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## ORIGINAL ARTICLE

### HUMANIZATION OF CARE IN BONE MARROW TRANSPLANTATION: THE PERCEPTION OF THE NURSING TEAM

#### HUMANIZAÇÃO DA ASSISTÊNCIA EM TRANSPLANTE DE MEDULA ÓSSEA: A PERCEPÇÃO DA EQUIPE DE ENFERMAGEM

#### HUMANIZACIÓN DE LA ASISTENCIA EN TRANSPLANTE DE MÉDULA ÓSEA: LA PERCEPCIÓN DEL EQUIPO DE ENFERMERÍA

Rosiane Mendes da Silva<sup>1</sup>, Kelli Borges dos Santos<sup>2</sup>, Girlene Alves da Silva<sup>3</sup>, Valesca Nunes dos Reis<sup>4</sup>, Angélica Mônica Andrade<sup>5</sup>

#### ABSTRACT

**Objective:** to understand the meaning of humanization in bone marrow transplantation according to the perception of the nursing team. **Method:** qualitative study. Data were collected through semi-structured interviews conducted with ten nurses working in a bone marrow transplant service of Minas Gerais and analyzed using content analysis technique. The project was approved by the Research Ethics Committee, CAAE 0074.0.420.000-11. **Results:** it was possible to identify the following empirical categories: << The subjectivity of the concept of humanization >>; << Pathways to humanization in BMT >>; and << Challenges for the Humanization >>. **Conclusion:** the concept of humanization has different meanings. The nursing service was regarded as humanized due to some activities cited. However, some challenges were identified for achieving a humanizing practice in bone marrow transplantation. **Descriptors:** Humanization of care; Bone Marrow Transplantation; Nursing.

#### RESUMO

**Objetivo:** compreender o significado da humanização em transplante de medula óssea segundo a percepção da equipe de enfermagem. **Método:** estudo qualitativo. Os dados foram coletados por meio de entrevistas com roteiro semiestruturado realizadas com dez profissionais de enfermagem que trabalham em um serviço de transplante de medula óssea de Minas Gerais e analisados por meio da Técnica de Análise de Conteúdo. Possui aprovação do projeto no Comitê de Ética em Pesquisa, CAAE 0074.0.420.000-11. **Resultados:** foi possível identificar as seguintes categorias empíricas: << A subjetividade do conceito de Humanização >>; << Caminhos para a Humanização em TMO >>; e << Desafios para a Humanização >>. **Conclusão:** o conceito de humanização possui diferentes significados. O serviço de enfermagem foi considerado como humanizado devido a algumas atividades citadas. Porém, revelaram-se desafios para o alcance de uma prática humanizadora em transplante de medula óssea. **Descritores:** Humanização da Assistência; Transplante de Medula Óssea; Enfermagem.

#### RESUMEN

**Objetivo:** comprender el significado de la humanización en trasplante de médula ósea según la percepción del equipo de enfermería. **Método:** estudio cualitativo. Los datos fueron recogidos por medio de entrevistas con guía semi-estructurado realizadas con diez profesionales de enfermería que trabajan en un servicio de trasplante de médula ósea de Minas Gerais y analizados por medio de la Técnica de Análisis de Contenido. Posee aprobación del proyecto en el Comité de Ética en Investigación, CAAE 0074.0.420.000-11. **Resultados:** fue posible identificar las siguientes categorías empíricas: << La subjetividad del concepto de Humanización >>; << Caminos para la Humanización en TMO >>; y << Desafíos para la Humanización >>. **Conclusión:** el concepto de humanización posee diferentes significados. El servicio de enfermería fue considerado como humanizado debido a algunas actividades citadas. Sin embargo, se revelaron desafíos para el alcance de una práctica de humanización en trasplante de médula ósea. **Descriptores:** Humanización de la Asistencia; Trasplante de Médula Ósea; Enfermería.

<sup>1</sup>Nursing Student, Nursing School, Federal University of Juiz de Fora, Juiz de Fora (MG), Brazil. E-mail: [roromendes@hotmail.com](mailto:roromendes@hotmail.com); <sup>2</sup>Master Professor in Public Health, Nursing School of the Federal University of Juiz de Fora. Juiz de Fora (MG), Brazil. E-mail: [kelli.bsantos@gmail.com](mailto:kelli.bsantos@gmail.com); <sup>3</sup>Nurse, PhD Professor in Nursing, Nursing School, Federal University of Juiz de Fora. Juiz de Fora (MG), Brazil. E-mail: [girleneas@terra.com.br](mailto:girleneas@terra.com.br); <sup>4</sup>Nurse, Master in Public Health, Bone Marrow Transplant and Hematology Unit, University Hospital/Federal University of Juiz de Fora. Juiz de Fora (MG), Brazil. E-mail: [valesca.nr@gmail.com](mailto:valesca.nr@gmail.com); <sup>5</sup>Nurse, Master and PhD in Nursing, Federal University of Minas Gerais/UFMG. Belo Horizonte (MG), Brazil. E-mail: [angelicamonica.andrade@gmail.com](mailto:angelicamonica.andrade@gmail.com)

## INTRODUCTION

The hematopoietic stem cell transplantation (HSCT), also known as bone marrow transplantation (BMT), is one of the major therapeutic modalities for patients with diagnoses of oncologic, hematologic and congenital diseases, enabling to prolong the life span or to obtain cure for some types of pathologies.<sup>1</sup> This therapeutic procedure provides the replacement of diseased or deficient bone marrow for healthy hematopoietic stem cells (HSCs).<sup>2</sup>

The HSCT can be divided into three distinct types: allogeneic, when HSCs or progenitor cells are obtained from a matched donor that may be related or unrelated; syngeneic, when the transplant takes place between identical twins; and autologous, when HSCs come from the patient himself.<sup>2</sup> Regarding the source of cells used for the procedure, they may be derived from bone marrow, HSCs circulating in peripheral blood mobilized in bone marrow, obtained through apheresis or from umbilical cord blood and from placenta collected immediately after delivery.<sup>2</sup>

The HSCT is not free from complications as it is a long, aggressive and complex therapeutic procedure that can cause injury or fatal consequences. During the hospital stay, the patient has severe immunosuppression due to chemotherapy or radiotherapy performed. For this reason, these patients have higher risks of viral, bacterial or fungal infections, which may impose the need for them to remain in an isolated environment, with the possibility of a prolonged period of hospitalization.<sup>3</sup>

A worsening of the clinical condition of the patient generates feelings of anxiety, dissatisfaction and fear in family members and in the patient himself.<sup>4</sup> Nevertheless, the patient experiences physical suffering during treatment, the need for being away from family and from the people of their social life, with the fear of death, uncertainties regarding the future, among others difficulties.<sup>5</sup> It is noteworthy, therefore, that in this situation there is a need of warmth presence and professional approach of the staff.<sup>4</sup> Patients need professionals prepared to meet them in order to minimize the distress related to treatment, i.e., they need quality care and, above all, humanized care.

Humanized care is a very important aspect of patient care that will be submitted to BMT, since healing does not occur solely due to technical and curative procedures but also by the feeling of friendship and love expressed in the care.<sup>6</sup>

In 2000 it was created the *Programa Nacional de Humanização da Assistência Hospitalar* (National Program for Humanization of Hospital Care - PNH) to improve the quality of health service provided, adding ethics to the technical-scientific science, with respect to the subjectivity of the user and the professional.<sup>7-8</sup> In 2003 the Ministry of Health (MOH) created the *Política Nacional de Humanização da Atenção e Gestão do SUS* (National Policy of Humanization of Care and Management of SUS - HumanizaSUS), which aims at the realization of the principles of the Brazilian Health System (SUS) in care and management practices. This policy proposes new relationship between SUS users and the health professionals that assists them.<sup>9</sup>

The humanization process must be analyzed according to several aspects, as the guiding principles of PNH include service to users, the working conditions of health professionals and care to institutional basic needs, namely, administrative, physical and human needs.<sup>8-9</sup> Among these, the relationship between health professionals and patients constitutes the focus of this study.

Through the above, the health care to the patient undergoing bone marrow transplantation should be humanized, valuing the life and the individuality of the patient, with respect to personal values and beliefs, bringing them to the current health/disease context.<sup>10</sup> In particular this study highlights the assistance provided by nurses. The nurse can contribute so that the essence of care is always focused on sensitivity, science and art.<sup>11</sup>

In order to effect improvement of care provided in hospitals and especially in sectors of HSCT, it is necessary that humanization is deemed as a continuous and not just momentary action.<sup>12</sup> However, despite the discussions about the humanization of hospital care, we observe that in practice it is not performed in a legitimized manner.<sup>12</sup>

It is believed that daily practices aimed at care humanization require a prior

understanding of the theme. However, humanization has polysemic concept generally used by health professionals with the meaning of treating with respect, affection, love, empathy, acceptance, dialogue, tolerance.<sup>13</sup> In academic research, humanization is described as the creation of bonds between professionals and users, quality of care, including the valuation of workers and recognition of users' rights, among others.<sup>13</sup>

There is also the concept of humanization that is linked to the concept of care, since when we think of humanization, we are reminded that it embraces ethical interpersonal relationships in a dynamics that involves potentialities of the human being, in addressing the issue of creativity and sensitivity, and commitment regarding the other's uniqueness.<sup>14</sup> In this context, the range of meanings of humanization of care and the scarcity of studies aimed specifically for BMT services justifies the need to know how nursing professionals of a HSCT sector understand humanization and also the need to know how it happens in practice, seeking new ways to facilitate humanization in these services effectively.

Thus, this research aimed to understand the meaning of humanization in bone marrow transplantation according to the perception of the nursing staff.

## METHOD

This study presents a qualitative research, with exploratory and descriptive approach that aims to understand the meaning of humanized care for nurses and other members of the nursing team working in a bone marrow transplant unit.

In the qualitative approach there is a close approximation between the subject and the object, both belonging to the same nature, and the focus is on to the intentions of the actors, making meaningful relationships.<sup>15</sup> The social practice and speech confront each other in the qualitative research in a complementary way, so this is the reason why we chose this approach.

The study was conducted in a university hospital in Minas Gerais. Study subjects were members of the nursing staff working in that service and who agreed to participate. Therefore, ten (10) nursing professionals working in bone marrow transplantation sector participated in this

research, among them four (04) nurses, one (01) nursing resident and five (5) nursing technicians. Two (2) employees of this sector have not participated in the research, one for refusal and another for being the advisor of this work.

We performed interviews guided by semi-structured script for data collection to those who voluntarily agreed to participate and signed the Informed Consent Form. Interviews were conducted in the workplace, in previously scheduled date and time, from November 3 to November 11, 2011, and were audio recorded and after transcribed in full.

The semi-structured script had the following questions: For you, what does humanization of nursing care mean? Do you think nursing care in the UH BMT/UFJF is humanized? How is it (which actions that are performed do you believe are humanized)? In your opinion, what are the difficulties for the humanization of nursing care in the UH BMT/UFJF? In your opinion which humanization measures could be performed and which have not been performed yet?

For the analysis of empirical data, we adopted the thematic content analysis from the exhaustive reading and interpretation of the transcribed interviews, which sought to highlight the meanings of humanization in HSCT for nursing staff through recurrences, tendencies and points of agreement.<sup>16</sup> In presenting the results, research subjects were identified by the code "I" followed by the reference number of the research database in order to protect the confidentiality of data.

To carry out this research we respected the ethical precepts according to Resolution No. 466, of December 12, 2012 from the National Health Council on Guidelines and Regulatory Standards for Research involving Human Beings of the Ministry of Health.<sup>17</sup> The data collection phase was carried out after consideration and approval of the Research Ethics Committee concerning the institution of the present study, with the certificate registration of presentation for ethical consideration - CAAE 0074.0.420.000-11.

## RESULTS AND DISCUSSION

Data analysis allowed revealing meanings, possible ways and also challenges for humanization in bone marrow transplantation sector from the perspective

of nursing professionals who work in this care modality. The findings were organized in empirical categories, namely: "The subjectivity of the concept of Humanization", "Pathways to Humanization in BMT" and "Challenges for the Humanization".

#### ♦ The subjectivity of the concept of Humanization

According to the testimonies of interviewees it was possible to reveal the subjective character of the concept of humanization. The perception of humanization depends on a whole context around working conditions, emotional aspects, and level of training, which characterizes it as a polysemic concept, that is, for each individual it has a different meaning.<sup>13</sup>

When asked about the meaning of Humanization of nursing care and about the humanization in bone marrow transplant it was revealed that, for the respondents, there are different ways of understanding the term humanization and its practical applicability, as it may be described in the statements below:

*Well, [...] most people understand humanization as the professional relationship itself with the patient, but when we start to study and to read, we start to see that it is [...] the humanization involves both the environment and interpersonal skills of professionals and also the relationship with the patient. (I1)*

*Yes, all the actions we do, doing, thinking of the patient we are doing a humanized action, you know, especially when we perform [...] certain care to the patient, we think that this care could be in ourselves. (I4)*

*Humanization of care is to provide quality care to the patient, whether it is a technical assistance [...] or the basic human needs themselves, the feeding issue, care about the well-being of that patient. (I6)*

According to reports, individuals have different concepts of humanization. Some have large and others, simplified concepts. However, most individuals could express their perception on humanization of care.

According to the Política Nacional de Humanização of the Ministry of Health, humanizing is: "to provide qualified care articulating the technological advances with welcoming, improving care settings and working conditions for professionals".<sup>18:6</sup>

For most respondents, the Bone Marrow Transplant Service in study is a humanized sector, as verbalized in the following lines:

*Well, [...], the BMT service here from [...] is one of the most humanized services I've ever worked. (I1)*

*It is [...] I think that yes, in the BMT the care is humanized, among the most common actions that we perform there and that we can see they are humanized, we treat the patient by name, patient's name is very valued; in the room door there is the name of the patient, in the placard outside, so you do not treat the patient as a number, as bed, but by name. (I3)*

*So I think there is a humanization of care, we try to welcome not only the patient but also the [...], companions. (I6)*

*Within the, the, the [...], I'm expected to talk good things about it, right, because since we work within the BMT we'll never be against it, you know, but as our sector is still a small sector, we are able to treat and to put this humanization into practice. (I10)*

However, one respondent said that the BMT service is partially humanized:

*I think it is partially humanized. (I2)*

It should be noted that the concept of humanization of care is linked to the concept of care.<sup>14</sup> It was possible to demonstrate this issue through the reports of some respondents who mentioned the term "care" for the definition of humanization.

*Humanization, well [...] I think that humanization of nursing care means to care, the care itself, a systematized care, a type of care in which you treat the patient comprehensively, in all their needs [...] not only the patient, but the family, including the community also, as long as you are with the patient all the time. (I3)*

*Humanizing care is to provide care according to the actual needs of the individual, respecting and valuing their particularities. (I4)*

The patient to be submitted to BMT is admitted to the procedure under severe emotional stress for fear of the treatment and its consequences, besides being hospitalized for a long period and requiring specialized nursing care, they also need a quality and humanized care. It is necessary that this patient is viewed holistically, in all aspects, physical, mental, social and spiritual, to be served in their entirety.

Among these, respect for the spirituality of the patient was mentioned by some interviewees. This is crucial because from the moment that the individual has some belief, this may encourage him and comfort him. This fact is important because it significantly reduces the levels of stress and anxiety, causing hospitalization to be a less traumatic experience.<sup>19</sup>

Respondents perceive humanizing actions carried out in BMT service in different ways, as described in the statements below:

*[...] we should assist the patient so that he feels less sad about the fact of not being in their home environment. [...] There is the issue of [...] you know, these leisure activities that we perform in our daily lives, for those who like, right, as the far as possible we try to accomplish them, right, as the practice of reading, [...] watching DVD movies, television, each room has its television, so the individual is not deprived of everything that's going on out here. (I2)*

*[...] they stay with a companion there all the time, the visit is open for them all the time they want to talk on the phone, so they have [...] this family warmth if necessary. [...] The spiritual aspect there is also an important thing, there is an action inside there in which depending on the patient's creed they are assisted, they can bring people from outside; we value a lot this issue of spirituality. (I3)*

*The ways we try are, in addition to our care, right, technical care, we try to minimize the suffering of the patient, encouraging the practice of reading, movies, [...] listening to patient, right. (I6)*

It is noteworthy that it is possible to humanize through various forms such as the development of recreational activities, entertainment, improvements in physical appearance of the service, which allows the hospital environment to become more pleasant and this is important, as these patients stay hospitalized for long time.<sup>20</sup>

Through the speeches, we realize that the most used entertainment forms in BMT refer to the practice of reading, availability of television and DVDs, enabling patients and caregivers, who experience part of the insulation, a form of entertainment.

Humanization in HSCT for nursing professionals comprises, therefore, different ways of understanding of its concept, being linked to the act of caring. It is noteworthy that the nursing care in BMT unit includes, besides technical procedures, emotional support throughout the transplant process, as this therapy is associated with an abrupt change of the way of life of individuals and a possible disadvantage in the future. In this regard, it is highlighted that, through affection, substantial therapeutic relationships are built, resulting in the establishment of trust between the subject of care, that is, between nurses, nursing technicians and patients.

#### ♦ Pathways to humanization in BMT

Respondents were asked about the possible ways to obtain improvements in the care provided, measures that can be implemented so that humanization becomes effective in the BMT service.

Of those interviewed, three said the assistance was enough to be considered humanized; two other respondents, despite claiming not to remember any measures, suggested some activities. There are some proposals suggested by respondents below:

*rescuing groups of family members, [...] perhaps a closer monitoring of nursing post-transplantation. [...] Putting some music with sound box, but I think this could be all over the hospital, you know, those quieter little songs to give a [...] (I2)*

*Perhaps a moment of leisure, you know, or when those doctors of joy come to the wards. (I5)*

According to the answers of respondents, despite the sector having humanizing assistance, some actions can also be implemented, always aiming to improve care for this group of patients.

Only one respondent expressed the desire on the expansion of physical space, thereby demonstrating a concern about the comfort provided to patients and companions. This concern is in line with the approach of humanization not only meeting the user, but extending to all involved, that in this case, is the family. Despite being recommended by the PNH the presence of companions, most hospitals do not have adequate physical structure to accommodate these accompanying family members.<sup>21</sup> The record goes on:

*we need a larger space for these patients and even companions there, for example, a refectory where companions could feed in the sector and out of contact with patients. (I6)*

Despite such concern, maybe that is the hardest suggestion to implement, since it depends on the institution itself, financial resources, in short, it goes beyond nursing care.

Another important point to note when it comes to humane care is that only the involvement of the nursing team is not enough, but of the entire multidisciplinary team so that the patients' needs are best met. This issue can be exemplified in the following reports:

*The psychologist goes every day and meets the patient every day. The physiotherapist works on the issue of the patient's need for [...] breathing exercise, muscle exercise, all*



*this motor function is also met. Nutrition, there is an action, I'm talking of nursing care, you asked about nursing care, but I'm talking about the other functions as well, other activities in there that [...] provide a feedback to the humanized nursing care, which is also the issue of the nutritionist visiting the patient there, so their food is personalized. (I3)*

*[...] trying to seek other professionals when we see that there is a need. (I6)*

To improve care in BMT, perhaps all the suggestions could be discussed among them, who belong to the same universe, so they can reach an agreement on whether or not to implement such measures. Moreover, such a discussion enables the exchange of knowledge between team members, allowing thoughts on the theme presented.

#### ♦ Challenges for the humanization

The humanized nursing care aims at care of patients in their comprehensiveness; however, we can see through the lines of respondents and also in the literature that currently there are still various challenges to put into practice this care. We can infer that among such challenges training is fundamental for its implementation.

It is necessary that humanization is more addressed during nursing undergraduate courses or even in technical courses so that professionals, entering in the labor market, have minimal knowledge to meet the user with dignity and quality.

It is noteworthy, therefore, that a major challenge faced in health for humanizing measures to be implemented in the care area is the lack of preparation of workers who have a basically technicist academic background.<sup>22</sup> One of the interviewees emphasized the need for continuing education for workers, demonstrated with the following report:

*[...] continuing education for workers, right, to be always remembering, renewing knowledge, I think it is also a difficulty that nursing faces. (I1)*

Discussions on humanization must start early in nursing degree phase also must also be carried out in other courses in the health area, since a multidisciplinary involvement is necessary. As mentioned previously, it is necessary that all professionals are prepared so that humanization is effectively put into practice.<sup>12</sup> Since professors have an important role in professional training and qualification of nursing, they should be part of these discussions.<sup>22</sup>

The report of one of the interviewees allowed better exemplification on the importance of education, as to humanize one must first know about humanization:

*Well [...] I did not have, I do not have much knowledge about the humanization of nursing care but the knowledge I have is little, it's about the humanization of SUS. [...] In the place I work we still have not had any talk, I have not had any talk about this issue of humanization, the knowledge I have is about the humanization of SUS and if it was disseminated, put into practice inside the hospital it would be very beautiful. (I4)*

The in-service education should be held to update professionals and so that there was continuous improvement of quality of service.

The physical structure was also mentioned and emphasized as a humanizing action, in accordance to different authors, which can be observed in the statements below.<sup>21,23</sup>

*[...] I see the physical aspect, the physical structure, because much as [...] it is nice, it is an adapted structure, right, so there are some things we cannot reach excellence because it is adapted. (I1)*

The humanized hospital ensures conditions for quality of care, which should be already covered in its physical structure.<sup>23</sup>

From the moment that professionals have their work needs met, they start to externalize this satisfaction in the performance of their duties, which is, in that case, patient care. The opposite can also occur, for when the worker is dissatisfied, they may end up taking this problem on people close to them, who may be family members, staff or the patients themselves.

The desire for better working conditions was found in one of the speeches of the interview:

*Better working conditions for nursing technicians. (I8)*

For a humanized environment, it is necessary that nursing professionals have proper working conditions, which involves higher wages, quality materials and resources in sufficient quantities for the performance of activities, human resources in sufficient number to avoid overwork to employees, moreover, it is important to have a physical structure in suitable size and in good condition, thereby providing a pleasant environment for service.

A respondent mentioned that due to the small number of human resources, the nurse takes on different functions, which hampers the effective implementation of comprehensive and quality care. One of the interviewees mentions this situation:

*I think that there are difficulties sometimes [...] because sometimes we take over various functions, right, due to the scarcity, right, of human resources, so sometimes we have to assume various functions and we leave certain activities that are focused on humanization in second place, right, by having to perform administrative activities, right, to participate in various committees, etc. (I2)*

The nurse mainly takes care and bureaucratic functions, which is evidenced in practice in any specialty and also in Bone Marrow Transplantation. The bureaucratic activities can be regarded as responsible for a separation between patients and nurses.<sup>24</sup>

It is observed that currently there are challenges to provide a quality care to patients undergoing BMT. However, we realized that despite the limitations, professionals seek, as far as possible, to meet these patients the way they believe it is humanized.

## CONCLUSION

We observed that the concept of humanization is polysemic, having therefore a subjective character. For the different actors of this research, the bone marrow transplant service studied has a humanized nursing care.

According to the nursing professionals, different activities are developed in the BMT service leading to a humanized patient care, such as providing television and DVDs in the rooms, encouraging the practice of reading, respecting religiosity, demonstrating empathy by the team, welcoming to families, among others.

However, there are still aspects to improve the care that must be investigated, such as the emotional aspect, psychological support to staff and improvement of the physical space. For the improvement of care it is worthy performing group discussion and in-service training, which was mentioned by several authors.

According to what has been described in the literature, we observed that numerous efforts are developed by the nursing staff to make the care to the patient submitted to TMO humanized, that is, a quality care.

The research objectives were achieved, as it was possible to understand the meaning of humanized care for nursing staff working at BMT, as well as the challenges faced by the team to carry out this practice, and we could also perform a brief analysis about how the humanization is held in practice in that unit.

There is need of further research addressing this theme with suggestions for activities that can improve the humanized care in BMT, also due to lack of work on the humanization in BMT, specifically.

It is hoped that this research will serve as input for a humanized nursing care in BMT or even for reflections about it.

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#### Corresponding Address

Kelli Borges dos Santos  
Universidade Federal de Juiz de Fora  
Jd. Liu  
Rua José Goreti, 10/103  
CEP 36033-225 – Juiz de Fora (MG), Brazil