

## Waiting room of the bone marrow transplant outpatient clinic: patient and companion experiences

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**Abstract:** Hematopoietic stem cell transplantation is a highly complex procedure that is becoming an alternative to some potentially serious diseases that trigger a series of conditions. The purpose of this study is to examine what the patient experiences during the transplant process, specifically while awaiting care in the waiting room. Using the narrative as a method of research, we work with the concept of unconscious, whose reference is the psychoanalytic theory. Results found refer to two axial points: the subject's immixing, i.e., how the issue of identity passes through the otherness; and the expectation of answers in a clinic where organic changes can be very threatening in their evolution. The path traversed gives rise to questions on the role of the word in hospital institutions and concludes with the proposal that we expand our view on those of whom we care.

**Keywords:** hematopoietic stem cell transplantation, occupational therapy, psychoanalysis, interdisciplinary research, hospital outpatient clinic.

### The beginning: issues observed in this space

Bone marrow transplantation (or hematopoietic stem cell transplantation - HSCT) is a highly complex procedure that has become a therapeutic alternative for several types of solid neoplasms, malignant or non-malignant hematological diseases, metabolic diseases and immunological deficiencies. Faced with a serious and occasionally fatal illness, followed by an often aggressive therapy with a highly invasive procedure that interrupts the continuity line of existence, patients face a number of limitations. And time, which may be little for a few and for others an eternity, is directly related to the reconstruction of the daily life of individuals who survived the transplant. Patients who have passed through this experience have an imperative need to rebuild their lives (Mastropietro, Santos, & Oliveira, 2006).

The path traversed by patients until reaching the HSCT is usually tortuous since they have already suffered from the impact of the diagnosis of a potentially fatal disease that triggers various types of conditions. Such conditions do not reach only those who become ill but extend to the whole family universe, imposing changes that require family dynamics reorganization to incorporate the care the disease and treatment demand into the daily routine (Oliveira-Cardoso, Mastropietro, Voltarelli, & Santos, 2009). In the waiting room of a

transplant center, patients and their companions await care. In this environment, one can become a reference, a mirror, to the other; many are the feelings that blend and emerge from this coexistence. Making this a constructive and less painful space has become a goal for us. Therefore, listening to the wishes and giving voice to these subjects was a path we sought, and part of this is portrayed in this research project.

This study starts from the observation that, during the stay in the waiting room, many exchanges occurred between patients who were at different stages of treatment. Due to the strangeness generated by the proposal of a new, unknown treatment that caused profound changes, we found the quest for sharing experiences and expectations was very frequent among those awaiting care. However, the effects of these meetings were different for each patient, according to the patients' own reports to the researchers. Starting from the question raised, we set out to investigate what the patient and their companion experienced while in the waiting room.

It should be noted the main objective of this study is to highlight aspects that have received little attention regarding transplantation. When the psychological issues are approached within the scope of the procedure, the chosen bias usually refers to the patient's adherence and the measurement of the quality of life, as can be observed in one of the main references on the subject, the book *Transplantation of hematopoietic stem cells* (Voltarelli, Pasquini, & Ortega, 2010). The success of the procedure starts to be sized from

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the functionality, or dysfunctionality, of the transplanted individual; and results are focused on quantifiable assessments, failing to capture what has been experienced by the patient (Kelly, Ross, Gray, & Smith, 2000).

The valuation of the quantitative aspects, to the detriment of the subjective ones, is not accidental. It responds to the current model, based on evidence associated with numbers, graphs and images. We intend to show the effects of listening to the patient may be of a different order than the ordinary notion of evidence. These effects can then be clearly established; but not always measurable. But what would be the space reserved for singularities? How to work under the prism of science and yet look at each one? And in a transplant unit, where the treatment passes through the incorporation of another into oneself, what is the space given for listening to the consequences of the use of such biotechnology?

From these questions, this research also translates the effort of an interdisciplinary work, as it was elaborated by professionals from different areas – Nursing, Occupational Therapy and Psychology – that follow the routine of this hospital institution. Thus, through the narratives, the project “Waiting room at the bone marrow transplant center” focuses on the examination of the patient’s experiences during the process, which have been little considered in scientific productions on the subject. It deals with the concept of the unconscious – which presupposes the idea of a cut, a discontinuity with the sphere of knowledge – and refers to another epistemological bias, whose reference is the psychoanalytic theory. Finally, it also has an interface with other areas of knowledge, proposing a dialectical relationship between psychoanalysis and biotechnology-related knowledge.

## The narrative as method

Narrating is the “faculty of exchanging experiences,” and these are the source of the narratives. And one of its characteristics is a certain utilitarian dimension: the narrator is someone who “knows how to advise”. However, advising is not so much answering a question, it is more about the possibility of making a suggestion, so that the history can follow (Benjamin, 1987). For these reasons – and thinking of the research object, that is, the interaction of service users in the waiting room – this method was chosen.

It should be emphasized we do not intend to work as if the words were univocity, nor as if the reports were reliable constructions as to what is happening. We are not interested in confronting the truth of what is told, but it is precisely in the lapses that we bet that something of the subject may come about. Likewise, we do not think of time in a chronological context – which would lead us to an attempt at normalization as to the stage in which the patient is. Rather, what we observe is the timelessness of the psychical processes, which is revealed when an

event of the present can only be elaborated *a posteriori*. Or when, even after being considered cured by the medical standards, there is a threat that remains to the patient, often manifested as the fear that the disease will return and be fatal. For the reasons listed and due to transiting in a field that is realized in the evanescent and the timely, we understand the methodology used approaches the practice with psychoanalysis, which justifies our choice for this referential (Bianco, Costa-Moura, & Solberg, 2010).

According to Benjamin (1987), the classic narrative has fallen into disuse with the growth of capitalist culture, in which values prevail that are in line with this economic model, such as individualism and large-scale consumption. The narrative, as the author says, requires that some conditions be present.

The first condition is that narrator and listener share the transmitted experience. It implies the notion of witness, “he who does not go away” but who accepts the words of the other as a means of carrying forward his story. It also implies the idea of transmission as a dimension that transcends the individual, because it will concern those who come later. What interests us are the trimmings that one draws from the experience of the one who narrates, the waste; and which constitute what we call symbolic (Gagnebin, 2006).

The other condition for the narrative to happen is that there is a time for such sharing. In this way, the artisan activities propitiate this exchange, in a community supported in a rhythm that makes possible its organization between life and word. Concurrently, like the artisan, the narrator leaves his traces in what he reports, thus imprinting his mark on the narrative.

Finally, it is necessary that narrator and listener be inserted within a common and living narrative stream. Reports obtained are not submitted to a search for a single, absolute and universal meaning. On the contrary, they just keep their potency by not being given explanations or justifications, instead, they remain open to future readings. What one is looking for are snippets of stories, in a joint narrative between the narrator and the listener. At this point, the difference between the narrative and what would replace it is marked: information and romance. This second is characterized by telling the story of a character and his search for the meaning of what affects him. Information, in turn, refers to the plausible and verifiable, containing in itself all the explanation and demanding veracity; for this reason, it is closer to the technological era (Benjamin, 1987).

Considering these characteristics, we do not propose a return to the classic narrative but, as already mentioned, an approximation between it and our practice, to carry out the research. Such approximation is a project elaborated and executed – after approval by the Research Ethics Committee of the National Cancer Institute under the CAAE number: 53128116.3.0000.5274 – in partnership with the Center for Bone Marrow Transplantation of INCA (CEMO/INCA) and the Federal Institute of Science and Technology of Rio de

Janeiro (IFRJ), consisting of two phases: the realization of occupational therapy (OT) activities in the waiting room and the application of a questionnaire. These phases were independent, i.e., participants who answered the questionnaire were not necessarily those who participated in the OT activities. However, we observe a congruence between the users' remarks – recorded in the next topic – and the written accounts.

To fill out the questionnaire, patients and/or companions who were waiting for care were randomly selected. The purpose of the study was explained, emphasizing that participation was voluntary. Those who agreed, after reading and signing the Free and Informed Consent Term, were asked to fill out the questionnaire, individually and confidentially, whose main question consisted of asking them to tell how they felt during their stay in the waiting room of the transplant center outpatient clinic. It should be noted the verb “to tell” was carefully chosen – since it refers to everything we have said about narrative –, as well as the emphasis given to our main interest, which was, in fact, how they experienced that moment. There were 14 participants (10 patients and 4 companions), all over 18 years old, whose treatments were in different stages: from pre-transplantation to three years after it. In order not to exclude people with writing difficulties, it was foreseen in the project that, in case any participant was unable to write, one of the researchers could record, *ipsis litteris*, whatever was said. This circumstance occurred in only one case and the final record was submitted and approved by the participant.

## The report of occupational therapists

Understanding the waiting room as a place of exchange, the activities proposed by the occupational therapists were in the field of artistic and recreational activities, which present different possibilities of expression. There were many limits to be observed: lack of adequate space, restriction on the use of materials that could bring risk of contamination or any type of immunological reaction, extremely diverse age groups and treatment stages, as well as the interests derived from each participant's peculiarities. Thus, storytelling and origami were proposed to contemplate the interests and respect the inherent limitations of the clinic.

The choice for these activities was also due to the effects they carry; as in the case of storytelling, when some refer back to childhood memories. An example of this was observed in one of the participants of continuous frequency in the waiting room, which had “tales” that, according to him, were “real”, albeit always experienced by third parties (*sic*). Such tales were significant in his life, for they taught him respect for nature. He called himself a “farm person;” the contact with nature brought him respect, but also the fear of what he was told throughout his life, such as the dangers of entering the forest at inappropriate times. What we observe is that such stories

mediate their relationship with reality, even with the treatment itself.

According to Lemos and Silva (2012), there is no contraindication in storytelling. It is fundamental that there is respect, ethics and delicacy in the selection and adequacy of the stories to the public and their needs, so that the encounter of the imaginary with the real is a soil of comfort, relaxation and learning. The comfort produced by listening or storytelling can reduce fear, stress, and distress in waiting for the consultation or exam result.

This possibility of re-signification of existence and intervention in external reality from the intention and desire of each one we encounter, often mediated by doing, is a motto of work for occupational therapy. According to Jorge (1990), human activities should be understood as occupations and, “before being understood as any work, they must be understood as an active way for the patient to intervene in the world and, thus, to actively be with himself and with others” (p. 19).

One of the cases illustrating the effects of working with origami was a gentleman who participated for the first time and stayed for a few minutes with the group. He had never participated in the activities of the waiting room and, at first, came in hastily and half suspicious, but allowed himself to make a boat through the folding technique. While doing the folding, he went on to tell how much that went back to his childhood; between smiles and stories, the activity lasted about 15 minutes and then he was called to the consultation. After about 30 minutes, this gentleman returned to the waiting room to bid farewell. Spontaneously he told us that we had no idea how much having performed the folding and being with us was important to him.

Another situation that made it clear that being in activity reduces the anguish and stress of waiting was that of a child who provided us a good meeting. Throughout one morning she was in our company performing origami, suggested some, learned many others, talked and laughed. By the end of this morning, two people from the medical team called her saying it was time for the hospitalization. She asks to finish the activity, takes one of the origami she had made with us to the hospitalization and leaves a little less tense, without having told us at any moment that this morning was the day of her hospitalization. An important detail is that the child kept doing the folds during the hospitalization, at a time when she was very restricted – about the possibility of playing – due to the procedure. This situation allows us to infer about not talking about what leads them to the hospital, while allowing us to talk about what each one's life has of most precious.

Being in the waiting room and producing something that was not just narratives of a sickening process was, for most people who were with us, a time to bring up their stories and rebuild them. A companion showed us this: although she did not participate in the making of the origami and in storytelling, the mother

of one of the patients became very present in all the meetings she had with us in the activity room. During the mornings there, she assisted those with difficulties, invited others to participate in the activities by saying how “they were good” (sic). Besides, this mother could, at each meeting, tell some of her history. At the same time, her daughter – who always participated but spoke very little – kept herself involved with the folds even when she was outside the waiting room, showing how much the work reverberated in her.

Storytelling and origami in the waiting room allowed us to observe that, even for brief moments, some participants allowed themselves to forget they were in a waiting room expecting consultation. So much so that some even delayed going to the office when they were called, to continue hearing the stories or developing the origami. This “forgetfulness” has made us reflect on the potential of artistic and creative activity. These were moments of exchanges of affection and transmission.

## The results obtained

Before we look at our findings, we must remember that in the history of psychoanalysis the concept of psychic apparatus has undergone some changes. In this article, we will adopt as basis the notions of ego, id and superego as the formative instances of subjectivity, as presented in the Freudian texts from 1920. We will also refer to the records of real, symbolic and imaginary – concepts belonging to the Lacanian clinic and also concerned with subjectivity. About these, we shall remember – in a very synthetic way – that the real should not be confused with reality: it refers to what is barred, to what escapes being symbolized, and it is precisely because of this correlation that it can be recognized. The symbolic corresponds to what distinguishes man (cultural, lives under the laws of society) from the animal (possessor of instincts, follows its nature) and that founds the unconscious. It precedes man and is the condition for the subject to come. The imaginary, in turn, relates to the image of the other and is updated in a specular way, as an identification.

Returning to the results found, these refer to two axial points, which unfold in some notes. The first axis we are confronted with is the subject’s inmixing: how the issue of identification necessarily passes through the otherness and its correlation with the recognition of what affects us. In two reports, specifically, we found the importance attributed to the meeting, in this place, with people in whom one can see something of oneself:

*I feel privileged to be here because I see many people begging for a vacancy, and I thank God for being here, when someone complains about something I say “I just have to thank”, I’m well treated, I try to help her understand that who makes the environment is us.* (Patient, 1 year and 11 months post-HSCT)

*I feel good, slowly I get to know the struggle of each one here, some laughter helps passing the time, when we are here we realize that we are all the same and that is what matters.* (Patient, 1 and a half months post-HSCT)

In talking about psychic suffering over time, Dunker (2014) brings us important contributions. He tells us that, before psychoanalysis, suffering was either a medical problem – which required a drug intervention – or a moral problem, requiring a pedagogical correction. With the advent of psychoanalysis, it begins to validate an experience of another order. In his theory, developed from his work with the hysterics, Freud realizes the cause of suffering was in the words – often unsaid –, as well as reminiscences. One of the (several) consequences of this theory is that, when someone has their pain recognized socially, there is a kind of movement to identify with that suffering. And the justification for such a tendency is that, when listening to a person claiming that a particular symptom is a form of saying “I am suffering and need help,” the subject may also make a demand. As if they were saying, “What is happening to them happens to me too, I can use this medium to make a request, a plea for recognition for this suffering.” Because pain is liable to have a representation, it can be shared through the symbolic, the word.

What is implied in this process is that the instance of ego is not primary – but the product of a psychical work, which will occur from the impressions received from the external world and from the memory remains there – and the whole process of its generation passes through the otherness. Freud (1923/2006) maintains that the body exercises a function in the formation of the self, which “can thus be regarded as a mental projection of the body surface” (p. 39), as a result of corporeal sensations. But that does not give it an exclusively genetic determination. When we are born, what exists is only a biological mass, entirely dependent on the care of someone who accepts and responds to our reflections, giving them meaning. It is only from this welcoming and investment by others that our psychic life begins: it comes to us from outside (Pacheco, 1996).

Still on the formation of the psychic apparatus, Lacan (1953/1986) makes a fundamental contribution in his dissertation on *The stage of the mirror*. Briefly, he tells us this stage is constituted from the moment in which the baby assumes as its own the image seen by the adult that holds him in front of the mirror. This *gestalt* is introjected; that is, it is not a natural perception of self, but something the baby identifies as being its body image – through what the other tells them –, which will intermediate its relationship with the external world. The mere sight of the human body as a whole gives the subject an imaginary domain of his own body; even before the motor domain. The subject anticipates the conclusion of the psychic domain and such anticipation

will mark their style in the later exercise of the real domain. This would be the primordial form of the self, correlated with the imaginary dimension, although already crossed by language.

It is at this level that the subject's image allows them to begin to situate what integrates the self or not. And the point we reach is that if, on the one hand, we constitute ourselves from what we introject – mediated by the symbolic –; on the other, there are things we do not want to know. "After all, there are perhaps internal limits to what can be said," according to Lacan (1953/1986, p. 306). The main function of the self, then, concerns its scale between dominator and dominated, repressor and repression: its job is to determine which ideas should reach consciousness and which ones should not. Still answering the question on how they felt in the waiting room, we see three precious accounts in this direction:

*I feel good, I like to talk to other people, to exchange experiences, with that we gain several experiences, but I try to absorb only the good, because each case is different from another.* (Companion of a pre-HSCT patient)

*I was expecting care once, and I heard a person talking about someone who went blind from the graft disease, and I was terrified, very afraid of becoming blind. As I was oriented by the doctors and psychologist I realized this does not happen as such, that you have to do the right procedure so that nothing bad happens.* (Patient, 4 months post-HSCT)

*Anxious. Relieved, crazy to be called and know the results of the exams. I like to stay in the dining room. I stay with transplant friends, I just do not like it when someone comes near me to talk about other patients who have not resisted and died, it makes me very sick.* (Patient, 8 months post-HSCT)

The second axis we found in the research is related to the expectation for answers. In a clinic where organic changes can be quite intense and rapid in their evolution, the problem of time – which is revealed in waiting – and of space – which is expressed in the contact with the waiting room environment – are frequent. Depending on the response, the patient may have the course of his life altered again, since the treatment often requires a hospital stay that directly interferes with their life routine and of their companion.

*Desperation, relief, crazy to be answered and know what you have, depending on the outcome. I do not like to talk about illness, I like to stay in the dining room. I'm a person who talks a lot, but I keep to myself at those times.* (Patient, 2 years and 8 months post-HSCT)

*I do not know why, but I do not have much patience to wait, I soon get annoyed to expect too much. Today the day for me is being horrible. It really pisses me off, I get really irritated.* (Patient in pre-HSCT)

*A little lost, impatient with the delay, it seems that I am in prison, and very anxious.* (Companion of a patient in post-HSCT for 6 months)

*Generally well, because the service is good and fast, but I find the waiting room a little cold, sometimes I get a little annoyed with the kids who play in the hallway, they make noise and bother even those who are working.* (Patient in pre-HSCT)

*Sometimes I am well, others I'm not, I am sad to see many children sick and unable to do anything. Sometimes it takes too long and nobody says anything about the doctor coming, or time passes and nothing happens! We cannot say anything. Just wait and invent something to do, tell stories, jokes, cell phone and so on.* (Patient, 2 years of post-HSCT)

We believe that the last report speaks well of what affects the patient in this place. Waiting for answers – whose impact on people's lives is always significant – is extremely distressing. On the other hand, the confrontation with the sufferings imposed by the disease, such as the inability to intervene in what one sees – present in the reference to children's suffering and in oneself – can be a source of great anger. It is important to stress the frequency with which aggression manifests itself in this clinic. An important step would be to consider that it is not about impotence – this is the generator of affections like frustration and animosity – but about what really escapes us, that is, our limits. And, perhaps, the finitude is the maximum representation of what limits us.

Returning to the issue of space, some participants mention they would like to stay in a "less icy" room, a cozier place to rest and read" and, finally, they say they even feel "good. . . The professionals are very attentive".

## There is still much to do

The path traversed gives rise to questions on the role of the word in hospital institutions – and, consequently, the role of the subject – in a hospital institution. A major problem faced in this trajectory was the lack of publications with the contribution of psychoanalysis in this field. On the other hand, this brings a certain novelty to the study and implies a *pari passu* construction between clinic and research.

The option for transplantation is less of a choice and more of a submission to the only path that is presented to the patient with certain potentially serious diseases. Only by this beginning, one can infer that deciding to

submit is something that undergoes a series of crossings. At the same time, because it is a relatively new procedure and has undergone some modifications in recent decades, its dynamics are still quite unknown to the general public. Such characteristic leads to, on the one hand, myths about it are fostered, and on the other hand, transplanted patients do not find – outside the institutional environment – people with whom they can share their experiences, given their uniqueness. Thus, it is extremely difficult to share what they have experienced, with little social recognition and consequent isolation. These combined aspects favor that much is spoken within the hospital, but these speeches do not seem to find a place to which they refer. Less often than they need, patient and companion have their speeches taken in order to experience that suffering has not been in vain. At this point, we return to the function of witness, as one who accepts the account, without withdrawing. When faced with another who listens to them, the patient and his companion can create new meanings for what they have lived and new bonds that support them in the face of uncertainties of the way. Hence the importance of giving place to these reports within the institution.

Concurrently, the invasion of science into almost every area of life causes in man the illusion that everything can be answered by it. Therefore, the expectation is that, in

the face of any threat to its integrity, science will intervene and put an end to its suffering. However, there is a distance between what is propagated and the practice of care itself, still far short of the illusion of eternal life. Specifically, with regard to bone marrow transplantation, the path is surrounded by uncertainties, due to the absence of total guarantees. This is how, faced with the limit, with the impossible – even with so much technology – patients and companions feel helpless, as if confronted with a promise that someone failed to fulfill. As a consequence of this helplessness, the most commonly seen pictures are of anguish, anger and impotence. This might not have occurred if there were greater clarity as to the limits of man, but this is not a topic valued by the current culture.

Many questions remain unanswered; however, some answers came from that experience. The realization of the project has transformed our relationship with patients and families, making the waiting room more than a physical space where users and staff travel. In it, we create the possibility of thinking and rethinking the present, as well as of making changes. We tighten the bonds and built a relationship that was not restricted to the professional/patient condition, but to the human condition. We dare say that, in a certain instance, their speeches also represent us. After looking at our patients and collecting their reports, we follow the proposal to expand our view and listen to those we care.

### **Sala de espera do ambulatório de transplante de medula óssea: experiências de pacientes e acompanhantes**

**Resumo:** O transplante de células-tronco hematopoiéticas é um procedimento de alta complexidade que vem se constituindo como uma alternativa para algumas doenças potencialmente graves e desencadeadoras de uma série de afecções. A proposta deste estudo é examinar aquilo que o paciente experimenta durante o processo do transplante, especificamente, enquanto aguarda atendimento na sala de espera. Utilizando a narrativa como método de pesquisa, trabalha com o conceito de inconsciente, cuja referência é a teoria psicanalítica. Os resultados encontrados remetem a dois pontos axiais: a imissão do sujeito, isto é, como a questão da identidade passa pela alteridade; e a expectativa por respostas em uma clínica em que as alterações orgânicas podem ser muito ameaçadoras em sua evolução. O percurso feito dá ensejo à pergunta sobre o lugar da palavra na instituição hospitalar e conclui com a proposta que ampliemos nosso olhar sobre aqueles de quem cuidamos.

**Palavras-chave:** transplante de células-tronco hematopoéticas, terapia ocupacional, psicanálise, pesquisa interdisciplinar, ambulatório hospitalar.

### **Salle d'attente de l'ambulatorio de greffe de moelle osseuse: expériences de patients et leurs accompagnateurs**

**Resumé:** La transplantation de cellules-souches hématopoiétiques est une procédure très complexe, qui représente une alternative pour certaines maladies potentiellement graves et capables de déclencher une série d'affections. Le but de cette étude est de s'attarder sur ce que le patient éprouve lorsqu'il se trouve dans la salle d'attente pour se faire soigner. Prenant le récit comme méthode de recherche, l'étude s'utilise du concept d'inconscient, emprunté à la théorie psychanalytique. Les résultats nous remettent à deux points axiaux: l'immixtion du sujet, c'est-à-dire, la manière dont la question de l'identité passe par l'altérité et l'espoir d'entendre des réponses au sein d'une clinique où les altérations de l'organisme peuvent se révéler très menaçantes au cours de leur évolution. Le chemin parcouru soulève la question de la place occupée par la parole dans l'institution hospitalière et conclut par la recommandation d'amplifier notre regard sur tous ceux à qui nous apportons des soins.

**Mots-clés:** transplantation de cellules-souches hématopoiétiques, thérapie occupationnelle, psychanalyse, recherche interdisciplinaire, ambulatorio hospitalier.

## Sala de espera del ambulatorio de trasplante de médula ósea: experiencias de los pacientes y sus cuidadores

**Resumen:** El trasplante de células madre hematopoyéticas es un procedimiento de alta complejidad, que se constituye como alternativa para algunas enfermedades potencialmente graves y desencadenantes de una serie de afecciones. La propuesta de este estudio es examinar lo que el paciente experimenta durante el proceso de trasplante, específicamente mientras aguarda en la sala de espera. Utilizando la narrativa como método de investigación, se trabaja con el concepto de inconsciente, cuya referencia teórica es la teoría psicoanalítica. Los resultados encontrados remiten a dos puntos centrales: la intromisión del sujeto, es decir, como la cuestión de la identificación pasa por la alteridad; y la expectativa por la respuesta en una clínica en que las alteraciones orgánicas pueden ser muy impactantes en su evolución. El recorrido realizado da lugar a la pregunta sobre el lugar de la palabra en el hospital, y concluye con una propuesta para que amplíemos nuestra mirada sobre aquellos que cuidamos.

**Palabras clave:** trasplante de células madre hematopoyéticas, terapia ocupacional, psicoanálisis, investigación interdisciplinaria, servicio ambulatorio en hospital.

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