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Personal autonomy of patients undergoing chemotherapy at the Instituto Nacional de Câncer

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Abstract

Patients are ensured personal autonomy through access to information and full knowledge of their health and treatment options for fully-informed decision-making. This qualitative study investigates how oncology patients perceive respect for their personal autonomy during chemotherapy. Data were collected by means of interviews with patients initiating drug therapy, followed by content analysis based on the bioethics of protection for presenting and discussing the results. Network and services organization of low quality can limit personal autonomy. Due to religious precepts or trust in the expert, as someone who holds specialized knowledge, patients may end up leaving decision-making regarding their treatment options to the professionals.

Keywords: Bioethics. Cancer. Personal autonomy. Oncology. Drug Therapy.

Resumo

Autonomia de pacientes em quimioterapia no Instituto Nacional de Câncer

A autonomia do paciente deve ser garantida pelo acesso à informação, sendo preciso que ele saiba de tudo que se passa com sua saúde e conheça as suas opções, para tomar decisões a partir do entendimento do que é melhor para si. O objetivo deste estudo é compreender, na perspectiva do paciente com câncer, em que medida há respeito a sua autonomia durante o tratamento quimioterápico. Trata-se de estudo qualitativo, feito a partir de entrevistas com pacientes no início da quimioterapia, com análise de conteúdo a partir dos parâmetros da bioética da proteção para apresentação e discussão dos resultados. Evidenciou-se que a carência na qualidade da organização da rede e dos serviços pode limitar a autonomia. Além disso, as escolhas do próprio paciente, baseadas no sistema religioso ou na confiança do perito, enquanto detentor de conhecimento especializado, podem fazer com que o processo decisório a respeito das opções de tratamento seja delegado aos profissionais.

Palavras-chave: Bioética. Neoplasias. Autonomia pessoal. Oncologia. Quimioterapia.

Resumen

Autonomía del paciente sometido a quimioterapia en el Instituto Nacional del Cáncer

La autonomía del paciente debe estar garantizada por el total acceso a la información sobre su salud y sus opciones para una toma de decisiones basada en la comprensión de lo mejor para sí mismo. Este estudio pretende comprender, desde la perspectiva de los pacientes oncológicos, si se respeta su autonomía durante el tratamiento de quimioterapia. Se trata de un estudio cualitativo realizado desde entrevistas con pacientes al inicio de la quimioterapia, con análisis de contenido basado en los parámetros de la bioética de la protección para presentar y discutir los resultados. La falta de calidad en la organización de la red y los servicios puede limitar la autonomía. Además, las propias elecciones del paciente, basadas en el sistema religioso o en la confianza en el experto como poseedor de conocimientos especializados, pueden hacer que el proceso de toma de decisiones sobre las opciones de tratamiento se delegue en los profesionales.

Palabras-clave: Bioética. Neoplasias. Autonomía personal. Oncología. Quimioterapia.

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Cancer is a chronic degenerative disease with aggressive and uncontrolled growth of abnormal cells, which spread to tissues and organs and may also affect distant sites¹. This pathology is one of the main causes of premature deaths (before the age of 70) in most countries².

According to Globocan, around 20 million new cases of cancer were estimated for 2020 worldwide, causing about 10 million deaths, with almost 700,000 new cases in Brazil^{2,3}. Diagnosed patients are usually subjected to aggressive treatments, such as chemotherapy, which, despite its benefits, can cause several unwanted effects and compromise the patient's quality of life. In this scenario, the care model and its limited protocols can restrain patient autonomy.

As reported by Schramm⁴, personal autonomy must be a decisive criterion for moral choices in democratic and pluralistic societies, such as the one we live today. Rego, Palácios and Siqueira-Batista⁵ note that respect for the patient autonomy must be ensured when explaining, in a clear and transparent manner, everything that is happening and the options that biomedical science offers. The patient's decision about the treatment must be respected; however, the literature highlights that such respect for patient autonomy is often not guaranteed.

Niemeyer-Guimarães and Schramm⁶ observe that health professionals tend to assume a position of power and control, feeling they are responsible for the disease, acting as an authority that determines the patient's interests. For these authors, this situation gives patients little or no choice over the disease, making them vulnerable to real pain and suffering. In this sense, Pontes and Schramm⁷ stress that the population must be informed about the protective measures adopted; otherwise, they will be perceived as paternalistic or arbitrary measures.

According to Felício and Pessini⁸, the protective role of social institutions for more vulnerable individuals presupposes a distinction between protection and paternalism. For these authors, the pendulum between professional paternalism and respect for patient autonomy must prioritize consideration for freedom, responsibility, and capacity. Patients must actively judge and choose, together with physicians, the therapeutic practices that are more consistent with their

priorities. This perspective of the relationships between professionals and patients is based on what has been called the bioethics of protection.

Bioethics of protection is a protective tool for reflection, understanding, and resolution of intrinsic moral conflicts of human praxis. The concept is applicable to vulnerable individuals, that is, those who are unable to protect themselves alone or who have no support from their families, groups where they belong, the State or society, and are particularly affected by this situation^{4,9,10}.

As reported by Schramm⁹, during the disease process, an asymmetrical and conflicting relationship is created between health professionals—or moral agents (initially empowered and authors of acts)—and patients—or moral patients (not empowered and recipients of practices of moral agents). The principle of protection applies specifically to moral patients, who fall into a range from susceptible to vulnerable individuals, and who, because of this unfavorable condition, have no condition to fully exercise their autonomy in making decisions about their health¹¹.

Also, the particularities of developing countries characterized by inequalities, such as Brazil, should be considered. In a context of scarce empowerment for a large part of the population, such as the context in which the Brazilian National Health System (SUS) operates, health actions and services should be guided by the bioethics of protection. The asymmetric relationship between a more educated population and a population deprived of rights must be recognized; therefore, protection must focus on the emancipation of subjects for decision making^{5,11}.

According to Garrafa¹², emancipation exists when a subject is able to ensure not only their own survival, but also choices of methods to achieve survival. For this author, power over oneself grants emancipation, making the person immune to the forces of subjection. Therefore, suppressing dependence is a precondition for emancipation.

In SUS, the publication of the National Humanization Policy (PNH) sought to encourage communication among administrators, workers, and patients to build collective processes. These processes aim to confront relations of power, work, and affection that produce dehumanizing attitudes and practices and inhibit the autonomy

and co-responsibility of health professionals in their work and patients in self-care¹³. The PNH thus seeks to guarantee the autonomy and emancipation of SUS patients, including cancer patients undergoing chemotherapy treatment.

Effective communication and humanized care are required to ensure patient empowerment in decision making about the chemotherapy treatment. To provide that, health professionals must be attentive to the patient's problems and understand the emotional, physical, and social impact of the disease on the patient and their family. Therefore, information must be adapted to what the patient wants to know and pay attention to how the message is received and interpreted¹⁴.

Despite the importance of the topic, there is a lack of studies addressing the patient's view of respect for their autonomy in chemotherapy treatment scenarios. Studies addressing the autonomy of patients with cancer are also mostly focused on end-of-life decisions, and not on decisions during cancer treatment^{6,15,16}.

Considering the above, this study aims to understand, from the perspective of cancer patients, respect for their autonomy and the development of their emancipation during the chemotherapy treatment process at the Hospital do Câncer I of the Instituto Nacional de Câncer José Alencar Gomes da Silva (Inca). This study is expected to help identify aspects that can improve the decision-making process during the treatment, given that the bioethical approach must achieve a descriptive and normative character, prescribing and proscribing behaviors for patient protection⁷.

Method

This is an exploratory qualitative study conducted in the chemotherapy sector of the Hospital do Câncer I, which belongs to Inca. Study participants were selected through convenience sampling, and the number of participants was defined by theoretical saturation, as described in the literature^{17,18}. In total, 15 cancer patients who had started their first cycle of scheduled chemotherapy treatment were included and no restriction was considered regarding their sociodemographic profile, tumor type or location, and chemotherapy protocol used in the treatment.

Patients had to be able to participate in the individual interview and it was not necessary to exclude participants due to refusal or inability to complete the interview due to the complex nature of the topic. Individual interviews were conducted from August to November 2021 and guided by a semi-structured questionnaire with open-ended questions regarding the patient trajectory at the institution, the disease and treatment process, and freedom to choose the chemotherapy treatment.

As recommended by Firdion¹⁹, new questions were added to the interview based on the interaction between the researcher and the participant, but respecting the study theme. The medical records of patients were also analyzed to collect sociodemographic and disease history information to reduce interview time and patient and interviewer exposure, considering the COVID-19 pandemic scenario. The interviews were conducted by the main researcher in an environment that guaranteed patient privacy.

All interviews were recorded and transcribed for analysis using the thematic content analysis technique described by Bardin²⁰, comprising the steps: 1) pre-analysis; 2) exploration of the material; and 3) treatment and interpretation of the results. The theoretical framework used was that of the bioethics of protection, as discussed by Schramm and Kottow²¹ and other authors addressing this topic.

The participants were informed about the study objectives, methods, risks, and benefits, and agreed to participate by signing an informed consent form. To guarantee confidentiality, the abbreviation Pat was used followed by random numbering to identify every participant's statements in the description of the results and discussion. Also, additions in brackets were made to the statements to help understand the context of the interview.

Results and discussion

The mean age of participants was 62 years and they were mostly male (60%), married (73%), self-declared Black (53%), residents of the metropolitan region of Rio de Janeiro (87%), with highest schooling level of complete

secondary education (66.67%). The mean time between diagnosis and start of chemotherapy treatment was five months, and most participants were diagnosed with adenocarcinoma of the gastrointestinal tract (46.67%) and were starting neoadjuvant chemotherapy (60%).

After data analysis, two main themes that impact patient autonomy were identified: 1) organizational issues of the oncology network and services, and 2) the patient's choices in their emancipation process.

Organizational issues and oncology service

This category represents aspects that limited patient autonomy due to an imposition of services, including organizational models and service quality, deficiency in health professional-patient communication, and influence of COVID-19 pandemic on the organizational flow of the network and routine of services.

Regarding the healthcare network organization and the service quality, lack of referral to an oncology hospital was observed. A chemotherapy protocol was used without indication for the patient's diagnosis, which led to damage and disease progression. Also, patient documentation and biopsy slides were lost (due to a tragedy of hospital fire) during the referral process to Inca, which resulted in delayed start of treatment. All these situations cause emotional reactions in the patient.

"It was a treatment that we didn't know if it was very effective, according to what was explained here. Here I do it on Tuesday, Wednesday, Thursday, Friday, Saturday, and Sunday, then I rest for 16 [days] and do it for five more [days]. And then, I did it once a week with alternate times. Which probably had a metastasis and it came back. (...) [the doctor here] kept asking 'Did you do it once a week only?' in such a long interval. He didn't understand it very well. But he didn't question the other doctor's protocol. He acted professionally. He only said 'Let's do the right thing.' Soon after that, I had a problem. It couldn't be understood and caused a huge confusion here. It was the second time that I saw the doctor and he said there was something in my urethra. And then I did the whole procedure again,

and my medical records [from the other hospital] had disappeared. Then they didn't know what material had been used on me and it was very complicated to continue the treatment. (...) Look, to be honest, when he said we were going to start chemo and so on, my wife and I went outside and cried together. This is really what we always say, I felt welcomed, I felt... you know? I didn't feel abandoned by the system" (Pat 4).

This feeling of abandonment reported by the participant results from the clear lack of communication between the different points of the healthcare network responsible for cancer patients. As described by Mendes²², building a healthcare network goes far beyond care points for the patients. For this author, it is also necessary to create and qualify logistical and support systems, which would include, for example, common clinical records of a patient for the whole network.

The adoption of digital medical records could bring benefits, such as making patient information instantly available to healthcare professionals of the network. It would qualify the decision-making process and facilitate the generation of information about patients, their diseases, and their treatments.

Another situation related to the service organization refers to clinical care by resident doctors and the preceptorship model adopted, which is considered the standard professional qualification, but whose success is closely related to the quality of SUS services. There are weaknesses in the preceptorship process for residents and professionals in training, who build knowledge through new experiences. Due to the training nature of the residency, preceptorship is essential to ensure safety for the patient, the health professional, and the service²³.

"I don't even know the color of her eyes [of the resident doctor], you know? She just didn't show up. Of course he [the supervising doctor] tried to justify the action of his colleague, and I didn't go into details because she doesn't interest me, she didn't come and I liked him. (...) She was completely unprepared, of course the resident is there to learn, I agree, but it felt very incipient, very poor in terms of experience, I would never assign her to see patients, I would still have her

with a supervisor, with the head, I don't know (...). There was no information! Then they went up to the supervision to see what was going on, then came down again and began the blood tests and request the removal of the biopsy slide. Let's say it was kind of a wasted day (...), no... wasted time, and I was very tired, because everything tires me, naturally (...) I suppose. And I also kind of got stressed, when the doctor arrived [the daughter took over communication with the doctor, as the patient was very stressed] I couldn't take it anymore, I was so tired that I couldn't take it anymore. And when I saw that it was [inappropriate words referring to the doctor], when I saw it was her [inappropriate words referring to the doctor], may God forgive me, I kept quiet and she [the daughter] was the one who solved everything" (Pat 3).

It is often said that the resident, as a professional in training, needs the support of the preceptor for proper development of skills related to care techniques. However, as important as clinical guidance is, the preceptor's role lies in the moral education of the resident, not exclusively as an example and model, but mainly explaining and discussing values that humanize relationships²³. Difficult situations for professional practice, so common in everyday oncology services, should be used with this focus on learning.

In a third situation, the participant reports a delay in treatment due to the unsatisfactory organization of the service. This situation caused a feeling of impossibility of resolution and aggravation of the case, which resulted in reduced therapeutic options.

"He said (...) he examined me and said I should come back, but he said he would call to do the biopsy. But it took a long time, almost a year, more than six months, for me to get it again. The doctor, [when] I came here last week, said to me, 'But why did you take so long?' Then I said 'We were waiting because the doctor said he was going to call us but he didn't. Then it took a long time, and these things can't take so long, right!? (...) The longer it takes, the worse. Because the doctor there in Rio Bonito told me I had a nodule on my liver and lung. And the time since he said that and the time it took to call me... it was a long time" (Pat 8).

In the three cases described above, the types of organization of the healthcare network and services impact not only the disease development, but also the emotions of patients. This impact, combined with the representations of cancer in society, implies challenges in self-managed care and particularly in the relationship between health professionals and patients, which are crucial to ensure patient autonomy and treatment quality. Therefore, care must be taken with the patient's emotions, assuming an empathetic attitude, showing respect and establishing an emotional relationship that can promote patient autonomy, despite the challenging situations patients went through that affected their emotions²⁴.

It is important to stress that health authorities have the responsibility to guarantee the well-being of the population and, in the hospital environment, the team of health professionals should ensure positive protection measures are performed⁴. Impactful and unexpected events may occur during the disease process, but the physician-patient relationship must be strengthened to avoid emotional reactions of patients that can place them in a vulnerable situation.

In this scenario, the conduct of health professionals and infrastructure problems represent a rupture with attention or risk of fragile health of patient, who may present a loss of autonomy and independence, becoming more vulnerable to traumas or psychological changes²⁵.

Regarding the communication between the health professional and the patient, which is a very important aspect of ensuring the right to emancipation, situations of deprivation of important information for the exercise of patient autonomy were identified.

"But then he prescribed me the medications that I will have to take. He explained these things more or less to me" (Pat 5).

"About (...) these parts [of chemotherapy], he didn't explain much. Like I said, I was going to do the exams, and so on. I didn't know about the process. But he gave me one (...), you can undergo chemo and then you will have a surgery. 'You're going to have to have this surgery!' (...) Then I said: 'Ok!' (...) No, he didn't talk about it [the medication]" (Pat 7).

"So, he told me what I had to do, right!? It was just how I told you. I arrived, had the TURP [transurethral resection], the next step would be the removal, but then I was sent to another doctor, who gave me this chemotherapy, right!? And then they're going to have another roundtable about the surgery, right!? (...) He said that it would be the right thing to do, that there was no other way. (...) Well, I didn't exactly have the control. (...) Yeah, it was kind of, I understood that it would be the right treatment for me, that there wouldn't be another one" (Pat 1).

Patients have the right to know about their health status and treatment options. This right is guaranteed in Regulation 1,820/2009²⁶, of the Ministry of Health (MS), which describes the rights and duties of healthcare patients. It states that everyone has the right to access their health status information, in a clear, objective, respectful, and understandable manner.

However, in the scenario of SUS chemotherapy, the options may be limited, either due to the difficult high-cost technological incorporation of new drugs or the low quality of non-specialized services for the treatment of cancer patients. These are different problems that require different actions, but which undoubtedly exist in the professional-patient relationship. Ultimately, they compromise the right to receive clear information about therapy options, whether or not they are available through SUS.

In some interviews, when asked if the doctor had properly explained the treatment, what they would feel or even whether they knew what medications would be used in the treatment, the participants expressed a lack of or insufficient information. This fact shows health professionals are unaware or disregard that information is an important "positive" protection tool, favoring human self-development and the exercise of patient autonomy⁴.

The omission of knowledge required to conduct an aggressive treatment can have implications for the patient's self-management and increase the risk of patient harm. However, the right to truth is not a transcultural norm, as variations exist depending on each situation, and the discussion must go beyond the dichotomy between paternalism and autonomy, including an agreement in the health

professional-patient relationship based on trust. Also, subtle communication is important, avoiding aggressive truths; after all, refusal of information is also a right inherent to autonomy²⁷.

During the interviews, the participants had poor information about chemotherapy before starting the treatment. In consideration of the researcher's training and her ethical and professional role to ensure the patient access to independent information about therapy practices officially recognized in the country in order to enable their free choice²⁸, pharmaceutical guidance was provided immediately after the interview. One patient participating in the study expressed interest in learning more about the medications he was using, the main side effects, and their management described in the post-chemotherapy medical prescription.

The COVID-19 pandemic covered the period when the interviews were conducted, which made accessing health care services more difficult due to social distancing guidelines. Moreover, the pandemic also impacted and delayed the itinerary patients need to traverse in the network, something that may have caused harm.

"They started by monitoring my blood. I started taking exams every three months. (...) Yes, but now it has increased and my platelets are decreasing a lot, and that's when he said (...) it's time now! You are vaccinated, you've already had two doses of the vaccine. Do you understand? I'm not going to bring you here, because otherwise (...) because you always come here, then you can be contaminated, (...) then it will make your situation more complicated" (Pat 2).

"Yes, the doctor said the delay in starting treatment and the disease progression were due to the pandemic" (Pat 13).

The oncology treatment requires interaction with different areas of health, and consequently, different health professionals in hospitals, clinics, and laboratories. Despite the risks involved, the recommendation to stay at home due to the pandemic cannot be applied to cancer patients because they have to take exams and continue their treatments²⁹.

Also, considering the clinical profile of cancer patients and their risk of developing COVID-19, isolation protocols were stricter in hospitals. The routine of services was altered, limiting treatment options and patient autonomy. According to Campiolo and collaborators³⁰, the pandemic led to the cancellation of elective surgeries, visits, and exams to make space for COVID-19 patients in the healthcare system.

Then, given the information analyzed, a significant impact on the autonomy of chemotherapy patients was identified due to organizational issues in the oncology network and services. Patients do not always obtain satisfactory information about their treatment or the conditions to participate in treatment choices. Moreover, their options are reduced, whether due to structural factors of SUS or the pandemic context.

In view of the above, tools must be implemented to detect and control weaknesses in the organization of the system, including strategies to improve communication, between the services that constitute the health care network, between health professionals, and between health professionals and patients.

Patient choices in their emancipation process

In addition to the impact on patient autonomy discussed above, in some cases, patients delegate their right to choose treatment to health professionals. In other words, they make use of their right to follow professional recommendations without restrictions, playing a more passive role in the decision-making process of their treatment.

Based on the feeling of helplessness that cancer and its social meanings represent, patients may choose not to be part of decision-making moments that involve doubts and pain. Such withdrawal often occurs due to a connection with a religious system (according to the ethical principle that, through divine intermediation, a relationship of trust is created with whoever is treating the patient) and/or trust in expert systems.

Faith and religiosity have been one of the main allies of cancer patients when handling situations related to the diagnosis, giving a new meaning to the disease-cure process, seeking a better quality of life, relief from distress, and hope

in the process. Considering the above, the World Health Organization included the spiritual dimension in the multidimensional concept of health, demonstrating its importance as a founding element of the human condition^{31,32}.

"I am not accepting it and will not accept it. So, my choice is not here now, I will wait on God and believe that everything has already worked out fine (...). And there's still this situation, an example from some time ago. I prayed for many people with cancer, and God healed them, God did wonders. (...) Then all the fuss starts, without our understanding. Those who believe in God will understand that it was a miracle from God. Those who don't believe get a little confused, ok!?" (Pat 7).

"It's really a blessing! I believe in a miracle from God, I believe in a miracle from God. So, I'm going to do my chemotherapy calmly, without any trouble, without murmuring, without saying anything. The only thing I can think now is that everything will be ok!" (Pat 9).

Spirituality can be an important tool to help take the patient out of a position of vulnerability since, through spirituality, patients can have a more positive and hopeful perspective of their disease and weaknesses, and become more receptive to the tools from the bioethics of protection. Despite the apparent contradiction, the abdication of certain information may be encouraged by the ethical principle of faith in the patient's decisions³³. This principle ensures the exercise of patient autonomy, which is observed through the belief in a deity who, in addition to promote cure, guides experts towards the best decisions.

According to Giddens³⁴, one of the founding characteristics of late modernity is the specialization of knowledge in expert systems, such as medicine and engineering. For Dumont and Gattoni³⁵, despite the access to information, a human being will never be able to master all aspects related to all expert systems and, therefore, tends to trust a system one does not know.

Therefore, trust in the system ends up configured according to its practical operating experience and regulatory forces that seek to protect consumers from expert systems. This trust can be reaffirmed or shaken in contacts between non-experts and experts (physicians,

engineers, lawyers)³⁶. Some study participants, who already feel vulnerable, develop mechanisms of trust in the health team in charge, assigning decision-making powers to these professionals. Patients then feel a conviction that physicians, who have more knowledge, should have the power of choice.

"No, I reached my limit, you know? If he has my exams in his hands... he has my exams, he's the one who ordered the exams. I'm always monitored. He knows what's good for me, do you understand!? He studied, he knows what's happening to me, you see? I'm not an expert, he's the expert. He studied, he's monitoring me, I have to follow what he is saying. If not, you have to take away his diploma, right? (...) The guy studied, right? He's monitoring me, he knows what he's talking about (...) I don't understand. Do you understand?" (Pat 2).

"I don't have information about that. I think it wouldn't be nice to change any kind of protocol they have defined here. So, I accept what they say (...) In this case, I'm not the best person, because I'm very quiet about the treatment. I don't question too much, because like I told you, I don't understand about it. There's no point in questioning something I don't know about. So, I prefer to follow their protocol, do you understand?" (Pat 4).

Vulnerabilities to which patients are subjected and the asymmetry in the relationship between health professionals and patients, despite existing in any society, are intensified in developing countries such as Brazil. Social and economic differences between these two groups result in relations of power of one group over the other, which affect all spheres of society, including health systems and services.

As a tool, the bioethics of protection raises reflections on this topic that consider the difference in education between the physician and the patient as a decisive factor of asymmetry⁹. Because of this asymmetric relationship, the chances that protectionism is mixed up with paternalism increase. As a result, patients may be prevented from receiving the required information to live a decent and free life, without depending on choices made by third parties (in this case, health professionals).

In part, the trust system, whether in a religious or expert system, may be related to a feeling of helplessness in the disease and its treatment. This feeling of helplessness can act as a trigger that may place patients in a vulnerable position. Therefore, tools from the bioethics of protection should be used in order to ensure patient emancipation.

"I felt helpless, right? (...) Because there was no definition. I'm not blaming anyone, ok? I'm just saying that they were trying (...). I even had a biopsy of this one, of the back, but the first one didn't work out and I had to do a second one. So, all these things took time, right?" (Pac 12).

Health professionals must pay attention to the susceptibility and vulnerability of patients with cancer, who are affected by the diagnosis itself. These are people with diseases that require therapeutic protection actions, which should be available and accessible in a timely manner to everyone, based on the protective role of the State¹¹.

This study presents limitations regarding the analysis of the entire phenomenon of the autonomy of patients undergoing chemotherapy, including the selection of a single center for data construction and collection, and the representation of the problem exclusively from the patient's perspective. Further studies should include other public and private services and the perspective of other agents involved in the process (health professionals, administrators, and family members).

Final considerations

This study highlighted, from the perspective of cancer patients, factors that impacted their autonomy and the development of their emancipation during the chemotherapy treatment process. Quality of network and service organization were structural factors limiting patient autonomy, as deficiencies were found in service qualification, computer systems, the professional training process, and the communication processes between health professionals and patients. These deficiencies, combined with the scenario imposed by the

COVID-19 pandemic, aggravate situations in which patients feel excluded from the decisions made for their own treatment.

Besides these factors, the patient's choices based on a religious or expert system may lead to patient delegation of treatment decisions to health professionals. Unlike previous cases, this process, if consciously made by patients, can be understood as an exercise of autonomy.

Regarding the bioethics of protection, permanent tools should be implemented in health services to detect and control factors that may put patient autonomy at risk. Health professionals and administrators must have sensitivity to understand the moment of vulnerability experienced by cancer patients. Agents must develop the technical and moral skills required to act with ethical and social responsibility regarding chemotherapy patients.

References

1. Herr GE, Kolankiewicz ACB, Berlezi EM, Gomes JS, Magnago TSBS, Rosanelli CP, Loro MM. Avaliação de conhecimentos acerca da doença oncológica e práticas de cuidado com a saúde. *Rev Bras Cancerol* [Internet]. 2013 [acesso 24 maio 2023];59(1):33-41. DOI: 10.32635/2176-9745.RBC.2013v59n1.540
2. Brasil. Ministério da Saúde. Instituto Nacional de Câncer José Alencar Gomes da Silva. Estimativa 2020: incidência de câncer no Brasil [Internet]. Rio de Janeiro: Inca; 2019 [acesso 24 maio 2023]. Disponível: <https://tinyurl.com/bdrpnud>
3. World Health Organization. International Agency for Research on Cancer. Globocan 2020 World. *Cancer Today* [Internet]. 2021 [acesso 24 maio 2023]. Disponível: <https://tinyurl.com/3x6du59h>
4. Schramm FR. A bioética de proteção: uma ferramenta para a avaliação das práticas sanitárias? *Ciênc Saúde Colet* [Internet]. 2017 [acesso 24 maio 2023];22(5):1531-8. DOI: 10.1590/1413-81232017225.04532017
5. Rego S, Palácios M, Siqueira-Batista R. Bioética para profissionais da saúde. Rio de Janeiro: Editora Fiocruz; 2009. p. 134.
6. Niemeyer-Guimarães M, Schramm FR. The exercise of autonomy by older cancer patients in palliative care: the biotechnoscientific and biopolitical paradigms and the bioethics of protection. *Palliat Care* [Internet]. 2017 [acesso 24 maio 2023];9:1178224216684831. DOI: 10.1177/1178224216684831
7. Pontes CAA, Schramm FR. Bioética da proteção e papel do Estado: problemas morais no acesso desigual à água potável. *Cad Saúde Pública* [Internet]. 2004 [acesso 24 maio 2023];20(5):1319-27. DOI: 10.1590/S0102-311X2004000500026
8. Felício JL, Pessini L. Bioética da proteção: vulnerabilidade e autonomia dos pacientes com transtornos mentais. *Rev. bioét. (Impr.)* [Internet]. 2009 [acesso 24 maio 2023];17(2):203-20. Disponível: <https://tinyurl.com/2ue689p7>
9. Schramm FR. A bioética de proteção é pertinente e legítima? *Rev. bioét. (Impr.)* [Internet]. 2011 [acesso 24 maio 2023];19(3):713-24. Disponível: <https://tinyurl.com/2wsm9mwd>
10. Schramm FR. Bioética da proteção: ferramenta válida para enfrentar problemas morais na era da globalização. *Rev. Bioética* [Internet]. 2008 [acesso 24 maio 2023];16(1):11-23. Disponível: <https://tinyurl.com/2a6k6ef7>
11. Boy R, Schramm FR. Bioética da proteção e tratamento de doenças genéticas raras no Brasil: o caso das doenças de depósito lisossomal. *Cad Saúde Pública* [Internet]. 2009 [acesso 21 set 2023];25(6):1276-84. DOI: 10.1590/S0102-311X2009000600010
12. Garrafa V. Inclusão social no contexto político da bioética. *Rev Bras Bioét* [Internet]. 2005 [acesso 24 maio 2023];1(2):122-32. DOI: 10.26512/rbb.v1i2.8066
13. Brasil. Ministério da Saúde. HumanizaSus: Política Nacional de Humanização: a humanização como eixo norteador das práticas de atenção e gestão em todas as instâncias do Sus [Internet]. 2004 [acesso 24 maio 2023];1-19. Disponível: <https://tinyurl.com/2f5bv4j>
14. Nunes FDBRS, Almeida ADL. Informação médica e consentimento de pessoas com câncer. *Rev. bioét. (Impr.)* [Internet]. 2018 [acesso 24 maio 2023];26(1):119-26. DOI: 10.1590/1983-80422018261233

15. Johnson SB, Butow PN, Kerridge I, Tattersall MHN. Patient autonomy and advance care planning: a qualitative study of oncologist and palliative care physicians' perspectives. *Support Care Cancer* [Internet]. 2018 [acesso 24 maio 2023];26(2):565-74. DOI: 10.1007/s00520-017-3867-5
16. Gaspar RB, Silva MM, Zepeda KGM, Silva ÍR. Fatores condicionantes à defesa da autonomia do idoso em terminalidade da vida pelo enfermeiro. *Rev Bras Enferm* [Internet]. 2020 [acesso 24 maio 2023];73(supl 3):1-8. DOI: 10.1590/0034-7167-2018-0857
17. Gil AC. Métodos e técnicas de pesquisa social. 6ª ed. São Paulo: Atlas; 2008.
18. Fontanella BJB, Ricas J, Turato ER. Amostragem por saturação em pesquisas qualitativas em saúde: contribuições teóricas. *Cad Saúde Pública* [Internet]. 2008 [acesso 24 maio 2023];24(1):17-27. DOI: 10.1590/S0102-311X2008000100003
19. Firdion JM. Construir uma amostra. In: Paugam S, coordenador. *A pesquisa sociológica*. Petrópolis: Vozes; 2015. p. 67-84.
20. Bardin L. *Análise de conteúdo*. São Paulo: Edições 70; 2016.
21. Schramm FR, Kottow M. Principios bioéticos en salud pública: limitaciones y propuestas. *Cad Saúde Pública* [Internet]. 2001 [acesso 24 maio 2023];17(4):949-56. DOI: 10.1590/S0102-311X2001000400029
22. Mendes EV. As redes de atenção à saúde. *Ciênc Saúde Colet* [Internet]. 2010 [acesso 24 maio 2023];15:2297-305. DOI: 10.1590/S1413-81232010000500005
23. Botti SHO. Desenvolvendo as competências profissionais dos residentes. *Revista HUPE*. 2012;11(supl 1):102-5.
24. Theobald MR, Santos MLM, Andrade SMO, De-Carli AD. Percepções do paciente oncológico sobre o cuidado. *Physis* [Internet]. 2016 [acesso 24 maio 2023];26(4):1249-69. DOI: 10.1590/S0103-73312016000400010
25. Freitas FFQ, Rocha AB, Moura ACM, Soares SM. Fragilidade em idosos na atenção primária à saúde: uma abordagem a partir do geoprocessamento. *Ciênc Saúde Colet* [Internet]. 2020 [acesso 24 maio 2023];25(11):4439-50. DOI: 10.1590/1413-812320202511.27062018
26. Brasil. Ministério da Saúde. Portaria nº 1820, de 13 de agosto de 2009. Dispõe sobre os direitos e deveres dos usuários da saúde. *Diário Oficial da União* [Internet]. Brasília, 14 ago 2009 [acesso 24 maio 2023]. Disponível: <https://tinyurl.com/4hcuz7cp>
27. Brasil. Ministério da Saúde; Conselho Nacional de Secretários de Saúde; Sociedade Beneficente de Senhoras Hospital Sírio-Libanês. *Manual de cuidados paliativos* [Internet]. 3ª ed. São Paulo: Hospital Sírio-Libanês; 2021 [acesso 24 maio 2023]. p. 624. Disponível: <https://tinyurl.com/ywkrwpm>
28. Conselho Federal de Farmácia. Resolução nº 596, de 21 de fevereiro de 2014. Dispõe sobre o Código de Ética Farmacêutica, o Código de Processo Ético e estabelece as infrações e as regras de aplicação das sanções disciplinares. *Diário Oficial da União* [Internet]. Brasília, p. 2, 25 mar 2014 [acesso 24 maio 2023]. Seção 1. Disponível: <https://tinyurl.com/mr37a3yt>
29. Corrêa KM, Oliveira JDB, Taets GGCC. Impacto na qualidade de vida de pacientes com câncer em meio à pandemia de covid-19: Uma reflexão a partir da teoria das necessidades humanas básicas de Abraham Maslow. *Rev Bras Cancerol* [Internet]. 2020 [acesso 24 maio 2023];66:e-1068. DOI: 10.32635/2176-9745.RBC.2020v66nTemaAtual.1068
30. Campiolo EL, Kubo HKL, Ochikubo GT, Batista G. Impacto da pandemia do covid19 no serviço de saúde: uma revisão de literatura. *Interam J Med Heal* [Internet]. 2020 [acesso 24 maio 2023];3:e202003046. DOI: 10.31005/iajmh.v3i0.140
31. Soratto MT, Silva DM, Zugno PI, Daniel R. Espiritualidade e resiliência em pacientes oncológicos. *Saude e Pesqui* [Internet]. 2016 [acesso 24 maio 2023];9(1):53-63. DOI: 10.17765/1983-1870.2016v9n1p53-63
32. Silva CAA, Rocha KAF, Ferro LRM, Oliveira AJ, Rivas MG. A influência da fé no tratamento de pacientes oncológicos. *Psicol Saúde Debate* [Internet]. 2021 [acesso 24 maio 2023];7(2):214-35. DOI: 10.22289/2446-922X.V7N2A14
33. Mundim ER. Bioética, ciência e fé. *Rev Med Minas Gerais* [Internet]. 2011 [acesso 24 maio 2023];21(3):348-52. Disponível: <https://tinyurl.com/3wjucvru>
34. Giddens A. *As consequências da modernidade* [Internet]. São Paulo: Editora Unesp; 1991 [acesso 24 maio 2023]. p. 91-1754.

35. Dumont LMM, Gattoni RLC. As relações informacionais na sociedade reflexiva de Giddens. Ciênc Inf [Internet]. 2003 [acesso 24 maio 2023];32(3):46-53. DOI: 10.1590/S0100-19652003000300006
36. Brasil. Ministério da Saúde. Reflexões sobre ensino e pesquisa no SUS: experiência no contexto hospitalar de alta complexidade [Internet]. Brasília: Ministério da Saúde; 2019 [acesso 24 maio 2023]. As redes de comunicação no cotidiano de usuários do Sistema Único de Saúde: aproximações etnográficas; p. 79-95. Disponível: <https://tinyurl.com/4wkx7uwv>

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Bruna Camelo Sedda performed data collection and analysis and participated in the study concept and article writing. Fernando Lopes Tavares de Lima participated in the study concept and collaborated in data analysis and article writing.

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