

## Psychological evaluation in Hematopoietic Stem Cell Transplantation

### Evaluación psicológica en Trasplante de Células Progenitoras Hematopoyéticas

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#### Abstract:

Annually, 30,000 Mexicans are diagnosed with hematological diseases, of which about 18,000 must undergo hematopoietic stem cell transplantation as the only opportunity to live and improve their quality of life. In this specialized medical procedure, psychosocial factors associated with biopsychosocial vulnerability, therapeutic adherence, final results of transplantation, and survival interact, hence the importance of psychosocial evaluation. The objective of this article was to integrate and describe a psychological evaluation protocol aimed at the transplant candidate. From the search and free review of theoretical and applied articles in different bases, a brief evaluation guide was pointed out, and it is concluded that its application facilitates the work of the psychologist in the context of hematological transplantation, it favors the adaptation of the recipient, donor patient, and their family. It contributes to the improvement of the quality of life.

#### Keywords:

*Hematology, psychological evaluation protocol, adaptation, quality of life*

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#### Resumen:

Anualmente, 30 mil mexicanos son diagnosticados con enfermedades hematológicas y cerca de 18 mil deberán someterse a un trasplante de células progenitoras hematopoyéticas como la única oportunidad para vivir y mejorar su calidad de vida. En este procedimiento médico especializado interactúan factores psicosociales asociados a la vulnerabilidad biopsicosocial, adherencia terapéutica, resultados finales del trasplante y supervivencia, de ahí la importancia de la evaluación psicosocial. El objetivo del presente artículo fue integrar y describir un protocolo de evaluación psicológica dirigida al candidato a trasplante. A partir de la búsqueda y revisión libre de artículos teóricos y aplicados en distintas bases, se puntualizó una guía breve de evaluación y se concluye que su aplicación facilita la labor del psicólogo en el contexto del trasplante hematológico, favorece la adaptación del paciente receptor, donante y su familia. Lo que contribuye a la mejora de la calidad de vida.

#### Palabras Clave:

*Hematología, protocolo de evaluación psicológica, adaptación, calidad de vida*

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### INTRODUCTION

In Mexico, leukemias, lymphomas, and multiple myeloma are among the top 25 causes of morbidity from neoplastic diseases. That is, each year about 30 thousand Mexicans, mainly children and young adults, are diagnosed with blood diseases and around 18 thousand must undergo a hematopoietic stem cell transplantation (HSCT) as the only

opportunity to live and improve their quality of life (Fidel et al., 2015; García-Flores, López-Chávez, & Ojeda-Cervantes, 2014; International Agency for Research on Cancer [IARC] & World Health Organization [WHO], 2019; Reynoso-Noverón & Torres-Domínguez, 2018; Tirado-Gómez & Mohar, 2007; Unidos Trasplante de Médula Ósea. Francisco Cásares Cortina [UNIDOS], 2019).

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HSCT is the treatment of choice for various hematological diseases, both hereditary and acquired, sensitive to chemotherapy and radiotherapy, that are in remission, or that have been refractory to various treatment schemes. It is a specialized and complex therapeutic option that is offered to the patient when the quality of life, the functional prognosis and the overall survival exceed the implicit and derived complications from the procedure (Alarcón-Prada & Millán-González, 2009; Bellver & Moreno, 2009; Catalá, 2015; Instituto Mexicano del Seguro Social [IMSS], 2017a; Knight, Lyness, Sahler, Liesveld, & Moynihan, 2013; Krauskopf, 2017; Masule, Arbabi, Ghaeli, Hadjibabaie, & Torkamandi, 2014).

It is estimated that 65 thousand HSCT have been carried out around the world. Annually, up to 5,000 transplants are carried out and between 60 and 85% show positive results. In Mexico, since 1979, the year the first HSCT took place, the practice has grown considerably. This is due to advances in obtaining and cryopreservation of hematopoietic progenitor cells (HSC), the simplification of methods for transplanting, as well as the implementation of non-myeloablative conditioning schemes. Thus, by 2003, 1,337 patients had been transplanted in different parts of the Mexican Republic. In recent years, although there is no precise information regarding the number of HSCT that are performed, it is evident that availability for patients has been increasing (Ascencio, 2011; Cruz-Rico & Cruz-Rico, 2000; Ruiz-Argüelles, 2005; Secretaría de Salud, 2001; UNIDOS, 2019).

However, it is estimated that only 35% of patients will find a donor since only 25% of the population has a compatible family member and the registry of unrelated volunteer donors is low, coupled with the strong investment of human and economic resources that represents for the patient, their family, and the health system. In this way, given the limited donors and resources, as well as the high complexity of a medical procedure in which psychosocial factors interact, the need has been identified for the transplant candidate to be evaluated and prepared not only concerning to medical aspects but from a psychosocial perspective (Alarcón-Prada & Millán-González, 2009; Bellver & Moreno, 2009; Catalá, 2015; IMSS, 2017a; Krauskopf, 2017; Masule et al., 2014; UNIDOS, 2019).

Thus, the objective of this article is to integrate and describe a protocol for psychological evaluation aimed at candidates for hematopoietic stem cell transplantation. For this, the characteristics of the HSCT, the psychosocial factors, and the legal framework that justify the insertion of the psychologist in the process are considered, with the ultimate goal of contributing to the adaptation of the patient and their caregivers, as well as improving their quality of life.

#### **METHOD**

A search and free review of theoretical and applied, prospective, and retrospective articles was carried out, as well

as systematic reviews on the PubMed databases; PubMedCentral; PsycINFO; Dialnet; Google Scholar; as well as full individual articles published between 2000 and 2019. The search terms were hematopoietic stem cell transplantation, bone marrow transplantation, psychological and psychiatric evaluation, in English and Spanish, in addition to their combinations with Boolean operators. For both searching, reviewing, and setting up the manuscript, the recommendations of Casasola (2014), Olson, and Meyersburg (2008) were followed.

#### **HEMATOPOIETIC STEM CELL TRANSPLANTATION**

HSCT replaces cells in the bone marrow that have ceased to perform their function correctly with healthy stem cells that have the ability to produce all hematopoietic lines, leave the bone marrow, transport through the blood, and graft. These characteristics make it possible to understand the HSCT procedure, which, in simple terms, consists of 1) mobilizing the HSC by subcutaneous application of a colony-stimulating factor; 2) draw whole blood from the donor to harvest the HSC by apheresis and preserve them using methods that ensure cell viability; 3) condition the patient before transplantation, that is, eliminate the largest number of cells found in the bone marrow with chemotherapy or radiotherapy while creating space for the graft; 4) infuse the patient with the harvested cells for implantation in the bone marrow (Ascencio, 2011; Bellver & Moreno, 2009; Cruz-Rico & Cruz-Rico, 2000; Olaya & García, 2012; Secretaría de Salud, 2001).

Although it seems like a series of easy steps to execute, in reality, it is a procedure whose complications can lead to infections, bleeding, graft-versus-host disease, multiple organ failure, and death. That is the reason why the patient is subjected to a series of measures such as the use of isolation rooms, prolonged hospitalizations, and the use of supportive treatments that help minimize the risks associated with transplantation. Finally, it should be noted that despite the care provided to the patient, there is the possibility of transplant failure and that eradication of the underlying disease is not achieved (Ascencio, 2011; Khan, Irfan, Shamsi, & Hussain, 2007).

#### **PSYCHOSOCIAL FACTORS ASSOCIATED WITH HSCT**

Every transplant represents a physical, psychological, emotional, and social impact for the patient and their family. It is not surprising that the literature points to HSCT as a significant stressor with psychological, and even psychiatric, manifestations that require the immediate and continuous participation of an expert (Alarcón-Prada & Millán-González, 2009; Ascencio, 2011; Bellver & Moreno, 2009; Catalá, 2015; El-Jawahri et al., 2016; Fidel et al., 2014; García-Flores et al., 2014; Khan et al., 2007; Knight et al., 2013; Krauskopf, 2017;

Masule et al., 2014; Rodríguez & Fonseca, 2015; Secretaría de Salud, 2001; Vybornykh, Olexenko, & Savchenko, 2016).

Various investigations have reported that, in the pre-transplantation phase, patients experience distress, fear, confusion, anxiety, and symptoms of depression. During hospitalization and isolation, irritability, depression, anxiety, panic, changes in sensory perception, delirium, insomnia, and progressive loss of interest due to the extended stay become relevant. While in the post-transplant phase, mixed adaptive disorders, post-traumatic stress, fear, dependency, fatigue, pain, anxiety, depression, insomnia, changes in the perception of body image, somatizations and sexual dysfunctions have been identified (Ascencio, 2011; Bellver & Moreno, 2009; El-Jawahri et al., 2016; García-Flores et al., 2014; Lee et al., 2005; Knight et al., 2013; Krauskopf, 2017; IMSS, 2017b; Masule et al., 2014; Rodríguez & Fonseca, 2015).

The importance of psychological components identification, and their interrelation with other factors such as the age of the patient, social network, level of information on HSCT and stage of the disease, lies in the fact that their presence and management is associated with the patient's responses before medical procedures and indications. In this way, they can predict biopsychosocial vulnerability and therapeutic adherence before, during and after transplantation; as well as the final results of the process and survival, hence the importance of involving the psychologist in the evaluation and preparation of the patient receiving HSC, their family and donor, as appropriate (Ascencio, 2011; Bellver & Moreno, 2009; Catalá, 2015; El-Jawahri et al., 2016; Khan et al., 2007; Knight et al., 2013; Krauskopf, 2017; Méndez & Maya, 2012; Masule et al., 2014; Rodríguez & Fonseca, 2015).

#### **LEGAL FRAMEWORK FOR THE PARTICIPATION OF THE PSYCHOLOGIST IN THE HSCT**

In Mexico, the Political Constitution indirectly contemplates organ, tissue, and cell transplantations by pointing out and protecting the right to health. While the practice, registration, delivery of operating licenses of organ, tissue and cell banks and waiting lists are regulated through the General Health Law, the Sanitary Code of the United Mexican States, the Internal Regulations of the Secretariat of Health, the National Transplant Council (CONATRA) and the National Transplant Registry (Ramírez, 2002; Secretaría de Salud, 2001).

The General Health Law, the Official Norm of the Federation and the Regulations of the same law on Transplantations specify that every health institution that performs this medical practice must have an Internal Transplant Committee, made up of different professionals, including a psychiatrist or psychologist whose evaluation guarantees that the recipient or donor candidate: 1) possesses awareness and capacity to understand the disease, risks, and possibilities of success and failure of the transplant; 2) it is presented of its own free will, without family pressure or moral obligations; 3) it does not

show psychopathological symptoms; and 4) has been trained to tolerate the stages of the transplantation (Alcázar et al., 2001; Cámara de Diputados del H. Congreso de la Unión [CDDHCU], 2018; CDDHCU, 2014; Viveros, Segovia, & Escutia, 2012).

In accordance with the current legislation in the country, the psychologist does not decide the transplantation contraindication when the candidate is medically suitable; their task is to promote their psychosocial suitability. Therefore, the psychologist must have specialized training in biological health-disease processes that allow him to evaluate, offer psychoeducation and provide specific treatment for the detected needs and thus facilitate that at each stage of the process there is the lowest emotional cost and the most significant psychological stability for those involved (Ascencio, 2011; Alarcón-Prada & Millán-González, 2009; Krauskopf, 2017; Ramírez & Fonseca, 2015).

#### **PSYCHOLOGICAL EVALUATION PROTOCOL FOR HSCT**

Few standardized protocols exist for transplantation related psychological evaluation. Is for this reason, and based on the literature review (Alarcón-Prada & Millán-González, 2009; Ascencio, 2011; Bellver & Moreno, 2009; Catalá, 2015; El-Jawahri et al., 2016; Horowitz & Confer, 2005; IMSS, 2017a, IMSS, 2017b; Khan et al., 2007; Krauskopf, 2017; Lee et al., 2005; Méndez & Maya, 2012; Masule et al., 2014; Olbrisch et al., 2001; Rodríguez & Fonseca, 2015) a psychological evaluation protocol for HSCT is integrated and described, which includes working with the recipient, donor, family, and caregivers throughout the transplantation process.

##### *Candidate recruitment*

The recruitment of the transplant recipient or donor candidate should be carried out, preferably, from the moment the patient receives the diagnosis of a degenerative hematological disease whose therapeutic measure in the short or medium term is HSCT, and the responsible physician has explained extensively, to the patient and family, the procedure, risks, and benefits (Alarcón-Prada & Millán-González, 2009; Bellver & Moreno, 2009; Fidel et al., 2015; García-Flores et al., 2014; Rodríguez & Fonseca, 2015).

##### *Initial evaluation*

Given the clinical heterogeneity and wide range of psychopathological disorders that have been identified in patients with blood diseases (Vybornykh et al., 2016), the initial evaluation should include a differentiated structured interview for recipient and donor and the administration of a battery of standardized tests that allow assessing personality, cognitive functioning, anxiety, and depression (Alarcón-Prada & Millán-González, 2009; Ascencio, 2011; Fidel et al., 2015; García-Flores et al., 2014; Khan et al., 2007).

The battery is proposed to include the *Hospital Anxiety and Depression Scale* (HADS), *Gordon Personality Inventory* (P-IPG), the *Mini-Mental State Exam* (MMSE) and the *Raven's Progressive Matrices* (RPM), which have been widely used in the evaluation of recipients and donors, have proven to be reliable and valid tests in the hematological population and its application is economical as it does not cause greater physical wear to the person to be evaluated (Alarcón-Prada, 2009; Ascencio, 2011; Freischlag et al., 2019; Fidel et al., 2015; Foster et al., 2009; Khan et al., 2007; IMSS, 2017a; Lee et al., 2005).

Likewise, the application of the *Psychosocial Assessment of Candidates for Transplantation* (PACT), or the *Transplant Evaluation Rating Scale* (TERS) is proposed, which have been specially designed, validated and used in the target population (Freischlag et al., 2019; Foster et al., 2009; IMSS, 2017a). Besides, the inclusion of the *Personality Belief Questionnaire* (PBQ) is suggested, in order to identify cognitive schemes related to personality traits (Beck & Freeman, 1995; Vybornykh et al., 2016) that may interfere with transplantation and *The Short Form-36 Health Survey* (SF-36), to detect the level of quality of life perceived before the transplantation, since the purpose of this medical procedure is precisely to improve the quality of life. It should be noted that in the case of minor donors, the psychologist must consider the implicit bioethical aspects to choose the appropriate evaluation tools, techniques, and strategies.

Finally, the results of the psychological evaluation will guide the design of personalized, flexible and inclusive programs, preferably with a cognitive-behavioral approach, which have shown effectiveness in working with psychological variables of the patient, their donor, caregivers and family, such as biases cognitive, anticipatory thoughts, anxiety, dysphoria and depression, which characterize this stage of HSCT (Bellver & Moreno, 2009; Bravo-González, 2014; Rodríguez & Fonseca, 2015).

#### *Presentation of the report to the Transplant Committee of the Hospital Unit*

In order to facilitate communication with the multidisciplinary team, as well as with the Transplant Committee of the Hospital Unit, it is suggested that the report derived from the initial evaluation include eight sections in which I. General Data; II. Instruments; III. Evolution of medical illness; IV. Understanding of the disease; V. Voluntary acceptance and motivation for the transplantation; V. Family relationship; VII. Psychological assessment results, and VIII. Final diagnosis. According to Ascencio (2011), the report must express whether or not, after the initial evaluation, the recipient and/or donor has the psychosocial condition that will allow them to face the transplant process. Likewise, follow-up suggestions should be included that favor the participation of the

psychologist during the harvest, hospitalization, and isolation in the Transplant Unit and discharge from the hospital.

#### *Continuous assessment*

The evaluation constitutes a process; as such, it is necessary to carry it out at various times to guide the participation of the psychologist in the care of the patient and their relatives. Hence the need to apply the battery of instruments used in the initial evaluation in each of the subsequent stages of the HSCT, approximately, every month. In addition, it is possible the administration of other tests that are considered pertinent as long as the medical and psychological evolution of the patient, donor, and their family justify it. It should be noted that the participation of the psychology professional must continue even when the patient leaves the Transplant Unit, either for follow-up with them, the donor and their relatives due to success or failure of the transplant, or to guarantee to adapt to the loss in the event of patient's death in the Transplant Unit (Ascencio, 2011; Krauskopf, 2017; Rodríguez & Fonseca, 2015).

## CONCLUSIONS

Given the clinical heterogeneity and the wide range of psychological symptoms and psychiatric pathologies that have been reported in patients with hematological diseases, in addition to the medical, psychological, social and ethical-legal complexity of HSCT, as well as the existence of few protocols for psychological evaluation standardized (Ascencio, 2011; Catalá, 2015; Horowitz & Confer, 2005; Khan et al., 2007; Krauskopf, 2017; Lee et al., 2005; Méndez & Maya, 2012; Masule et al., 2014; Ramírez, 2002 ; Vybornykh et al., 2016), in this work a brief guide to continuous psychological evaluation was integrated and described, the application of which facilitates the work of the psychologist who participates as a member of the multidisciplinary team of HSCT and the Internal Transplant Committee, favors the adaptation of the patient and their family, including the donor, to each of the stages of the procedure without signifying more considerable physical and psychological wear than they are already subjected to and contributes to improve the quality of life.

It is important to point out that the proposal presented does not intend to make a thoughtless transposition of the evaluation procedures derived from clinical, educational or other psychology, to a specialized and dynamic field such as the health sector. What is proposed is the use of psychological theories and technologies that have been validated for the population of interest in order to respond to the needs of the field and, at the same time, fulfill the objectives, functions, and scope conferred on the psychologists in the current legal framework and in accordance with the object of study of their science, discipline and profession. Therefore, the psychologists who maintain contact with patients, candidates for recipients and donors, family members, caregivers, and

health personnel involved in HSCT must not only be inserted in health scenarios but also have formal and/or complementary specialized training that enables the ethical, responsible and respectful professional practice.

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