ISSN: 2230-9926

Available online at http://www.journalijdr.com

IJDR

International Journal of Development Research
Vol. 10, Issue, 01, pp. 33399-33405, January, 2020

RESEARCH ARTICLE OPEN ACCESS

HEALTH CARE UNDER THE ONCOLOGICAL PATIENT'S PERSPECTIVE

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ARTICLE INFO

Article History:
Received 28th October, 2019
Received in revised form
17th November, 2019
Accepted 19th December, 2019
Published online 31st January, 2020

Key Words:

Ethics, Humanization of care,
Professional practice,
Hospital oncology service,
Health personnel.

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ABSTRACT

Objectives: To describe how health professionals act in the care of patients treated by a hospital oncology service. **Method:** This is a qualitative study, whose data collection was performed through semi-structured interviews. They were transcribed and analyzed by the Collective Subject Discourse technique. Twenty-five patients who were admitted to the oncology department of a public hospital participated in this study. **Results:** Three central ideas were identified that indicated inappropriate conduct of professionals and three that demonstrate an appropriate positioning. Negative aspects: In addition to ethical failures, distancing, impatience, harshness, lack of veracity in notes, delayed care, excessive bureaucracy, noise in the hospital environment, lack of listening, clinical examination and anamnesis were evident. Positive aspects: welcome, affection, empathy, use of spirituality, friendship and use of complementary therapies. **Final considerations:** Even though potentialities were found, significant weaknesses were observed, demonstrating that some important aspects for humanized care are disregarded, reinforcing the need for professionals to value the precepts of ethics as the next, so that the suffering inherent to the health process -sickness is minimized. This opens space for the potentialities pointed out to be optimized in order to qualify the health care of these patients.

Citation: Melina Raquel Theobald, Alessandro Diogo de Carli, Sonia Maria de Oliveira Andrade *et al.* 2020. "Health care under the oncological patient's perspective", *International Journal of Development Research*, 10, (01), 33399-33405.

INTRODUCTION

Cancer is a public health problem, especially among developing countries, when about 80 percent of the more than 20 million new cases estimated for 2025 will happen in these places. A worldwide estimate made in 2012 indicated that of the 14 million new cases predicted, over 60% will occur in developing countries. For mortality, the situation worsens when it is found that of the 8 million predicted deaths, 70% will occur in these same countries (BRAZIL, 2015). In recent decades, an important advance has been made in the area of oncology, with emphasis on the implementation of the 60-day Law, which, combined with technological and scientific advances, has provided significant increases in the scope of cancer diagnosis and treatment (BRAZIL, 2012). The result of all this therapeutic arsenal and political efforts is the current expectation of cure of about 50% of cases (BRASIL, 2008).

For coping with the disease, as relevant as the set of technologies for its diagnosis and treatment, it is extremely important to identify and value a patient's mood, fears, insecurities and doubts (SECOLI *et al.*, 2005). In caring for the cancer patient, there is no chemotherapy more efficient than a mild word, no more beneficial radiation than the touch of a stroking hand. The doctor itself can be a great medicine, but neither he nor his therapeutic arsenal can be more effective than the patient's own healing potential (ANDRADE, 2011). Studies have been conducted to assess the degree of satisfaction of health service users (MULLER, 2003; MATEOS *et al.*, 2009). One of the main points discussed is

the growing and increasingly consensual opinion that most health actions have not taken patient agreement and acceptance into account (RESENDE, 1999). Analyzing patient satisfaction implies presenting a judgment about service characteristics, therefore, about quality (TRAD; BASTOS, 1998), since it provides information to complete and balance the quality of services. From this perspective, it is worth noting that from the perspective of the user of health services, satisfaction involves dimensions inherent to the service, such as access, quality, physical and organizational structure, as well as relational aspects between patients and health professionals (ESPERIDIÃO; TRAD, 2005). The user's perception is extremely important in assessing the quality of care, as it can be influenced by the patients' own expectations, as well as the care received. It should be considered, as it allows the professional to approach comprehensive care and contributes to the improvement of the health system (JESUS; CARVALHO, 2002; FRANCO; MERHY, 2013; SENARATH *et al*., 2006; MURRAY *et al*., 2001). This study aimed to understand, from the perspective of patients treated in an oncology hospital service, how the health professional acts in the care of these users. It is an aspect little researched so far and that requires deepening, with the purpose of subsidizing professionals for a care based on a critical-reflexive process, essential in the search for a dignified, authentic and humanized care.

MATERIALS AND METHODS

It is a research of qualitative approach, of descriptive and exploratory nature, that intends to answer particular questions, based on the aspects that cannot be analyzed only from the quantitative point of view (MINAYO, 2007). We studied the patients who were hospitalized during the period of data collection in the Oncology sector of a public teaching hospital, linked to the Unified Health System (SUS). Participants were individuals over 18 years old, with adequate level of awareness and understanding about the proposed objectives. Those with speech, comprehension, expression, or any discomfort during data collection such as pain, nausea, dizziness, and emesis were excluded. Data collection was performed through semi-structured interviews, whose script was designed in search of "ideal questions" that would lead the interviewee to produce a speech, in order to encourage the participant to answer more accurately what the researcher investigates. To this end, the questions were understandable, clear and pre-tested (LEFÈVRE; LEFÈVRE, 2014). The interview script was prepared with a view to the objectives of the study and then forwarded to professionals specializing in oncology and experienced in scientific research, to proceed with the semantic analysis of the content. This stage aimed to elaborate questions with greater specificity, in order to resolve possible biases and subjectivities.

Thought as a significant matter can be perceived as a qualitative and quantitative variable. This study was made possible by the qualitative aspect of the Collective Subject Discourse - DSC (LEFÈVRE; LEFÈVRE, 2014), with selection of Key Expressions - EC - that deal with the most significant excerpts of the answers contained in the Central Ideas - CI - which in turn. refer to the discursive content synthesis of the CEs that give rise to the CSD. The choice for the CSD was due to the possibility of redemption and to present the social representations, which approach "the opinions as they are in fact practiced by collectives of social actors", understood here as individual / collective and subject speaking / spoken (LEFEVRE; LEFEVRE, 2014; p. 503). The quantification of the interviews was guided by the saturation criterion. This considers successive analyzes parallel to data collection and signals the moment of its completion when in the interviews the speech begins to repeat and the objectives of the study were achieved (MINAYO, 2007). The research protocol of this study was approved in its ethical and methodological aspects by the Human Research Ethics Committee of the Federal University of Mato Grosso do Sul, under protocol no. 890,370 and CAAE no. 36392914.6.0000.0021.

RESULTS AND DISCUSSION

Participated in this research 25 patients admitted to the service studied during the data collection period. Individual interviews were conducted, whose results after analyzing presented six CIs that underlie the CSD and contributed to the understanding of the process of care in oncology, from the patient's perspective. CI 1 presents the professional performance performed inappropriately. This speech was constructed with IC 1: About us, they do not talk to us, they do not hear us and they do not look at us, and they say the following:

> *"There are nurses who come into our room talking about the other patients, and there was a doctor talking to his students about me in the hallway and I was listening to everything from the room. Most of the nurses I have nothing to complain about, but a couple, to me they are terrible because they do it stupid and wonder if they think it's bad and they respond with an ugly face. They go boring and punching us and they don't say anything, they do things without asking, that's brutality to me. Air in the serum I was reprimanded by the nurse, now I withdraw with fear of being reprimanded, and a nurse wrote in the report that I did not want to take the medicine and that was a lie. There are some oncology doctors who can't even see the patient, there are some professionals who barely look at you, in the health center this happens too, because before finishing talking are already giving the prescription and he said shouting to me "(P1, P3, P4, P6, P10, P12, P13, P14, P15, P24, P18, P19).*

This CSD highlights the lack of communication and ethics. Patients are not informed about what will be done and the attitude of the professionals involved shows that they do not interact effectively with their patients. This may compromise care by considering that communication realigns the professional's encounter with the patient on the most crucial axis of an interpersonal relationship, when dealing with dignified people in a helping relationship (BERTACHINI, 2012). The speech demonstrates that the professional does not seem to consider it relevant that the patient be informed about the procedures that will be performed, as well as do not value the speech and disregard the patient's questions, when interrupting him harshly and impatiently. In general, health professionals do not give due importance to the patient in front of them regarding their insecurities, questions and fears, they are not willing to clarify doubts and explain the procedures that will be performed (TADDEO *et al*., 2012; TESTON *et al*., 2018). By not fulfilling fundamental aspects in respecting the patient, the professional possibly ignores the fact that communication is a humanizing factor in health care; that favors the understanding of everything that involves the

disease and its meaning (s). As a humanization factor, the health communicative process challenges professionals to find technical mediations with human competence to build new postures, where communication and care are not denied, but implemented in the best possible way (BERTACHINI, 2012).

In this context, it is important to reflect on fragility in relational issues in the practice of care. Numerous factors inherent in the health work process can influence the relationships between professionals and patients, such as work overload, professional devaluation and lack of infrastructure. However, it is important to think that the precariousness of the work process does not justify practices opposed to humanized care and with emphasis on light technologies. The attitude of the professional at work is related to the capacity for self-government, because through it, as much as the worker is captured by the doing instituted by the dominant model, it is possible to make escape lines from the effects that emerge from the intercessor encounter with the user (FRANCO; MERHY, 2013). Another aspect that interferes with professional performance is the uniqueness of each individual, so even if individuals are under the same normative guideline, their action in the production of care is unique. From the perspective of authentic, dignified and respectful care, we realize the need to recover solidarity with the suffering and needs of others. To this end, the exercise of empathically putting oneself in the other's place is crucial. In this sense, the continuous reflection by the worker is important. For this reflection it is opportune that the professional asks himself about how he would receive the care that he now offers to the patient, or even how he would evaluate this care if it was offered to his family.

From this perspective, the professional regulations that establish how to act are not able to guarantee that respect, qualified listening and appreciation of the other are at the center of the therapeutic process. This does not depend on financial resources or hard and light-hard technologies, but on ethical and moral principles that must be imbedded in both professional practices and living in society. The CSD1 presents patient discomfort when hearing that the doctor talked about his health situation with students in the corridor. Sharing aspects related to the clinical condition of patients in an inappropriate environment, such as in corridors, in front of other patients, implies ethical failure, which to some extent is trivialized and is already present in the undergraduate training processes and that can perpetuate oneself throughout one's professional life. There is much to change in the traditional teaching model to achieve adequate training related to ethical and bioethical aspects, in order to favor that such principles are incorporated into the daily work of health. There are urgent and not just simple programmatic changes, but paradigmatic changes that involve the incorporation by teachers and students in relation to new attitudes (SIQUEIRA, 2009). Medical students report that they observe inappropriate medical conduct by their teachers. Medical teachers have a social responsibility to transform students into doctors and should be an example to promote the integrity of these future professionals (VIEIRA; NEVES, 2009). Certainly such postures are not inherent in the medical profession, they are also present in other health professionals, as identified in the speeches of patients participating in this study. The ethical flaw also relates to another circumstance that was exposed in the CSD1, when the patient reports that the information written in the nursing report was not true. In this context, it is clear that the worker involved in the situation violated the regulations of the Code of Nursing Ethics, especially its article five, which emphasizes honesty in the exercise of the profession (COFEN, 2007).

Several of the aspects highlighted in CSD1 may favor the emergence of stress for the patient. Such situations should be avoided, as hospitalization itself is a factor of vulnerability to the patient that may interfere with the expected therapeutic results. In an investigation into the occurrence of stress in patients admitted to a private general hospital, it was found that 82.5% of the participants were stressed, with no association of stress level with days of hospitalization and disease. These results highlight the urgent need to rethink the forms of intervention in the hospital context (MACENA; LANGE, 2008)

The CSD 2 also has a negative aspect, discrimination.

> CSD 2: "*They serve differently who has and who has no Money".*
> *"If you have money they speak softly and treat you well, if they don't have it, you can wait and talk loudly. They serve differently" (P4, P16).*

By analyzing this discourse, it is clear the adoption of different professional practices in the treatment of more or less economically disadvantaged people, besides showing a longer delay to meet the needs of lower social class users, as well as harsh and disrespectful attitudes by professionals. . There is evidence that health workers practice iniquities by granting advantages to socially privileged users in terms of access to diagnostic services, hospitalizations or waiting times for care (MENDES; JUNIOR, 2001), as well as discrimination against economically disadvantaged people. (GOLVEIA *et al*., 2011; BAUMGARTEN *et al*., 2015). The different spaces of health promotion and care should defend fundamental human rights and reduce inequities; however, a series of complaints and studies reveal potentially discriminatory treatment to certain users in health services (CABRAL *et al*., 2005). Such postures are unacceptable at any time, especially when people are weakened by illness. This problem cannot be ignored and permanent health education can represent a great device for the collective reconstruction of everyday labor reality, considering that it presupposes critical action and reflection (ÁVILA *et al*., 2014). A policy to combat discrimination, privileges and social inequalities that despite the overwhelming evidence of social discrimination in health services does not yet permeate the SUS. This agenda must be prioritized and guided by actions that inhibit such practices and avoid stigmas.

Next, the CSD 3 is allusive to a potential attention to the user, based on IC 3: They are cool, happy and put me up.

> *"When the staff at my post learned of the diagnosis, they went home to pick me up. Nursing gives you an easy smile, they are always happy and they put you up, come and give you a hug. The cleaning people are also very nice, when I'm home, come visit me. It's nice to have a friendship with the professional. The doctor was also very nice and helped me a lot, he said that everything would work out, because his work was a function of life and with faith in God, everything would work out "(P1, P15, P19, P13).*

The content of this CSD demonstrates the implication, commitment and affection of professionals towards patients and is in contrast to the findings of previous studies that

highlighted the lack of humanized and welcoming care (MOIZAS *et al*., 2010) and the predominance of authoritarian practices by health professionals health (MENDES; JUNIOR, 2001). There is joy and affection in the meeting between professional and user, represented by the nurse's embrace, the visit of the cleaning workers and the positive and welcoming attitude of the doctor. In this situation, the encounter permeated by affection is very powerful, in the sense that affectivity can mediate transformative actions (SAWAIA, 2003; GLEIZER, 2005). Emotion and affective relationships are inherent characteristics of the human being and become even more evident in the care process. The idea of non-emotional involvement should not be possible in health care. Relationships and affects are the factors that drive the professional to perform care in a way that surpasses the limitations of technical-scientific knowledge (MENEGÓCIO *et al*., 2015).

Friendship was also an aspect identified in CSD 3, as can be observed in the excerpt "*It's nice to have a friendship with the professional...*". It is perceived an atypical posture of the professional, as he usually keeps some distance from patients, especially cancer patients, because cancer is a chronic degenerative disease that causes suffering to both sick people and their families, as well as professionals of health. Nursing professionals must be equipped with conditions to exercise good technique, but that is not all, as nursing actions should promote holistic care for the individual (DUARTE; NORO, 2010). The patient should be viewed as a person with feelings, thus, respect and affection should be incorporated for helping to make the patient more peaceful and secure in the treatment. Although involvement with the cancer patient may cause suffering to the professional, this relationship may also produce a sense of gratification. Contrary to what was perceived by professionals in this CSD, workers usually do not approach patients. In Brazil there are gaps in the training of health professionals to deal with the common terminality present in cancer patients, which can interfere with the provision of comprehensive and humanized care (SANTANA *et al*., 2009; AMADOR *et al*., 2011). It is appropriate to highlight the excerpt from this CSD, "*...and with faith in God, all would be well...*". From the user report it is noted that the professional involved in this circumstance inserted in his care the religious dimension, an unusual event, which contradicts the fact that health professionals commonly do not understand the spiritual and religious field as part of the patient's therapy, although respect it impartially, but disregard it as a therapeutic approach (ALVES *et al*., 2010). In this perspective, by accepting that there is no humanized attention without considering all dimensions of the user, respect for religious and spiritual aspects is essential for professionals seeking best practices. Therefore, a paradigm shift is needed in relation to the biomedical model, which considers only the technical and biological issues in the therapeutic approach.

The CSD 4 was built from IC 4: They treat me well, with respect and affection, when referring to the performance of nursing technicians.

> *"I call and they come, everything I need they are always available, they never told me anything I didn't like, they always treat me well, with respect and affection. Nursing is spectacular, because it changes us with love. One day I was embarrassed because I had diarrhea and pooped every twenty minutes. But they always came with a smile on their faces to change me (P1, P18, P23).*

By analyzing this discourse, it is clear that the professional positions himself empathically in relation to the patient. Such attitudes favor the establishment of welcoming and bonding with the user, guiding axes in health care, when quality depends on the relationships that are developed and strengthened between professionals and users, true partners in the search for health services. Garzin and Melleiro (2013) analyzed the ethics that permeate the quality of nursing care and found individuals who felt welcomed by these professionals in 84.3% of cases.

It is noticed that the technicist practice, still common in health, is not evidenced in this CSD, this may be due to a change in teaching. In this context Fracolli and Castro (2012) found in their study that they intended to discuss the competences that were in use in undergraduate nursing education, the weakening of the supremacy of technological education, because teaching in the researched school valued the human being, the solidarity, the caregiver. DSC 4 demonstrates that users are satisfied with the service they receive. In a systematic literature review study on user satisfaction with the nursing service, users were satisfied with emergency nursing care. Attributes of friendliness, courtesy, respect, comfort measures, information sharing and professional competence were strongly valued by users. However, it also pointed out negative aspects related to satisfaction, such as the long waiting time for care, the inability to share feelings, depersonalization and the lack of help in understanding the disease. It also identified that interpersonal relationships such as sympathy, courtesy and respect, in addition to aspects of professional competence, have a strong influence on the satisfaction and expectations of those receiving care (ACOSTA *et al*., 2016). The aspects identified by Acosta *et al*., (2016) that are valued by users, such as friendliness, courtesy and comfort measures were evidenced in DSC 4. Although this discourse demonstrates user satisfaction regarding the care received from Nursing Technicians, in parallel. CSD 1 and CSD 2 show care practices with serious gaps in the scenario of humanization and comprehensive care. There are policies that induce humanized care and this aspect of health care has been explored in daily training and health services often, however, there are still opposite attitudes to what is advocated as a humanized care.
This study was developed in a single health service and distinct professional practices were identified in relation to light technologies and humanized care. This fact demonstrates that in relation to working conditions, it is the choices and individual postures of each health worker that determine their practices, which can be aligned with the precepts of humanization or not.

It is argued that it is necessary and possible the adoption of an empathic posture, with attention and affection in care, regardless of the negative factors that are usually present in the personal and professional life of each health worker. Such attitudes should be part of the health professionals' toolbox, which should at all times prioritize the production of life with the people under their care.

CSD 5 presents IC 5: "I feel well cared, they are competent and caring".

> *"In the post I was in a lot of pain and nothing and nothing to improve, so the professional acupuncture on me. Here doctors and all professionals give me a lot of freedom and they answer exactly what I want to know. They are always*

joking and talking, there is a doctor, who only her way already raises the mood of us. The doctor gave me the greatest strength, I feel well taken care of by the doctor and also by nursing, because they are competent and affectionate with me. But we realize that they have a restriction not to get too involved with the patient and not to be very friendly (P2, P3, P7, P8, P9, P11, P23).

In the analysis of this CSD, the power of the meeting between worker and user is highlighted (FRANCO; MERHY, 2013). From this meeting, regardless of institutional norms, the self-governance capacity of individuals is evident, which in this case intervened in the user's pain situation through acupuncture.

In the same perspective, the following excerpt is verified as the professional's posture can interfere with the patient's mood: "*...there is a doctor who only her way already raises our mood...*". Emotional status is an aspect that greatly affects the health of the individual, so attitudes such as those identified in the CSD 5 are highly fruitful in health services, since emotional disturbances impair the proper functioning of the immune system, can cause biochemical changes and constitute thus one of the factors responsible for the origin and development of diseases. The influence of psychological factors on biological aspects has been demonstrated by studies with a type of cell produced by the immune system, the Natural Killer (NK) cell, which has an association between some psychosocial variables and their functioning (GLASER, 1989).

Another aspect evidenced in the CSD 5 was the professional's distance from the patient, a situation that can be explained due to the unpreparedness to deal with the other, associated with the position of superiority of the professional for working in a health service and the other needing this servisse (COELHO; JORGE, 2009). The distancing may also be related to the feeling of helplessness in view of the typical severity and terminality found in the oncological specialty. This aspect was striking in the study by Silva *et al*. (2015b), as well as the sadness, anguish and insecurity reported by undergraduate Nursing students participating in the research, as well as the evident distance between professionals and users. Similar findings were identified in a review study, which showed that through the emotional unpreparedness of the nursing professional to deal with the patient at the end of his life, this worker, in most cases, assumes a posture of removal of the patient and his Family (ROSA; COUTO, 2015). In the analysis of this aspect, it is worth mentioning the importance of providing emotional support to health professionals, an aspect that is commonly disregarded not only by institutions, but also by public policies.

Another possibility that may be associated with the distancing of the professional from the patient was highlighted in a study by Silva *et al*., (2015a), which identified among health professionals a higher frequency of Burnout Syndrome in nursing professionals. They are exposed to causes that directly predispose to the onset of this disease, such as high work demands, excessive workload, stress caused by direct contact with the patient and their companion and the multiple responsibilities attributed to the nursing professional. From this perspective, it is noteworthy that there is still the exercise of power relations in the performance of work in health services, which commonly reduce the patient to object of learning / labor productivity and disconnect him from his active and critical role to face the problem disease and its treatment. Finally, the CSD 6 enables the identification of significant problems in the performance of care. Such a CSD was built with the Central Idea "disrespect".

"He didn't even get up from his chair to examine me and said the pain in my mouth was from the cold, nor did he look at my exams that were all with me and said it was dengue. And then he punched me there about forty pills and the other day I had to go back, then he gave me the prescription before I finished talking. I also had a lump in my breast and he told me it was breast dysplasia without asking for any mammogram or ultrasound. And now that I'm hospitalized, when I call the nurses they take a lot to come see me. I was hospitalized for four days and there was no doctor to see me, none. These days I asked them to take a shower and only got it four hours later, and the bomb goes off and no one comes. Also one thing that caught my attention is that here in the hospital there is that poster with a woman asking for silence, but sometimes it's a noise and a mess" (P1, P2, P10, P19, P25).

The delay in performing care and meeting patient requests evidenced in CSD 6 may be related to the large workloads of Nursing staff, which would imply difficulty in performing differentiated work, due to the high demand for service (GUEDES *et al*., 2013). This fact also points to the gaps between protocols and regulations that are proposed by public health policies and what is achievable by those who implement them in the field of practices (SILVA *et al*., 2013). In the same speech, another evident aspect was the lack of complete medical history and physical examination by the professional, as shown in the following excerpt "*…He did not even get up from his chair to examine me and said that…*", This finding corroborates the statement by Pessini (2007) who points out that with the support of laboratory and imaging tests, which are increasingly specific to certain diseases, anamnesis and dialogue with the patient have been disregarded. Due to the new and sophisticated techniques of elucidation of diagnoses and treatments, attention is reduced to the patient's experiences and subjectivity (RODRIGUES, 2004; CAPRARA; RODRIGUES, 2004).

Having waited four hours for the bath, for a procedure that promotes well-being, certainly generated distress and suffering in the user and exposes the possibility of misunderstanding. However, in order to establish humanized relationships with users of health services, it is necessary that the professional be sensitive to the suffering of the other (CYRINO, 2004). This fact, often due to the busy daily life of the service and aspects related to professional / personal training, unfortunately is still common in health production actions. The same CSD alluded to the disrespect for the hospital environment, referring to excessive noise and disorganization by professionals, which reaffirms the need for reorientation and qualification of ethical training of health professionals (SIQUEIRA, 2009). Promoting a peaceful and quiet environment is essential for the patient's recovery and well-being. Therefore, the professional acting in the exposed scenario should think about their practices and empathize with the patient's needs. Listening to the user is an intriguing task, especially considering the points mentioned in the speeches that refer to the practices that are strongly rooted in health practice by all professionals. From the content of the

CSD presented, it is noted how complex this scenario of professional-patient relationship, care itself and the incompleteness of actions that are generally performed with the intention of instituting the rebalancing of the health-disease process. This becomes even more special in the context of cancer patients, who have a weakness in the way they experience the dynamics of the disease.

Final considerations

According to the patients, there were weaknesses in the study service, which demonstrates that important aspects for humanized and patient-centered care can be disregarded. These findings point to the need for change in the way professionals act in daily life, when the precepts of ethics and valuing others should be more present, so that the suffering inherent to the health-disease process in question is minimized. Positive aspects were also evidenced, which demonstrates that professionals, even in the same institution, governed by the same norms, coming from similar backgrounds in the same policy can present their own unique behaviors. Thus, it is clear that the proper, cultural, ethical and moral issues can exert a significant influence on the behavior of health professionals.

It is important that institutions recognize the relevance of relational and personal issues in the context of micropolitics, in the dynamics of work and thus make efforts to favor the work process, based on the development and reflection of this aspect. Even in the face of difficulties, having the self-governance capacity that each worker presents, it is possible to obtain benefits for patient care. Thus, the practice of dignified and authentic care may be more closely related to relational and personal issues, where the micropolitics of care that is inherent to the worker has great influence and should be valued in the organization of services.

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