



Practices of healthcare professionals from the perspective of older adults living with cancer

Práticas de profissionais de saúde na perspectiva de idosos que convivem com câncer

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Objective: understanding the care practices of health professionals caring for older adults living with cancer in outpatient treatment. **Methods:** a qualitative research conducted in a hematology oncology outpatient clinic in southern Brazil. A semi-structured interview was conducted with 15 older adults. Data were submitted to thematic analysis. **Results:** a category of care practice of health professionals amongst older adults living with cancer emerged with two subcategories: disclosure of the disease diagnosis and authoritarian educational practices. **Conclusion:** despite the existence of legal instruments made available to users of healthcare services, healthcare professional practices are still based on asymmetric relationships through which they place themselves as the only ones responsible for the care of the older adults, demanding adherence to their prescriptions without question, and disregarding the older adult's care of themselves.

Descriptors: Aged; Neoplasms; Personal Autonomy; Nursing Care; Nursing.

Objetivo: compreender as práticas assistenciais dos profissionais de saúde com idosos que convivem com câncer em tratamento ambulatorial. **Métodos:** pesquisa qualitativa, realizada em um ambulatório de hemato oncologia do Sul do Brasil. Realizou-se entrevista semiestruturada com 15 idosos. Os dados foram submetidos à análise temática. **Resultados:** emergiu a categoria: a prática assistencial dos profissionais da saúde junto aos idosos que convivem com câncer com duas subcategorias: a revelação do diagnóstico da doença e práticas educativas autoritárias. **Conclusão:** mesmo diante dos instrumentos legais à disposição dos usuários dos serviços de saúde, as práticas dos profissionais de saúde ainda fundamentam-se em relações assimétricas, por meio das quais colocam-se como os únicos responsáveis pela saúde dos idosos, exigindo adesão às suas prescrições sem questionamentos, desconsiderando o cuidado de si.

Descritores: Idoso; Neoplasias; Autonomia Pessoal; Cuidados de Enfermagem; Enfermagem.

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Introduction

One of the great challenges of public health is the aging population. Changes in the demographic profile are accompanied by epidemiological changes, characterized by a higher incidence of chronic diseases, including cancer. In 2030, the global estimate is that there will be 21.4 million new cancer cases with 13.2 million deaths. In Brazil, the valid forecast for the years 2014 and 2015 foresees the incidence of approximately 576,000 new cancer cases per year, reinforcing the relevance of the problem in the country⁽¹⁾.

More than half of patients diagnosed with cancer are older adults, with a growing trend in this number⁽²⁾. The development of cancer is linked to the cellular aging process. As the years go by, external aggressions generate a build-up of damage in genetic cell coding, favoring the development of the first cells responsible for malignant tumors. For this reason, old age is a risk factor for the onset of most common malignant neoplasms⁽³⁾. Thus, the need for additional and efficient actions of health promotion and disease prevention becomes obvious, especially in the form of laws and regulations in order to allow for enduring quality care.

Over the centuries, cancer was considered a disease to be hidden and silenced. Despite the advances in health care and the higher number of effective treatments, cancer is still associated with being a fatal disease, producing feelings of pain and hopelessness in patients and family members⁽³⁻⁴⁾. Patients experience many changes in their daily lives resulting from the treatment of cancer and its stigma⁽⁵⁾. For older adults, this is an even more complex situation, because along with the diagnosis, prognosis, treatment and all the stigma of the disease, they still have to live with age-related anatomical and physiological changes, as well as old age stereotypes present in society.

Old age can be an extremely difficult time for some people, many of them cannot adapt to the

physical, psychological and social changes that occur in this stage of life. A major difficulty lies in the feeling that accompanies the process of loss and physical decline, of deep reflections on life and the proximity of death. Added to this, in today's society aging has been synonymous with unproductiveness⁽⁶⁾.

Consequently, aging and experiencing a chronic condition such as cancer by itself can lead to loss of autonomy for older adults. Preserving autonomy and independence at an older age is a key goal for individuals and society, constituting a central component of healthy aging⁽⁷⁾. However, aging is surrounded by prejudices that influence the health care directed at the elderly. Health professionals often undervalue the ability of older adults in making decisions by providing superficial information about their treatment and diagnosis, thus preventing them from exercising autonomy over what they think would be best for their own care⁽⁸⁾.

Autonomy of health service users is a need and promoting increasing autonomy is a responsibility of health professionals⁽⁹⁾. Autonomy is a key factor in self-care, enabling individuals to be independent about the decisions for themselves, about their body and their mind⁽⁴⁾. Dialogical and participatory care, health education and information are conditions that empower older adults in caring for themselves.

Given the above, this study aimed at understanding the care practices of healthcare professionals for older adults living with cancer in outpatient treatment.

Methods

This is as a qualitative study which took place in a hematology oncology outpatient clinic of a university hospital in southern Brazil. Participants were 15 older adults who had been diagnosed with cancer.

The selection of subjects for the study sample was carried out by analyzing the medical records of patients undergoing outpatient chemotherapy treatment and applying the following inclusion

criteria: being an older adult (60 years or more), having cancer, be receiving treatment for a minimum period of three months, having comprehension skills and verbal communication ability and having knowledge of their cancer diagnosis. The time criterion of treatment was established by adopting an initial time limit for the older adults to experience the diagnosis and treatment. Older adults who were finishing the treatment cycle at the time of the initial approach were excluded.

Older adults were then invited to participate by observing the established inclusion and exclusion criteria. After clarification of the objectives and methodology of the research, data collection was scheduled. The interviews had an average duration of 50 minutes and took place in a hematology oncology outpatient clinic from February to April 2010; they were conducted by the main researcher, recorded and transcribed with the permission of the participating older adults. The collections were suspended when a saturation of data was achieved, which was determined by repeated responses and satisfactory achievement of the proposed objective.

The interview followed a semi-structured guideline composed of two major axis: sociodemographic data of respondents (gender, age, marital status, origin, education, number of children, main professional activity that they are or were involved in, income, who they reside with, health problems and treatment time) and guiding questions related to the objective of the study (participation in health care and aspects related to living with cancer).

Data were submitted to thematic analysis, with one of the methods for content analysis based on the regularity of statements, in this case denoting relevant structures, reference values and behaviors present or underlying in the statements. After reading, the material was grouped into fragments that were repeated and/or contained semantic similarity in different testimonies, followed by categorizing the components of each theme, thereby completing the three stages of analysis: pre-analysis;

material exploration and analysis of the results and interpretation⁽¹⁰⁾.

The study complied with the formal requirements contained in the national and international standards of regulatory research involving human subjects.

Results

The study subjects consisted of 15 older adults, eight females and seven males. Their ages ranged from 61 to 84 years. Regarding education, two were illiterate, 12 had incomplete primary education and one completed secondary education. Regarding marital status, ten of the participants were married, three were widowed and two were divorced. The older adults were retired, with income between one to four national minimum wages (estimated value at the time being R\$510.00 to R\$2,040.00, equivalent to approximately \$272.00 to \$1,090.00USD). Regarding the type of cancer, six of the participants were undergoing treatment for breast cancer; five for prostate cancer; one for colon cancer; one for lung cancer; one for skin cancer and one for pancreatic cancer.

From analyzing the interviews, a thematic category emerged: care practices of health professionals caring for older adults living with cancer in outpatient treatment, along with two subcategories: disclosure of the disease diagnosis and authoritarian educational practices.

Disclosure of the disease diagnosis

The older adults participating in the study reported how the diagnosis disclosure went: *The doctor told me straightforward what the diagnosis was. No one ever hid anything from me, I asked about everything, even when the tests showed nothing, they came back as benign cells. Then one day I went to the doctor and he said: 'It's cancer. It one of those that kill slowly if not treated. It's not one of those violent cancers that kill within three or six months. You have many years of life ahead, but your diagnosis*

is cancer.' The doctor was surprised at me, at my reaction, at my age I was alone, but he told me straightforward (P2). About ten years ago I heard it through the doctor, it wasn't possible to do the surgery (P3).

The attitude of the health professional in objectively disclosing the diagnosis to the older adult was an exception in this study. Of the 15 respondents, two were made aware of the diagnosis prior to the family, while 13 were told after the family: *They only they told me what I had after, after the stitches were removed. I wasn't frightened; I was already suspicious because nowadays everything is (cancer). So I thought this could be malignant, and it was. The children already knew, he told them quickly, but I only knew the day I went to get the stitches out. Four of my children went with me, they already knew, they were afraid that I would be frightened, in shock. But no, I said, 'ok doctor, that is what I was imagining. And I'm not afraid to die. I'm afraid to die suffering' (P1). He called my husband to speak to him in private, but when he was going to tell him I entered the room and he didn't say anything, then I felt very suspicious. The exams came and confirmed it. The doctor even said, 'Look, it's cancer!' At that time, I felt weak. And right then I said that God was greater than it all, because I have Divine protection, and I do (P8). He (the doctor) asked to meet with my daughters after the results of the second biopsy came (P14). He (the doctor) did not tell me what I had, I only knew I had three nodules in my pancreas; they took a piece of my spleen, a piece of intestines, I spent twelve days without eating or drinking (P15).*

According to the testimonies of the older adults, diagnosis, prognosis and treatment had already been discussed between the doctor and family members. It is noticed that the family and health professionals chose to hide the diagnosis from the patient with the intention of saving the patient from suffering from bad news. In these cases, individual autonomy is underestimated, going in the reverse direction from the emerging proposals for expanding the routine practices of health services in respecting the autonomous decisions of individuals. For older adults, this issue still deserves further discussion, since the legal criteria regarding age should not mean presence or absence of individual competence for making decisions.

Experiencing a diagnosis of cancer can trigger

a series of feelings, especially negative ones, of helplessness, hopelessness, fear and apprehension, which are not restricted to patients and their families, but expanded to all those around them. This fact is evident throughout this study from the troublesome condition generated by the term 'cancer,' as it was expressed in participants' testimonies: *Sometimes I feel like stopping all these chemo sessions, because I feel like I have nothing more to give, I think that I don't have the bad disease anymore (cancer) (P1). Finding out about the disease (cancer) did not change my life in anyway, I'm not afraid to die (P3). I found out about the disease (cancer) now, I came here to do a biopsy, I'm doing the chemo (chemotherapy sessions) to see if it (cancer) dries out, if it diminishes. Because this tumor (cancer) that I have here didn't start today (P4). This problem (cancer) got me in the prostate (P5). I think something changed after I found out about this disease (cancer), my body seems different (P12). I have a prostate problem (cancer) (P13). I went to get examined because my nephew had the problem (cancer) and I went to check and I found out that I had the same problem (cancer), too (P14).*

Authoritarian educational practices

In addition to the ethical discussions regarding the disclosure of cancer diagnosis, this study observed the relationship of power exercised by health professionals regarding the self-care of the older adults who are living with cancer, as can be identified in the following testimonies: *I eat little and I eat according to what the nurse tells me. I eat what I should eat, only beans, rice, pasta. I can eat cassava, potatoes and carrots and beet salad, cauliflower, everything boiled, nothing raw. I do not eat tomatoes (P1). It's all well taken care of, according to what the doctor says (P5).*

In the testimonies, the older adults claimed that they follow the health professionals' recommendations, without questioning them about the reason for the need in changing habits. But often, in their fragility, the older adults do not perceive themselves as a person with autonomy to ask questions and make suggestions, passively accepting what is imposed by feeling, and in many situations, being ashamed or embarrassed: *When I went to see the doctor I was almost paralyzed.*

I felt pain in my legs, in my whole body, to pee too, sometimes there was some blood in my urine. Then I started to have some tea, it cost \$98 (the price of the specific prostate antigen) and then went to \$17. I had Cambara tea, even the doctor was surprised, I make it from tree bark. I didn't tell the doctor, I was embarrassed to. I was prescribing my own treatment, what was he going to think? (P13).

It is observed that the older adult kept the use of tea secret in fear of it being disapproved by the doctor. This fact shows that the dialogue between the patient and the health professional is fragmented and sometimes even non-existent. The testimony also reveals a fundamental cultural issue: the patient, older or not, nourishes the expectation that the health professional, an expert in the area, has more capacity in decision-making. In this relationship (professional-patient), it is clear that the second is being submissive to the knowledge of the first.

Conflicts between professional practice and the patient's right to decide and give an opinion on behalf of their own interests in relation to their health were constant in the group studied. *When I went to see my doctor, he told me I was fat, trying to make conversation. I could not eat and he said it was good because I was fat. I lifted my shirt and showed him my stomach; it felt like I was pregnant. But the doctor did not believe me. He saw that I was losing weight, going yellow. Then I asked him: 'Doctor, will I get better or not?' And he replied, 'will it make a difference if you know that?' (P15).*

The neglect of the symptoms reported by the patient demonstrates the little importance given by professionals about the symptoms manifested by the older adult. By ignoring her report, the professional disregards her self-knowledge. Thus, the doctor does not recognize that the older patient is able to acknowledge themselves and their needs, making it even harder for their professional practice; older patients' knowledge in addition to their professional expertise could enable identifying the problem and selecting procedures to solve it much quicker. The testimony also shows that the professional denied the patient information about their prognosis, limiting their participation in the therapeutic process. This situation shows that there is no room for dialogue

and that the professional-patient relationship did not take place, which can have a negative impact on the continuity of care.

Discussion

In this study, the family acted in the role as intermediaries for the disclosure of the cancer diagnosis provided by health professionals. These data converge to those obtained in Singapore where the rate of non-disclosure of diagnosis was 23.0% for patients compared to 2% for family members. The same study pointed out that non-disclosure occurred mainly in patients of an advanced age (≥ 70 years)⁽¹¹⁾. This reveals that diagnosis disclosure for cancer patients has a key role in the adaptation and the ability to cope with the disease. A study conducted with terminal cancer patients concluded that the disclosure of detailed information about the disease contributed to improving the quality of communication between health professionals and patients⁽¹²⁾. Providing necessary information, diagnosis, prognosis and treatment options, regardless of the consequences the disclosed information may have, is considered to be an ethical obligation of professionals, to respect individual autonomy⁽¹³⁾.

In the case of diagnosing cancer, emotional impact caused by the disclosure is evident. Therefore, this moment should take into account the psychosocial and spiritual conditions of the individual, their values and principles, as well as the appropriate language for communicating their disease in order to avoid disciplining and alienating the older adult in relation to the decision-making process regarding their health⁽¹⁴⁾. In this study, non-disclosure was conceived as a form of protection for the older adult. By adopting this paternalistic attitude, professionals and family do not value the older adult's judgement to exercise their own self-care⁽⁸⁾.

The right to autonomy for the older adult who is living with cancer in outpatient treatment was not fully respected. This assertion is based on the

perception that health professionals were not sensitive to the needs which are considered important for the older adult, whether they are support, information or specialized care. Thus, older adults find themselves being misunderstood and not having autonomy, characterizing a conflict between the professional practice and the patient's right to decide and give an opinion on behalf of their own interests.

It was observed that the nursing staff remained largely focused on authoritarian educational practices and on unilaterally selected knowledge understood as necessary, based on technical criteria and contradicting ethical and bioethical principles of professional practice^(13,15). The established relationships, techniques, procedures and routines that are part of health services cannot disrupt the exchange between professionals and older adults⁽¹⁶⁾. Moreover, despite nurses recognizing their key role in the disclosure process of cancer diagnosis⁽¹⁷⁾, the involvement of these professionals in facilitating the adaptation of the older patient and their family in facing this new reality was not observed, which could promote more comprehensive and humane care.

Based on the data obtained in the study, it is important that the population in general is more efficiently informed about their rights regarding their position as healthcare service users. Specifically regarding older adults, the Elderly Statute⁽¹⁸⁾ refers to the entitlement of health service users to make choices between the available health treatments. Article 17 of the referred Statute states that "the older adult who is in control of their mental faculties is assured the right to choose the health care that seems more favorable to him"^(18:14). However, in order to be able to choose the treatment, older patients need to be informed and guided about the therapeutic options.

In the National Curriculum Guidelines for the Nursing Graduate Course⁽¹⁹⁾, article 4, item I, states that professionals must perform their services within the highest standards. Such standards include the quality of care and service based on the principles of ethics/bioethics, taking into consideration that the

responsibility for care does not end at the technical act, but only with the resolution of the health problem. These guidelines emphasize humanized training, in which the person is understood in all their existence as a citizen possessing rights. However, we find that it is still necessary that bioethical issues be worked on daily in health services⁽²⁰⁾.

The limitations of this study are related to the qualitative approach, linked to the particular nature of the sample of older adults, meaning older adults living with cancer being treated at a hematology oncology outpatient clinic of a university hospital in southern Brazil, which in turn limits the generalization of data. Concomitantly, we believe that further studies are necessary to further investigate the health professional practices with older adults based on the perception of professionals. This understanding could evidence different practices and formulate new alternatives from those presented here. Despite these limitations, we believe that the outlook presented herein is important for actions targeting older adult patients living with cancer.

Conclusion

The practices of health professionals providing care for older adults living with cancer in outpatient treatment are based on actions in which family members play the role of intermediaries in disclosing the cancer diagnosis provided by health professionals. Non-disclosure of the diagnosis was conceived as a form of protection for the older adult, disregarding their decision making ability in exercising self-care. It was recognized that communicating the diagnosis of cancer has a key role in the older adult's adaptation and ability to cope with the disease.

The right to autonomy among older adults who experience cancer outpatient treatment was not fully respected, as health professionals were not sensitive to the needs which they considered important, whether those were support, information or specialized care. Thus, conflicts between professional practice and

older adults' right to decide and give an opinion on their own interests in relation to their health were evidenced.

The nursing staff remained largely focused on authoritarian educational practices and on knowledge unilaterally understood as being necessary, based on technical criteria, thereby contradicting ethical and bioethical principles of professional practice. In addition to this, there was no involvement of nurses in order to facilitate the older adults adapting to experiencing the diagnosis and treatment of cancer.

In general, it is important that the population is more efficiently informed about their rights regarding their position as healthcare service users. Discussion regarding bioethical aspects of assistance to older adults who experience cancer should be encouraged in the training of new professionals and in everyday practice of healthcare services in order to promote comprehensive and more humanized care.

Collaborations

Rocha LS, Beuter M and Neves ET contributed to the conception and study design, data collection, critical analysis, data interpretation, article writing and final approval of the version to be published. Both JE, Perrando MS and Venturini L contributed to the writing of the article and final approval of the version to be published.

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