








GUIDELINES FOR THE SELF-MANAGEMENT OF PEOPLE SUBJECTED TO HEMATOPOIETIC STEM CELL TRANSPLANTATIONS

Poliana Novais Mendes¹ 
Marléa Crescêncio Chagas² 
Herica Silva Dutra¹ 
Sabrina da Costa Machado Duarte² 
Beatriz Francisco Farah¹ 
Gleiziany dos Santos Mateus¹ 
Nádia Fontoura Sanhudo¹ 

¹Universidade Federal de Juiz de Fora, Programa de Pós-Graduação em Enfermagem.
Juiz de Fora, Minas Gerais, Brasil.

²Universidade Federal do Rio de Janeiro, Escola de Enfermagem Anna Nery, Departamento de Metodologia da Enfermagem.
Rio de Janeiro, Rio de Janeiro, Brasil.

ABSTRACT

Objective: to know meanings and demands for the self-management of home-based care for Hematopoietic Stem Cell transplant recipients and to discuss these demands with nurses, aiming at proposing guidelines.

Method: a qualitative study based on the convergent care research study developed between December 2020 and August 2021 in a Hematopoietic Stem Cell Transplantation Service from Juiz de Fora – Minas Gerais, carried out in two stages: semi-structured interview and small group discussion. 17 people participated in the study: 12 transplanted individuals and five nurses. Data analysis was supported by the Iramuteq software and by the synthesis and theorization proposed by convergent care research.

Results: in Stage 1, performed with transplanted patients, six classes emerged that were interpreted in four subcorpuses and pointed out the meanings and demands for self-management. In Stage 2, performed with nurses, the demands found in Stage 1 were submitted to reflection in the discussion group and ratified. Based on the findings, the guidelines to meet the health self-management demands of transplanted people were as follows: professional monitoring, adherence to the treatment, maintenance of the prescribed care measures, search for guidelines and information, implications of the diagnosis, restoration of immunity, inclusion in the job market, physical limitations, and changes in everyday habits.

Conclusion: the guidelines proposed reflect the understanding of the needs experienced for an individual to adapt to the health/disease process in the post-Hematopoietic Stem Cell Transplantation phase, and express the importance of carrying out strategies that promote self-management.

DESCRIPTORS: Self-management. Hematopoietic stem cell Transplantation. Chronic disease. Cancer. Oncology. Nursing care. Organization and administration.

HOW CITED: Mendes PN, Chagas MC, Dutra HS, Duarte SCM, Farah BF, Mateus GS, Sanhudo NF. Guidelines for the self-management of people subjected to hematopoietic stem cell transplantations. *Texto Contexto Enferm* [Internet]. 2023 [cited YEAR MONTH DAY]; 32:e20220297. Available from: <https://doi.org/10.1590/1980-265X-TCE-2022-0297en>

DIRETRIZES PARA O AUTOGERENCIAMENTO DE PESSOAS SUBMETIDAS AO TRANSPLANTE DE CÉLULAS-TRONCO HEMATOPOÉTICAS

RESUMO

Objetivo: conhecer significados e demandas para o autogerenciamento dos cuidados em domicílio de transplantados de Células-Tronco Hematopoéticas e discutir com enfermeiros essas demandas, visando à proposição de diretrizes.

Método: estudo qualitativo baseado na pesquisa convergente assistencial desenvolvido entre dezembro de 2020 a agosto de 2021 em um Serviço de Transplante de Células-Tronco Hematopoéticas em Juiz de Fora – Minas Gerais, realizado em duas etapas: entrevista semiestruturada e pequeno grupo de discussão. Participaram 17 pessoas, sendo 12 transplantados e cinco enfermeiros. A análise dos dados foi apoiada pelo *software* Iramuteq e pela síntese e teorização proposta pela pesquisa convergente assistencial.

Resultados: na Etapa 1 realizada com transplantados, emergiram seis classes que foram interpretadas em quatro subcorpus, e apontaram os significados e as demandas para o autogerenciamento. Na Etapa 2, realizada com enfermeiros, as demandas encontradas na Etapa 1 foram refletidas no grupo de discussão e ratificadas. Com base nos achados as diretrizes para atender às demandas de autogerenciamento à saúde de pessoas transplantadas foram: acompanhamento profissional, adesão ao tratamento, manutenção dos cuidados prescritos, busca por orientações e informações, implicações do diagnóstico, restabelecimento da imunidade, inserção no mercado de trabalho, limitações físicas, e mudanças de hábitos cotidianos.

Conclusão: as diretrizes propostas refletem a compreensão das necessidades vivenciadas para a adaptação do indivíduo ao processo de saúde/doença na fase pós- Transplante de Células-Tronco Hematopoéticas e expressa à importância da realização de estratégias promotoras ao autogerenciamento.

DESCRITORES: Autogestão. Transplante de células-tronco Hematopoéticas. Doença crônica. Câncer. Oncologia. Cuidados de enfermagem. Organização e administração.

PAUTAS PARA EL AUTOMANEJO DE PERSONAS SOMETIDAS A TRANSPLANTES DE CÉLULAS MADRE HEMATOPOYÉTICAS

RESUMEN

Objetivo: conocer significados y requisitos para el automanejo de las medidas de atención domiciliaria para personas sometidas a trasplantes de Células Madre Hematopoyéticas y debatir dichos requisitos con enfermeros, con vistas a proponer pautas.

Método: estudio cualitativo basado en la Investigación Convergente Asistencial y desarrollado entre diciembre de 2020 y agosto de 2021 en un Servicio de Trasplantes de Células Madre Hematopoyéticas de Juiz de Fora – Minas Gerais, siguiendo dos etapas: entrevistas semiestruturadas y grupo de discusión reducido. Participaron 17 personas: 12 pacientes trasplantados y cinco enfermeros. El análisis de los datos contó con el apoyo del *software* Iramuteq y de la síntesis y teorización propuesta por la Investigación Convergente Asistencial.

Resultados: en la Etapa 1, realizada con pacientes trasplantados, surgieron seis clases que se interpretaron en cuatro subcuerpos y señalaron los significados y los requisitos para el automanejo. En la Etapa 2, realizada con enfermeros, los requisitos que se encontraron en la Etapa 1 se sometieron a reflexión en el grupo de discusión, para luego ser ratificados. En función de los hallazgos, las pautas para suplir los requisitos de automanejo de la salud de personas trasplantadas fueron las siguientes: monitoreo profesional, adhesión al tratamiento, mantenimiento de las medidas de atención prescritas, búsqueda de orientación e información, repercusiones del diagnóstico, restablecimiento de la inmunidad, inclusión en el mercado laboral, limitaciones físicas y cambios en los hábitos cotidianos.

Conclusión: las pautas propuestas reflejan el entendimiento de las necesidades experimentadas para que una persona se adapte al proceso de salud/enfermedad en la fase posterior a un Trasplante de Células Madre Hematopoyéticas e indican la importancia de implementar estrategias que promuevan el automanejo.

DESCRIPTORES: Automanejo. Trasplante de células madre Hematopoyéticas. Enfermedad crónica. Câncer. Oncología. Atención de enfermería. Organización y administración.

INTRODUCTION

With the advancement of science, the outcomes in chronic diseases have been changing, thus highlighting strategies that promote independence and quality of life, based on a new patient-centered care paradigm, aiming at chronicity self-management¹.

Self-management is a strategy supported by educational actions aimed at building skills in individuals, their family members and/or caregivers in the face of decision-making on various aspects related to illness in the chronicity stage, of biological, psychological, social and spiritual origin, and in a relationship of mutual respect and planning²⁻³. Its interventions are focused on training individuals, transforming them into active partners in the health field by providing diverse information and skills that promote increased aptitude for health self-management, this being a *continuum* in which individuals present various skill levels⁴.

In onco-hematological diseases, Hematopoietic Stem Cell Transplantation (HSCT) is a complex and aggressive method that requires specialized care in several professional areas, in addition to being a long treatment that exposes people to a series of complications demanding care to avoid life-threatening situations and quality of life impairment⁵.

Individuals are understood as multidimensional beings; therefore, a person subjected to an HSCT may have several dimensions of their life affected. Considering people as complex beings, complexity should not be thought of only in terms of scientific advances; it should be sought in situations where it is apparently nonexistent, such as in everyday life, for example⁶.

In the HSCT context, there is lack of focus on self-management in the post-transplant follow-up period. Although this term is not clearly consolidated, the definitions of self-management and self-care have been used interchangeably and confusingly, as both concepts refer to a variety of methods and behaviors performed by individuals to manage their health and disease process in favor of positive results⁷. Thus, in health education, the importance of promoting self-management is highlighted, an innovative perspective where individuals are the protagonists in all stages of the health and disease process.

In the research scenario of this study, the health team created an instrument containing post-HSCT guidelines; however, lack of actions promoting self-management was verified. Given the problem, the following study guiding question emerged: "How do people living with an onco-hematological disease and who underwent an HSCT develop home-based health care self-management?"

Considering the assumption that self-management can be an important tool for coping with difficulties living with the chronicity of an onco-hematological disease, the following study object was outlined: health care self-management for people with onco-hematological diseases subjected to HSCTs; and, as a general objective: "to know meanings and demands for home-based care self-management of Hematopoietic Stem Cell transplanted patients and to discuss these demands with nurses, aiming at proposing guidelines."

METHOD

This is a qualitative and exploratory research study, with Convergent Care Research (CCR) as methodological framework. CCR uses the real environment as a research scenario and as that of the researcher's professional experience, making the question to be researched emerge in a junction between theory, practice and research, contemplating the conception, instrumentation, scrutiny and analysis phases⁸.

The conception phase corresponded to choice of the theme, formulation of reflections about the research object, delimitations, the inter-relational process, arguments and contextualization that represent the elaboration of a research project. These aspects are detailed in the Introduction to this manuscript.

In the instrumentation phase, the research scenario, study participants and data collection instruments and techniques were defined. The data were collected at the hematology outpatient service of the University Hospital belonging to Federal University of Juiz de Fora (*Hospital Universitário-Universidade Federal de Juiz de Fora*, HU-UFJF). This sector was inaugurated in 2002 and is accredited by the Ministry of Health (*Ministério da Saúde*, MS) to perform autogenic and allogeneic HSCTs⁹.

The study was developed in two stages and had 17 participants, 12 of whom were transplanted people and five were nurses from this service.

The people/patients included in Stage 1 were those aged at least 18 years old with onco-hematological chronicity, who were in the late HSCT phase in the period between 100 days and two years. The time criterion is justified due to the fact that the post-HSCT phase begins after hospital discharge, being subdivided as follows: immediate, a period of up to 100 days from the infusion of hematopoietic stem cells (HSCs), the stage in which most of the complications take place; and late, starting from 100 days¹⁰. In addition, the limiting post-transplant time of up to two years was established in order to cover a representative sample of participants, as the pandemic situation caused by the new Coronavirus (SARS-CoV-2) culminated in a reduction in the number of transplants.

The researcher herself recruited and selected the participants in the sector's HSCT record book and medical charts, verifying that 32 transplants were performed in 2019 and 21 in 2020, totaling 53 procedures. However, following the inclusion criteria, the potential transplanted participants totaled 52, and 48 phone calls were made.

The strategy used to make the calls corresponded to the transplantation order that was included in the book. In case of a person showing interest, the Free and Informed Consent Form (FICF) was sent by mail via Sedex, by email or through the WhatsApp messaging app. If in agreement, the person signed and sent a photograph or scanned document back to the researcher and the interview was scheduled after due reception.

The data were collected in from January 14th to February 5th, 2021, through interviews conducted by means of telephone contacts, with the aid of a semi-structured script consisting of diverse information to characterize the participants and guiding questions directed to the object of this study, referring to the changes, skills developed and needs after HSCTs. The interviews lasted a mean of 13 minutes, varying between five and 36. A total of 12 interviews were carried out and it was possible to notice that no new facts emerged from the seventh interview onwards. Data saturation was characterized by regularity of the information¹¹. Therefore, another five interviews were conducted to confirm saturation.

It should be noted that 9 people refused to participate in the research, that eight possible participants died and that 19 calls were not completed, only rang or showed busy lines.

Once this stage was completed, Stage 2 was initiated, which consisted of a small discussion group. This is characterized as a living system, made up of human subjects who have their own language, culture and conscience¹². It is based on Edgar Morin's Paradigm of Complexity¹², which is assembled in line with the CCR methodology and must achieve cohesion, as changes and innovations depend on it⁸.

For this stage, the following inclusion criterion was defined: nurses working in the research sector, with seven potential participants. Of these, five nurses consented to their participation by signing the FICF. They were invited by telephone contacts and via the WhatsApp messaging app. The

group met online on August 25th, 2021, for 1 hour and 35 minutes and via a video call on the Google Meet platform. There, the demands found in Stage 1 were reflected on.

In all data collection stages, the testimonies were recorded and transcribed and anonymity was guaranteed through codes, using the letter “P” for patients and the acronym “ENF” for nurses (“*Enfermeiro*” in Portuguese), followed by the number corresponding to the order in which the statements were obtained. For all participants, impaired verbal communication aspects were defined as exclusion criterion. However, no one was excluded.

The scrutiny phase concomitant with the previous phases was carried out by the interaction between the researcher and the participants, through an approach between the individuals and conducting the investigative process to obtain data and proposals for changes in the care practice, promoted through individual semi-structured interviews that were carried out with the transplanted patients and in the small online discussion group, conducted with the sector’s nurses.

In the analysis phase, in Stage 1, the data obtained from the individual semi-structured interviews were transcribed and organized in Word for Windows and submitted to lexical content analysis with the aid of the Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires (Iramuteq) textual data analysis software.

Iramuteq is a software program for processing textual data that seeks to identify the structure and organization of texts, showing the relationships between the most frequently presented lexical spheres, based on words used in similar contexts, related to the same lexical sphere¹³. The Descending Hierarchical Classification (DHC) presents the Text Segment (TS) classes that have similar and different words at the same time as the TSs from the other classes, considering as consistent any textual material with a minimum retention of 75% (TSs)¹⁴.

The findings of Stage 1 were the meanings and demands for home-based care self-management of people subjected to HSCTs. In the analysis of Stage 2, with the small discussion group, the collected data were transcribed and organized in Word for Windows and consulted by the researcher who, based on the analysis of the testimonies, elaborated a synthesis and theorization as recommended by CCR⁸. The demands of Stage 1 discussed in this group were ratified and, based on these data, the self-management guidelines were organized. The research was carried out after due approval by the Committee of Ethics in Research with Human Beings of the aforementioned institution, made available on February 17th, 2020, in compliance with Resolution 466/2012 of the National Health Council.

RESULTS

The Stage 1 participants were 12 patients: 50% female, aged between 20 and 68 years old, 42% in the predominant age group between 41 and 60 years old, 50% with Complete High School, 67% Catholics and 75% married. In relation to place of birth, 67% were from the state of Minas Gerais and the others came from the state of Rio de Janeiro. Regarding work activity, 50% were active, 25% were away from work receiving sick pay, and another 25% were retired. As for undergoing HSCTs, 58% did so in 2020 and 42%, in 2019.

In the textual analysis, the general *corpus* consisted of 12 texts/interviews, which were separated into 215 TSs with leverage of 175 TSs, which equals to 81.40% of the *corpus*. 7,316 occurrences emerged (words, forms or terms), 1,452 of which were distinct words and 816 with a single occurrence.

The analysis *corpus* was divided into four *subcorpuses* and six classes: *Subcorpus A* was comprised by class 6 (13.71% – 24 TSs); *Subcorpus B* consisted of classes 4 (22.29% – 39 TSs) and 1 (13.14% – 23 TSs); and *Subcorpus C* was subdivided, comprised by class 5 (15.43% – 27 TSs) and *Subcorpus D*, with classes 3 (17.71% – 31 TSs) and 2 (17.71% – 31 TSs). The DHC Dendrogram (Figure 1) is a graphic representation of the classes obtained from the interviews.

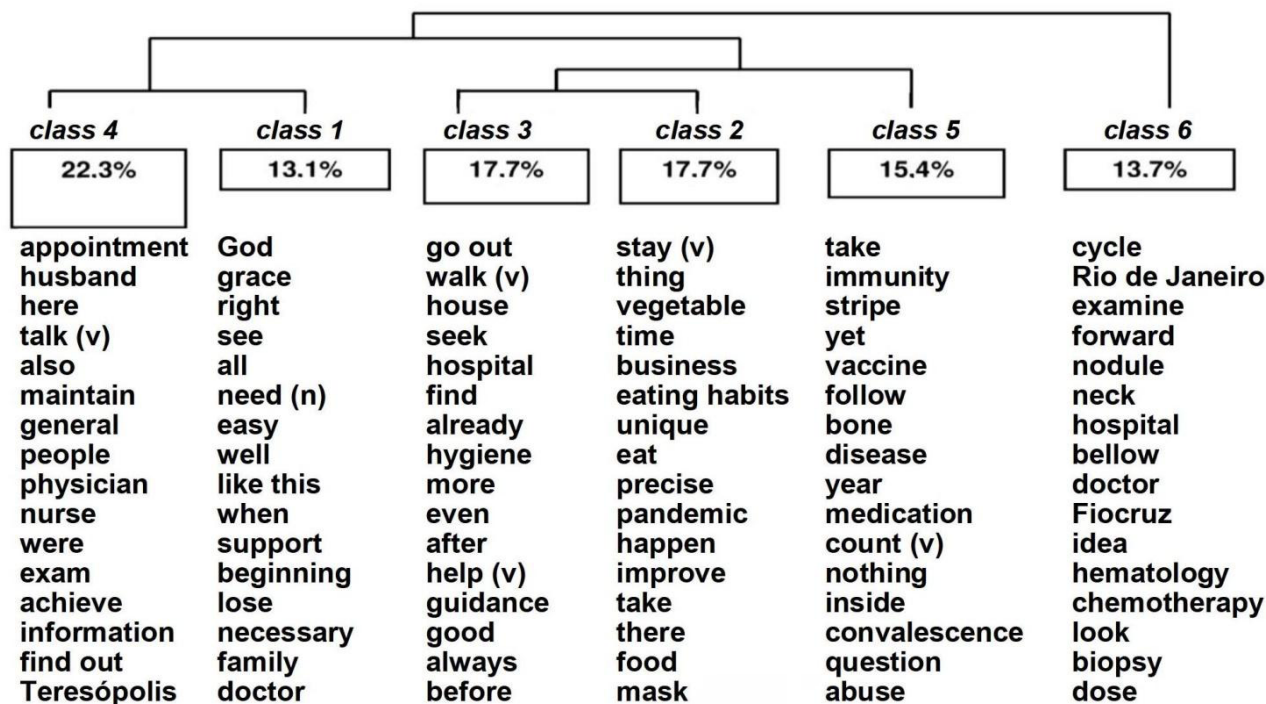


Figure 1 – Descending Hierarchical Classification (DHC) dendrogram generated in the Iramuteq 0.7 *alpha 2* software, adapted by the researcher. Juiz de Fora, MG, Brazil, 2021.

The results were presented considering the topics that emerged and the order in which the classes appeared. The terms presented in each class (Figure 1) assisted in interpreting the findings; thus, the classes and subcorpora were named by the researcher based on the analyzable words and the TSs.

Subcorpus A: The cancer diagnosis and course of the treatment

Class 6: The cancer diagnosis and course of the treatment

This class includes the participants' reports about the cancer diagnosis history and their path in the search for treatment.

[...] the result was disturbing. [...] the Doctor removed two nodules that were in the intestine, in the rectum, where the colonoscopy test passes through, he removed two nodules. [...] Before the biopsy, it had already entered the second cycle, he said: "I'm sure it's going to be a relapse of the same cancer". Which was confirmed after the biopsy [...] (P 01).

Subcorpus B: Perceptions, needs and support: subsidies for self-management

Class 4: Needs and the importance of family support and professional monitoring in the health care guidelines

This class presents how the search for information regarding health care in the post-HSCT phase was carried out and the clarification of doubts, in addition to presenting the importance of the family members participating in the person's life in the face of a comorbidity and its treatment. The terms "consultation" and "husband" are the most frequent and significant, as they refer to the way of

obtaining diverse information for health care, received in follow-up consultations and by accessing the Internet, in addition to the support of family members, mainly spouses (husband/wife) throughout the process, from diagnosis to post-treatment.

[...] the information I seek is with my doctor. Because she talked to me a lot, she did the procedure and I follow what she says [...]. I got information from her, my wife got information from the Internet, and we even have a friend who was diagnosed with me, on the same day [...] (P 11).

Class 1: Beliefs, feelings and support in the face of the health and disease process

In this class, the participants' perception regarding the feelings, beliefs and support of family members and health professionals in adapting to this new reality of life was presented. The term "God" stood out the most in the interviewees' testimonies and was associated with gratitude, hope and faith for a better health condition. The research participants understand that, at the onset of cancer and in the experience of its treatments, overcoming is related to positive thoughts and belief in God, so as to face situations over which human beings do not have control.

[...] you need to have positive thoughts, that it'll work out, that you'll succeed, putting God always ahead of everything. Because, thank God, it wasn't easy, but it came to an end, I went through the treatment well, I went through the recovery well, and I'm seeing God's hand at all times in my recovery. It's trusting and having faith that everything will work out (P 04).

Support from the family, meeting the needs that arise, and the health professionals' attention as a basis for care, were equivalent to support for the patients, contributing to a positive evolution of their health condition.

[...] the support from my family giving better support, they're always trying to see you better, sometimes holding back a little from going out, doing something that's not so necessary, and holding back a little with this pandemic (P 09).

Subcorpus C: Adherence to the treatment after the hematopoietic stem cell transplantation

Class 5: Adherence to the treatment after the hematopoietic stem cell transplantation

The participants' testimonies portrayed the care measures they adopted after their HSCTs.

[...] I'm not going to abuse it, it'll jeopardize my immunity. I keep my distance, everything right, strictly following the issue of food, drink, to go out. [...] it's an eternal treatment, let's say, eternal with you, but that you, following the standards, are able to administer, so that you're not surprised by a relapse, anything from the disease [...] (P 06).

Subcorpus D: Health care self-management actions

Class 3: Preparing for the changes in health care after the transplantation

The search for preparation to deal with the change in lifestyle after an HSCT was evidenced. Regarding the changes in health care, the limitation regarding physical disposition were reported, referring to lack of resistance to practice physical exercises, as well as the limitation regarding independence to perform activities of daily living.

[...] every time I go out, there's always someone with me, that part that changed, that I no longer do what I used to do. [...] I think that, after the transplant I'm a little limited in things, it's no longer the same in many ways [...] (P 02).

In addition to that, after being asked how they developed skills and sought information for health care, the guidelines provided by health professionals were reported, as well as the patient's and family's interest in seeking knowledge and information from the consultations and the Internet, aimed at preparing the individual to face this intense health care phase.

[...] I always read a lot on the Internet about this case, this transplant, I read a lot. I also got guidance at the hospital and they gave me quite a lot the day I left (P 04).

Class 2: Health care maintenance and concerns after the transplantation

The participants discussed about the changes in habits and post-transplant concerns. The pandemic was a term that showed significance, considering that a transplanted person already requires differentiated health care and represents a risk group for contamination by the Coronavirus (SARS-CoV-2), due to the frailty of the immune system that is still being reestablished after an HSCT.

[...] I try to improve, eat more types of greens, legumes and in terms of cleaning too, because even more now, with this pandemic thing, you have to be more careful with this gel alcohol thing, these things (P 10).

In addition to that, concerns were mentioned with situations arising from everyday life, such as financial support, apprehension about the future of their lives and other needs that arose as a result of an HSCT.

[...] I spend some time studying, because the job market is like this, weird. With this pandemic, we 'on't know the future, when I'm discharged from the INSS, I can be employed or not [...] (P 01).

[...] now, at the moment, I need to do this expertise, because I need to work, and I depend a lot on people [...] (P 12).

After analyzing and interpreting the results found in each class, a scheme was created that represents the synthesis of the guidelines, conferring visibility to the meanings and demands for the health care self-management of individuals who underwent an HSCT (Figure 2). For the analysis of these findings, it is important to emphasize that the "meanings" represent the participants' notion about the actions to self-manage their health care at their homes, and that the "demands" represent the individuals' needs and adaptation after an HSCT.

In Stage 2 of the research, a small discussion group was held, with the participation of five nurses. The group was led by the researcher with the aim of promoting reflections and dialog on the development of home-based health care self-management, in order to ratify or not the demands found in Stage 1 of the research, presented in Figure 2.

The methodology was validated by the participants, who consolidated the entire research process as totally relevant for capturing phenomena and issues that surround a person's complexity, in addition to contributing to the professional practice.

[...] the patient comes here for a consultation and, suddenly, he's already made a consultation with a whole multiprofessional team, he's already received a flood of information and hasn't processed it. [...] today I see the need for this transitional care, so as not to leave with so much demand, and so that he can organize himself. [...] So, understanding the patient's perception and the team's view about the transplant process, I think it'll be important for growth, in this way, as you're giving this feedback to me, but mainly to the sector [...] (ENF 01).

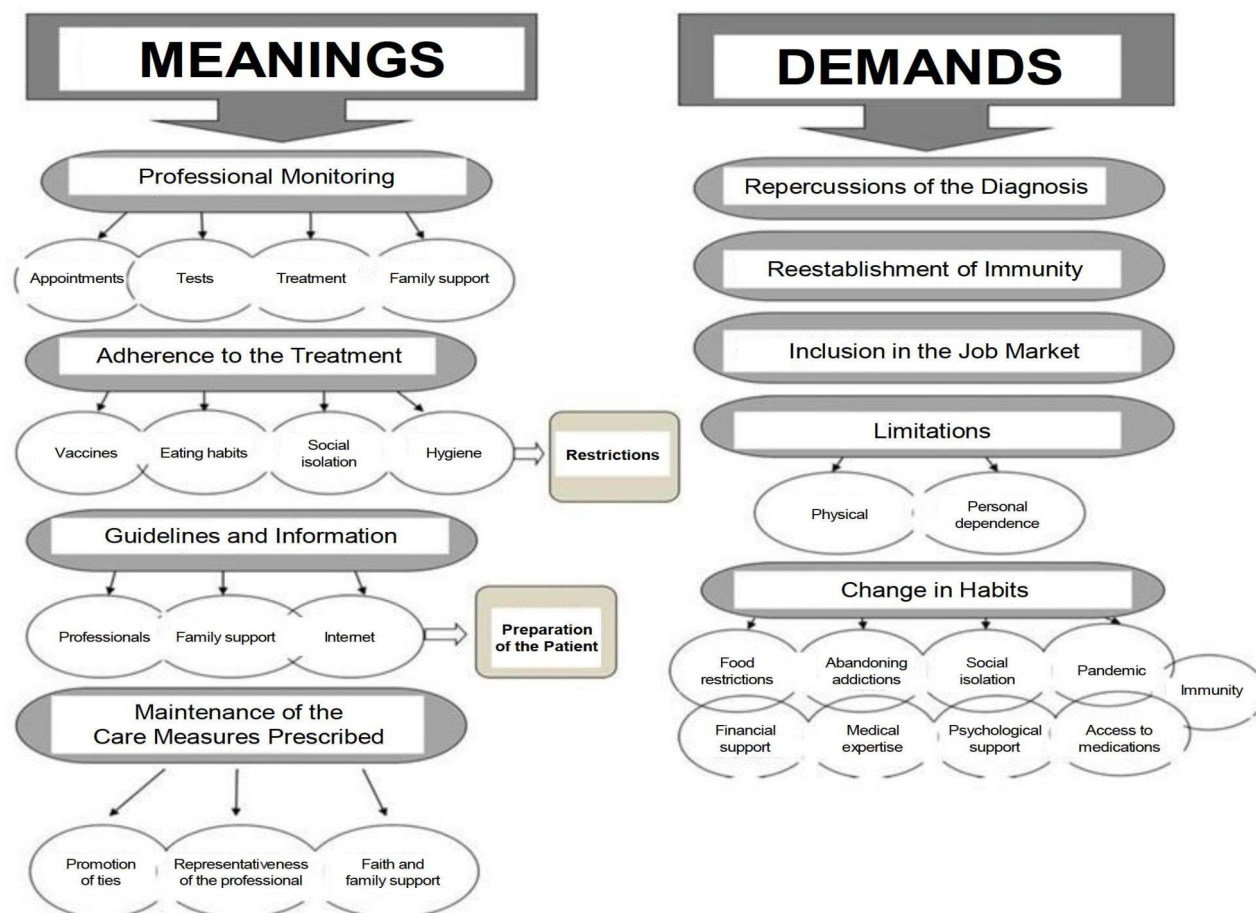


Figure 2 – Guidelines for the self-management of people subjected to an HSCT. Data from the research prepared by the author, Juiz de Fora, MG, Brazil, 2021.

In addition to ratifying all the demands encountered, the discussion group recognizes that they will serve as support for nurses to encourage the development of health care self-management for patients after an HSCT.

[...] I believe that it's extremely important for the patient to be empowered even by the treatment, its limitations, the outcomes that they'll present in the short-, medium- and long-term too. [...] So I believe that its results will contribute a lot to the care that we provide to these patients, to the patients themselves, so that they are increasingly aware and empowered by the treatment and the disease (ENF 02).

The result of the analysis corresponding to the stages of this research pointed to the guidelines (Figure 2) for the health self-management of people subjected to transplants, which encompassed the importance of professional monitoring and adherence to the treatment, maintenance of the prescribed care measures, search for guidelines and information, the cancer diagnosis implications, the path to reestablish immunity, inclusion in the job market, physical limitations and changes in daily habits.

DISCUSSION

The elaboration of guidelines for the health care self-management of people subjected to HSCTs is linked to the meaning of the hematological cancer diagnosis. In turn, for the person and

their family members, this diagnosis represents a stressful factor, with the necessary treatments and their risks added to this, including death⁵. It is understood that the social stigma attributed to cancer is related to something incurable and with consequent death, which can negatively affect the individual's attitude towards the treatment, coping with the disease and its implications.

HSCT is a life-saving procedure, but it also carries an increased mortality risk, corresponding to a worldwide survival rate of 50% to 60%¹⁵. In addition to that, with hospital discharge, the person becomes responsible for self-managing the medication and care therapeutic plan, with the possibility of any error in following the treatment leading to serious complications, such as infections or pathology relapse¹⁵.

Based on the context of the interviews with the transplanted individuals, it was noticed that many of them linked success of the treatment to the commitment to carry out all the prescribed guidelines, such as medication adherence, vaccination schedule, adoption of a diet, social isolation, hygiene measures and contact precautions, seeking to take all the necessary precautions to restore the immune system.

After an HSCT, the individual and their family need to adapt to the demands that arise in everyday life and, due to complexity of the treatment, continuous monitoring and guidelines are necessary¹⁶. Some aspects influence the therapy, including the weak health condition and the demand for differentiated care measures, such as: dietary restrictions, social isolation and responsibilities with personal and environmental hygiene, among others¹⁷. Thus, family and professional ties assist the individual in developing these self-management actions, being marked by instructions and support.

In this perspective, preparation of the patient and family is a fundamental point for good results in the phase in question. Effective communication between transplant recipients, their family and health professionals emerges as a foundation for coping with comorbidities and proper management of possible complications that may arise.

Undoubtedly, cancer patients are more susceptible to respiratory infections when compared to the population without this pathology. This is due to the systemic immunosuppression caused by some tumors, as also by their treatments, represented by chemotherapy, radiotherapy and HSCT¹⁸. In view of these aspects and the proportion reached by the Covid-19 pandemic scenario, strengthening care was a concern due to the increased severity and mortality risks in these individuals¹⁹⁻²⁰.

Another aspect that emerged from the results influencing self-management concerns emotional disturbances, which tend to destabilize the individual, negatively affecting their health status. In oncological diseases, emotional distress, spiritual disorders, anxiety and depression crises, physical exhaustion and changes in quality of life and survival may be present²¹.

Therefore, it is inferred that self-management should encompass the individual in their complexity, as it permeates singular and multidimensional aspects, involving them in an in-depth and integrated exposure of the dimensions that comprise them, facing the health and disease process.

Therefore, professional and family ties can constitute the foundation for self-management. Social support, positive thoughts, organization, motivation and the diverse information made available have already been identified by transplanted people and their caregivers as facilitating aspects for self-management, being used as coping strategies¹⁵.

The guidelines can assist in coping with difficulties encountered in everyday life. It is understood that self-management is an educational strategy for health care that can be applied in different ways, modifying the way in which an individual experiences their illness process, contributing to their autonomy and coping with different situations associated with the pathology and its treatments.

Family support and the presence of faith provide patients with an appreciation of life and help them cope with the negative feelings that afflict them, such as fear, anxiety and anguish²². Several strategies are used in coping with an oncological disease, with religiousness and spirituality as the

predominant ones²³. The figure of God emerges as an essential point of support and well-being, and faith induces hope for a cure, providing greater control of the disease²³.

It is noted that the emotional externalization experienced by a person with cancer demands support and protection, which is up to people who already play this role in their lives, especially the family²⁴. This makes up the main foundation for coping with the pathology, representing itself as essential support in the HSCT phases, as it conveys security and companionship to the patient in the face of this delicate moment in their life²².

In addition to that, through its indispensable work, the Nursing team provides greater comfort to the patients through humanized assistance, offering care that goes beyond technique, promoting bonding, trust, friendship and empathy, thus valuing the biopsychosocial-spiritual dimensions²⁵.

It is understood that the participating nurses' perception about the guidelines provided permeates the entire health and disease process. Thus, in the transplantation service, health education is considered one of the fundamental competences of nurses, which contributes to the care of patients and their family members, representing a facilitating strategy for health care²⁶.

In addition to that, Nursing care configures a social practice that identifies equalities and disparities, involving communication and mutual influence between patients and nurses, acknowledging the inter-relational complexity of the individual with the care process²⁷. From this perspective, it is understood that patient care implies a series of issues surrounding uniqueness, which must be considered when working on self-management strategies.

The importance of adopting the small group discussion with the nurses is highlighted, as a strategy to discuss the guidelines that encompass the meaning and demands for self-management of people subjected to HSCTs. From the perspective of complex thinking, conferring voice to the group was equal to uniting the single to the multiple; therefore, the single was not extinguished in the multiple and the multiple was part of the single⁶.

In this view, the nurses' unique reflections on self-management are part of multiple perceptions of the term in question. Although it was clarified in the small group discussion meeting, it is understood that there is still a need to strengthen it in the professional practice, as there is a perception attributed to it as a synonym of self-care.

Self-care concerns the attitudes and decisions taken independently of the interaction with a health professional, whereas self-management can be mentioned as a self-care subcategory, and its particularity is the collaborative roles played by patients and health professionals, together, for better chronic care management⁷.

In the evaluation carried out by the participants from the small group, the process of this research was considered valid and totally relevant to the current situation experienced in the post-transplant context. Research as a social practice means that, in the knowledge construction process, the researcher is inserted in a complex network of negotiations²⁸. CCR is a promising method in qualitative research studies to be carried out by the Nursing and Health areas, due to their close relationship between the professional practice and research knowledge construction²⁹⁻³⁰.

As a limiting factor, from the CCR perspective, developing a study during the Covid-19 pandemic period emerged as a challenge to meet the premise of a research study, in an integrative and participatory way of thinking. In addition to that, this is a local study that investigated the demands of the population in question.

CONCLUSION

This study made it possible to know the meanings and demands for the home-based health care self-management of people subjected to HSCTs. In this perspective, the results point to guidelines (Figure 2) that reflect the understanding of the needs experienced for the person to adapt to the health/

disease process in the post-HSCT phase, and express the importance of carrying out strategies that promote self-management. The guidelines proposed have the potential to improve the already existing post-HSCT guidance instrument in the service, being convergent with the improvement of the health care process.

The use of CCR in this study enabled reflections in the professional practice and enabled a different look on the relationship between theory and care; uniqueness and complexity of human beings. The researcher's immersion in the practice scenario, as well as the development of the other phases of the method, especially the analysis phase in the transfer process, enabled the recognition by professional nurses regarding the need to carry out health research studies that show the person's perception and the role of the health team in the face of the illness process, encouraging self-management.

Self-management in the post-HSCT phase can beneficially influence recognition and prevention of possible complications. It is believed that this study presents subsidies for the elaboration of care protocols that encourage self-management development, so that people know how to act in different situations and recognize possible complications that may affect them. Consequently, this fact may help minimize costs related to the health system, in addition to rendering individuals more proactive and confident in the face of their health/disease process.

REFERENCES

1. Malibrán-Luque D, Piñones-Martínez M, Gutiérrez-Gómez T, Rivero-Álvarez R, Lévano-Cárdenas M, Vejarano-Campos G. Diferencias del automanejo en personas con enfermedades crónicas en población peruana. *Enferm Univ* [Internet]. 2021 [cited 2022 Oct 18];18(1):43-55. Available from: <https://doi.org/10.22201/eneo.23958421e.2021.1.951>
2. Hortense FTP, Bergerot CD, De Domenico EBL. Quality of life, anxiety and depression in head and neck cancer patients: a randomized clinical trial. *Rev Esc Enferm USP* [Internet]. 2020 [cited 2021 Mar 09];54:e03546. Available from: <https://doi.org/10.1590/S1980-220X2018040103546>
3. Howell D, Mayer DK, Fielding R, Eicher M, Verdonck-de Leeuw IM, Johansen C, et al. Management of Cancer and Health After the Clinic Visit: A Call to Action for Self-Management in Cancer Care. *J Natl Cancer Inst* [Internet]. 2021 [cited 2022 Nov 4];113(5):523-31. Available from: <https://doi.org/10.1093/jnci/djaa083>
4. Nost TH, Steinsbekk A, Bratås O, Gronning K. Twelve-month effect of chronic pain self-management intervention delivered in a easily accessible primary healthcare service – a randomised controlled trial. *BMC Health Serv Res* [Internet]. 2018 [cited 2019 Sep 10];18(1):1012. Available from: <https://doi.org/10.1186/s12913-018-3843-x>
5. Marques A da CB, Szczepanik AP, Machado CAM, Santos PND, Guimarães PRB, Kalinke LP. Hematopoietic stem cell transplantation and quality of life during the first year of treatment. *Rev Lat Am Enfermagem* [Internet]. 2019 [cited 2019 Oct 26];260:e3065. Available from: <https://www.revistas.usp.br/rlae/article/view/156006>
6. Morin E. *Introdução ao pensamento complexo*. 5th ed. Porto Alegre: Sulina; 2015.
7. Loh SY. Self-care or self-management in palliative survivorship care in Asia: A call for more research. *Nurs Palliat Care* [Internet]. 2018 [cited 2021 Mar 9];3:1-3. Available from: <https://doi.org/10.15761/NPC.1000195>
8. Trentini M, Paim L, da Silva DMGV. *Pesquisa Convergente Assistencial – PCA: delineamento provocador de mudanças nas práticas de saúde*. 3rd ed. Porto Alegre: Moriá; 2014.
9. Ebserh. Hospital Universitário da Universidade Federal de Juiz de Fora – HU-UFJF. *Estrutura administrativa. Gerência de atenção à saúde. Especialidades. Unidade de Oncologia/Hematologia*:

Serviço de hematologia [Internet]. Juiz de Fora: Ebserh; 2021. [cited 2021 Mar 02]. Available from: <http://www2.ebserh.gov.br/web/huufjf/especialidades>

10. Souza GPSCM, Marca LM, Silva MZ, Hofelmann DA, Rattmann YD. Epidemiological characterization of patients submitted to hematopoietic stem cell transplantation at a reference center in Curitiba, Paraná, Brazil, 2011-2015. *ABCS Health Sci* [Internet]. 2018 [cited 2019 Oct 08];43(2). Available from: <https://doi.org/10.7322/abcshs.v43i2.1014>
11. Deslandes SF, Gomes R, Minayo C de S. *Pesquisa social: teoria, método e criatividade*. 3rd ed. Petropolis: Vozes; 2013.
12. Alves MC, Seminotti N. The small group and the complexity paradigm in Edgar Morin. *Psicol USP* [Internet]. 2006 [cited 2021 Jul 13];17(2):113-33. Available from: <https://doi.org/10.1590/S0103-65642006000200006>
13. Salvador PTC de O, Gomes AT de L, Rodrigues CCFM, Chiavone FBT, Alves KYA, Bezerril M dos S, et al. Use of IRAMUTEQ software in the Brazilian healthcare research: a scoping review. *Rev Bras Promoc Saúde* [Internet]. 2018 [cited 2020 Apr 02];31:1-9. Available from: <https://doi.org/10.5020/18061230.2018.8645>
14. Camargo BV, Justo AM. Tutorial para uso do software Iramuteq (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires) [Internet]. Florianópolis: Laboratório de Psicologia Social da Comunicação e Cognição, UFSC; 2018 [cited 2021 Mar 15]. Available from: <http://iramuteq.org/documentation/fichiers/tutoriel-portugais-22-11-2018>
15. Morrison CF, Pai ALH, Martsof D. Facilitators and barriers to self-management for adolescents and young adults following a hematopoietic stem cell transplant. *J Pediatr Oncol Nurs* [Internet]. 2018 [cited 2021 Jul 27];35(1):36-42. Available from: <https://doi.org/10.1177/1043454217723864>
16. Sanches K dos S, Herbert JS, Rabin EG. Mobile apps for post bone marrow transplant patients: integrative review. *Rev Recien* [Internet]. 2022 [cited 2022 Oct 13];12(38):206-17. Available from: <https://doi.org/10.24276/rrcien2022.12.38.206-217>
17. Rodrigues JAP, Lacerda MR, Galvão CM, Gomes IM, Meier MJ, Caceres NT de G. Nursing care for patients in post-transplantation of hematopoietic stem cells: an integrative review. *Rev Bras Enferm* [Internet]. 2021 [cited 2021 Aug 10];74(3):e20200097. Available from: <https://doi.org/10.1590/0034-7167-2020-0097>
18. Nascimento CC do, Silva PH dos S, Cirilo SSV, Silva FBF. Challenges and recommendations for cancer care during the Covid-19 Pandemic. *Rev Bras Cancerol* [Internet]. 2020 Sept 25 [cited 2021 Aug 12];66:e-1241. Available from: <https://doi.org/10.32635/2176-9745.RBC.2020v66nTemaAtual.1241>
19. Araujo SEA, Leal A, Centrone AFY, Teich VD, Malheiro DT, Cypriano AS, et al. Impact of Covid-19 pandemic on care of oncological patients: experience of a cancer center in a Latin American pandemic epicenter. *Einstein* [Internet]. 2020 [cited 2021 Aug 12];19:eAO6282. Available from: https://doi.org/10.31744/einstein_journal/2021AO6282
20. Silva TTM da, Araújo NM de, Sarmiento SDG, Castro GLT de, Dantas DV, Dantas RAN. Impact of covid-19 in patients with cancer: a scoping review. *Texto Contexto Enferm* [Internet]. 2021 [cited 2022 Oct 22];30:e20200415. Available from: <https://doi.org/10.1590/1980-265X-TCE-2020-0415>
21. Silva GCN, Reis DC dos, Miranda TPS, Melo RNR, Coutinho MAP, Paschoal G dos S, et al. Religious/spiritual coping and spiritual distress in people with cancer. *Rev Bras Enferm* [Internet]. 2019 [cited 2023 Apr 04];72(6):1534-40. Available from: <https://doi.org/10.1590/0034-7167-2018-0585>
22. Szczepanik AP, Marques A da CB, Maftum MA, Palm RDCM, Mantovani M de F, Kalinke LP. Coping strategies used during treatment by patients undergoing hematopoietic stem cell

transplantation. *Rev Enf Ref* [Internet]. 2018 [cited 2021 Aug 17];4(19):29-8. Available from: <https://doi.org/10.12707/RIV18055>

23. Silva DA da. Cancer patients and spirituality: an integrative review. *Rev Cuid* [Internet]. 2020 [cited 2023 Apr 04];11(3):e1107. Available from: <https://doi.org/10.15649/cuidarte.1107>
24. Wakiuchi J, Marcon SS, Oliveira DC de, Sales CA. Rebuilding subjectivity from the experience of cancer and its treatment. *Rev Bras Enferm* [Internet]. 2019 [cited 2021 Aug 19];72(1):125-133. Available from: <https://doi.org/10.1590/0034-7167-2018-0332>
25. Anacleto G, Cecchetto FH, Riegel F. Humanized nursing care to cancer patients: An integrative review. *Rev Enf Contemp* [Internet]. 2020 [cited 2023 Apr 5];9(2):246-54. Available from: <https://doi.org/10.17267/2317-3378rec.v9i2.2737>
26. Izu M, Silvino ZR, Santos LM dos, Balbino CM. Nursing care for patients undergoing hematopoietic stem cell transplantation. *Acta Paul Enferm* [Internet]. 2021 [cited 2023 Apr 5];34:eAPE02892. Available from: <https://doi.org/10.37689/acta-ape/2021AR02892>
27. Allande-Cussó R, Fernández-García E, Porcel-Gálvez AM. Defining and characterising the nurse-patient relationship: a concept analysis. *Nurs Ethics* [Internet]. 2022 [cited 2023 Apr 5];29(2):462-84. Available from: <https://doi.org/10.1177/09697330211046651>
28. Becker VT, Diotto N, Brutti TA, Lauxen S de L. Scientific research as a social practice of women's resistance. *RevInt* [Internet]. 2021 [cited 2021 Oct 12];8(1):349-62. Available from: <https://doi.org/10.33053/revint.v8i1.371>
29. Cortes LF, Padoin SM de M; Berbel NAN. Problematization methodology and convergent healthcare research: praxis proposal in research. *Rev Bras Enferm* [Internet]. 2018 [cited 2020 Oct 18];71(2):440-5. Available from: <https://doi.org/10.1590/0034-7167-2016-0362>
30. Figueiredo TWB, Mercês NNA das, Silva LAA da, Machado CAM. Protocol of nursing care on zero day of the Transplantation of Hematopoietic Stem Cells: collective construction. *Texto Contexto Enferm* [Internet]. 2019 [cited 2023 Apr 7];28:20180010. Available from: <https://doi.org/10.1590/1980-265X-TCE-2018-0010>

NOTES

ORIGIN OF THE ARTICLE

Extracted from the dissertation – Self-management of people subjected to hematopoietic stem cell transplantation, presented to the *Stricto Sensu* Master's Graduate Program in Nursing of *Universidade Federal de Juiz de Fora*, in 2021.

CONTRIBUTION OF AUTHORITY

Study design: Mendes PN, Sanhudo NF.

Data collection: Mendes PN.

Data analysis and interpretation: Mendes PN, Sanhudo NF.

Discussion of the results: Mendes PN, Sanhudo NF.

Writing and/or critical review of the content: Mendes PN, Sanhudo NF, Chagas MC, Duarte SCM, Dutra HS, Mateus GS, Farah BF.

Review and final approval of the final version: Mendes PN, Sanhudo NF, Chagas MC, Duarte SCM, Dutra HS, Mateus GS, Farah BF.

ACKNOWLEDGMENTS

To *Universidade Federal de Juiz de Fora* – Minas Gerais; to the University Hospital, especially the professionals working in the Hematology and Bone Marrow Transplantation Service; and to the patients who collaborated with their participation by sharing their experiences to carry out this study.

APPROVAL OF ETHICS COMMITTEE IN RESEARCH

Approved by the Research Ethics Committee of the University Hospital belonging to *Universidade Federal de Juiz de Fora*, opinion No.3,842,779/2020, Certificate of Presentation for Ethical Appraisal 28528620.1.0000.5133. Amendment No.4,418,375; CAAE 28528620.1.0000.5133.

CONFLICT OF INTEREST

There is no conflict of interest.

EDITORS

Associated Editors: Luciara Fabiane Sebold, Ana Izabel Jatobá de Souza.

Editor-in-chief: Elisiane Lorenzini.

HISTORICAL

Received: November 22, 2022.

Approved: May 15, 2023.

CORRESPONDING AUTHOR

Nádia Fontoura Sanhudo

nadiasanhudo@gmail.com

