond and horizontality of care, in addition to ensuring more safety in established actions⁽¹⁰⁾. It is thus believed that research on the satisfaction of those who use the healthcare service may contribute to improve the quality of care⁽¹¹⁾.

In this respect, the aim of this study strengthens the need for understanding the perceptions of users with cancer concerning the care provided by primary healthcare professionals. This aspect is essential for the improvement of professionals' daily practice, because they must engage in recognizing the users' needs, with a focus on their expectations and individuality.

Therefore, the objective of this study was to understand how users with cancer perceive the performance of the FHS teams.

METHODOLOGY

A descriptive study of qualitative approach was conducted with users with cancer domiciled within the coverage area of the FHS teams in a city in the northwest of the state of Paraná. The city has 71 FHS teams divided into 29 primary healthcare units (*UBS*, as per its acronym in Portuguese)⁽¹²⁾.

The present study sought to include users assisted by *UBSs* that had a higher number of FHS teams, selecting one with four teams and two with five teams, totaling 14 teams approached. A survey of users with cancer was carried out in each of the teams and, subsequently, individuals who were to participate in the study were drawn one by one.

The participants in the study had to be 18 years or older, present physical conditions and preservation of their cognitive status to respond to the questions, and have finished the outpatient or hospital antineoplastic therapy. After the identification of the users, community health workers (CHW) gradually invited each one of the individuals to provide their address and phone numbers for the researchers. After agreement, visits were scheduled by telephone.

Data collection was conducted from April to June 2012 at the users' homes, based on the guiding statement: Tell me about the care provided by the Family Health Strategy during your cancer treatment. Data analysis was conducted simultaneously with the research. Data collection was completed with all nine participants when new facts no longer emerged and the objectives of the study were achieved.

The interviews were stored in a digital recorder and fully transcribed. Data analysis was guided by the steps of content analysis and thematic modality⁽¹³⁾, which consisted in pre-analysis, material exploration and processing of results, inference, and interpretation. At the end, a discussion was held about the data found, with the aim of associating them with the concepts of care technology⁽¹⁴⁾ and the current literature on the theme.

The development of the present study was approved by the standing human research ethics committee of the State University of Maringá under protocol no. 435/2011. In order to ensure secrecy and anonymity, the users were identified by the letter S (Subject), followed by two numbers, one indicating the interviews' order and another indicating the participant's age. All participants signed two copies of an informed consent form.

RESULTS

The nine participants in the study were between 47 and 74 years old, and seven were women. Four were under medical follow-up for breast cancer, two for uterine cancer, one for bowel cancer, another for prostate cancer, and another for larynx cancer. Two categories emerged from their records, as presented below.

Receiving care based on knowledge and instruments: technologies operating the composition of the work of teams

This category encompasses records of aspects that users value in their treatment, and that were identified as related to soft-hard and hard technologies. For these participants, the availability of medical appointments and examinations is extremely important, as they are considered essential for care:

Therefore, they [team] have helped me, so when I am feeling pain, I go there, they talk to the doctor to get some medication, I take it and I get relief [...] Every time I need a form or a medical appointment, I am assisted. (S3, 62 years old)

[...] it was excellent. He asked for examinations, I did them, I gave him, he analyzed them, and soon, I think in about two months, they told me that my surgery was scheduled. (S4, 64 years old)

The users' statements reinforce that, sometimes, the health care is structured according to the resolution of specific problems, which is of great value for those who need it:

[...] there is a small room here in the unit, where every month they supply us with continued-use medication, and they always have them! [...], every time I need a medical appointment, I have one. Yes, it helps. (S3, 62 years old)

[...] when I meet her [the CHW] in the street, and I tell her that I need a certain medication, she writes it down. She is really helpful. They supplied me with all the material I used for bandages! Everything! Everything! They treat me very well; it is well-equipped. (S4, 64 years old)

When questioned about the FHS care, the users mentioned situations of prompt attendance, as well as linking care to the supply of materials and inputs:

Oh! They [team] give me everything they have, for example, gauze, DERSANI oil, medications. Excellent! (S5, 69 years old)

[...] even after the surgery, when I needed diapers, shower chair, they [team] helped me, they supplied me with everything I needed from this unit. (S4, 64 years old)

So, I go there, I ask for gauze for my bandage, they also give me physiological serum, very nice. (S2, 58 years old)

I feel satisfied! Gee, I thank God, because if the doctor had not guessed, discovered, I think I would not be here today! (S9, 50 years old)

Soft technologies permeating care to users with cancer

In contrast to the records of the previous category, a user showed the need for gestures that refer to zeal and dedication in providing care. The importance of being remembered and feeling noticed stands out:

The doctor does not look at us. This is very clear, and I am not lying; he does the same with everybody else, it is not only with me. [...] He may ask for all examinations, the problem is attention. He does not give me

attention. He does not look at you, he does not measure your blood pressure, there is no contact with the patient. (S1, 54 years old).

In addition, some users highlight the importance of the soft technologies, reporting, for example, the value that they attribute to HVs:

The family's doctor used to come at the beginning, when I moved here. He used to come. . . He never came back, neither for me, nor for her [neighbor]. (S1, 54 years old)

I went to the unit to make the bandage, then they told me that they had to come here in my house to make the bandage [...]. I left there, I made the bandage and she [the nurse] did not come to talk to me, so I forgot about it. So, in this respect, I think it is a little bit flawed. A failure! (S6, 59 years old)

On the other hand, the statements also describe behaviors of professionals who, when respecting the singularities of every person, showing empathy and worry, become active members of these individuals' life:

They [team] understand me, for everything I went through. They assist me well, when I arrive there, especially Dr. "J". The girls who know me, they all assist me well [...] Sometimes, they call me here at home asking how I am, and when a medical appointment has already passed the time, they call to notify, they look for [...] They worry about us. I think this is nice, to see that they worry. . . And I am satisfied with everything. (S7, 48 years old)

There [in the UBS] I am well received. I am happy when I go there, I get satisfied. They all know me, they all are happy and pleased to see me. Nothing is missing there. They do a great job! (S8, 74 years old)

Regarding the feeling of compassion and zeal by healthcare professionals, the recognition is present among users, and is expressed by means of appreciation of the workers' characteristics, in addition to feelings of affection and gratitude:

Since I moved here, I was transferred to here, they are polite women, different doctors, you know, they are all polite. So, I cannot complain about them here [...] they have so much patience and calm to explain things for us. (S9, 50 years old)

When the CHW discovers that I have a problem, she says: "Oh, but we will try to solve this for you, sir." It is very nice. . . She is so nice, poor girl [laughs]; she is an excellent person. (S3, 62 years old)

The service is very nice there, I like it. Everybody treats me very well there. Everybody knows me there [...]. And that is why I am really satisfied, because they help me a lot. I do not know what it would be if they did not help me. (S2, 58 years old)

Yes, they are really helpful. I just have to thank, because we only see where love is when we are in pain [laughs]. They are like my family. (S4, 64 years old)

DISCUSSION

Historically, the establishment of the health care model remained based on hard and soft-hard

technologies, producing an organization of services directed to medical appointments, where clinical knowledge imposes upon other professionals' work and the production of care ends up based on such technologies⁽¹⁴⁻¹⁵⁾.

Regarding the care provided to people with cancer, the researchers found that efforts have been directed towards the cure of the disease, that is, focused on high technological interventions based on treatment, which kept PHC as marginal in antineoplastic therapies⁽³⁾. Combined with such an outlook, patients with cancer feel safe with the available technological devices, because although there are chances of cure for cancer when previously diagnosed, they have to deal with the possibility of recurrence and metastases, raising feelings of fear of death, prejudice, and social discrimination⁽¹⁶⁾.

In this respect, the use of hard and soft-hard technologies for a better diagnostic accuracy and improvement of treatments is of utmost importance, with a continuous development of new therapy and care methods⁽¹⁷⁾. The use of technology in these situations occurs in a subordinate space, where the interaction between professionals and patients is supported by the undertaking of procedures, and the bond with another human being becomes with an examination, a medical appointment⁽¹⁴⁾.

As described in the participants' statements, when providing care based on relational technologies, some CHW end up with their work embedded in the biologic model of intervention, making reference to hard technologies that do not have enough power to implement a technological transition in their health team. Therefore, the care remains guided by the previous model, imprisoned by dead, established, and organized work⁽¹⁴⁾.

When working in patients' homes, professionals may use soft technologies, as well as develop their creative ability to solve health problems with more power, and also interact better with the knowledge-caregiver of families⁽¹⁴⁾. However, it is worth mentioning that although CHW are PHC workers who have more contact with users in their homes through HVs, their professional category was found as that with lesser previous work experience with patients with cancer⁽⁵⁾. This might limit their possibilities of performing in the face of the complexity of neoplasms, and perpetuating the bureaucratic sanitary care culture.

In these cases, the care dimension of assistance, within the hegemonic logic of the neoliberal medical model, is reduced to a role that does not consider the users' needs in a holistic way, although they do not always perceive the need for care. Despite the satisfaction shown by users, it is possible to identify that their expectations are based on the specific need to solve their physical health problem, but not without considering their expectations and feelings. Therefore, depending on the time experienced by them, it might be necessary to approach other technological aspects, aiming for a more integral and decisive care.

In this respect, some records show the perceptions of users who require an individualized contact with the healthcare team. For them, the proximity and empathy with the team might affect their daily routine and quality of life by means of a differentiated care. Such a perspective is supported by the FHS proposal in offering health care based on the physical and social environment of users and their families. The use of professional practices that extrapolate the curative context is imperative, with different technological

resources available for this purpose⁽¹⁸⁾. This type of work is understood as soft technology, which establishes relationships of interaction and subjectivity, and may be present in healthcare models⁽¹⁴⁾.

From the PHC perspective, soft technology is necessary among health actions, because it is able to extrapolate barriers and implement a comprehensive care. Providing care based on comprehensiveness as a PHC essential attribute meets the need to appreciate individuals' subjectivities, and this is the maximum possibility of establishing care interventions based on users⁽¹⁸⁾. These relationships are extremely important for care, because their absence might cause damage to the development of bonds, hosts, and accountability^(15,19).

For users with cancer, the absence of healthcare professionals in their homes represents a gap in the care for their needs, since all mishaps and suffering concerning the fight against the disease are present inside their homes. It is worth mentioning that the undertaking of HVs by the FHS members is an essential tool for overcoming behaviors of indifference and little interaction, and it consequently helps in the performance of PHC actions⁽²⁰⁾.

Being present and having active participation in the individuals' lives are imperative actions for public health, in addition to demonstrating dedication to patients' problems. Although the culture of users and their families is focused on biomedical care, the achievement of seeing to their needs remains far from what is expected. This causes them to express their dissatisfaction regarding the practice of healthcare professionals who do not fully develop relational aspects involving the soft technologies that are inherent to care. Therefore, in their care, users seek the simultaneous use of soft-hard technologies, which are represented by medical appointments and diagnostic examinations, and for soft technologies, when showing the need for gestures that refer to zeal and dedication in providing care.

A friendly glance, manifestations of affection, and sensible listening are pillars of maintenance of affection between professionals and users, because they qualify the care provided regarding needs, making its perception positive in the presence of such behaviors. In this understanding, the exclusive concreteness of the hard technology is overcome, giving space to actions that are subjective or not, but that have care as a purpose, by means of soft and soft-hard technologies in the maze of care⁽⁵⁾.

The way relationships between professionals and users of healthcare services occur is essential to providing care. When this relationship is based on live-action work, that is, the professional counts on high degrees of freedom, thus better performing the necessary creativity for health care and strengthening the relational aspects of their work⁽¹⁴⁾, the opening for finding care that meets the users' real expectations is promoted.

What determines whether a technology dehumanizes and transforms care into an object is not only the technology itself, but especially how it is used in the care context⁽¹⁰⁾. In order to overcome the existing hegemonic medical model, the management of healthcare organizations in a more collective way is necessary, with a coherent reorganization and healthcare actions based on a "users-focused" logic—that is, grounded on the establishment of bonds and in the care of individual and collective needs⁽¹⁵⁾.

FINAL CONSIDERATIONS

Considering the results of the present study, it was found that the use of hard and soft-hard technologies towards the cure of cancer has its relevance. However, it is clear that the participants aim for a “users-focused” performance of the FHS based on soft technologies, because they show the need for behaviors that refer to zeal and dedication from professionals when providing care.

From this perspective, for users, the presence of devices that help in diagnosis and treatment is of utmost importance, in addition to the availability of material inputs that meet their demands. The soft-hard technology must permeate the health care as a whole, by means of an association between scientific knowledge and professional responsibility with individuals who need care. Furthermore, in this context, the correct use of soft technologies is, at the same time, tool and strategy able to promote a holistic care to users with cancer, allowing these individuals to have support and not feel alone in confronting their health status.

In this respect, the comprehensive and empathetic care provided to patients with cancer, especially in their homes, is characterized as a challenge that permeates the care provided in the FHS context. Therefore, healthcare professionals, especially members of the nursing team, may be more present in the users’ daily life, and obtain support to promote comprehensive actions that might effectively help them and their families in confronting cancer.

There are gaps that remain regarding care for the real needs of individuals and their families. Nevertheless, the results of the present study may confer support for all those who work in the FHS, and for all nursing professionals who stay with patients during their cancer treatment, aiming at making them reflect, continuously, about the technologies being used in their process of work. In addition, it may enable them to identify weaknesses in their own performance.

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