

QUALITY OF LIFE OF PATIENTS WITH AUTOIMMUNE DISEASES SUBMITTED TO BONE MARROW TRANSPLANTATION: A LONGITUDINAL STUDY

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This study aimed to assess the quality of life of patients with autoimmune diseases (AID) submitted to Bone Marrow Transplantation (BMT) at two different moments: when the patient is admitted at the hospital and at the moment of hospital discharge (30 days after the transplantation). Patients who attended the BMT unit, were older than 18 years, with conditions and availability to voluntarily collaborate to the study were selected. Data were collected through a semi-structured interview and the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36). The sample consisted of 19 patients attended at a university hospital in the interior of São Paulo State, Brazil. The collected data suggest these patients' quality of life is reduced before the realization of the transplantation, followed by a progression in their diseases. Immediately after the transplantation, an improved capacity to perform daily activities is observed, as well as a renewed possibility of making future plans.

DESCRIPTORS: quality of life; bone marrow transplantation; autoimmune diseases; hematopoietic stem cell transplantation

CALIDAD DE VIDA DE PACIENTES CON ENFERMEDADES AUTOINMUNES SOMETIDOS A TRANSPLANTE DE MÉDULA ÓSEA: UN ESTUDIO LONGITUDINAL

El objetivo de este estudio fue evaluar la calidad de vida de pacientes con enfermedades auto-inmunes (EAI), sometidos al Transplante de Médula Ósea (TMO), en dos momentos distintos: en la admisión del paciente y durante la ocasión del alta hospitalaria (30 días después del transplante). Fueron seleccionados pacientes atendidos en la unidad de TMO, mayores de 18 años, que presentaron condiciones y disponibilidad para colaborar voluntariamente. Para recolectar los datos se utilizó un cuestionario de entrevista semi-estructurado y el Cuestionario de Evaluación de Calidad de Vida - SF-36. La muestra fue compuesta por 19 pacientes atendidos en un hospital-escuela del interior del Estado de San Pablo, Brasil. Los datos obtenidos sugieren depreciación en la calidad de vida de esos pacientes antes de la realización del transplante, acompañada de la progresión de sus enfermedades. Inmediatamente después del transplante ya se observa una percepción de mejoría en la capacidad de realizar actividades del cotidiano y la posibilidad renovada de trazar planos futuros.

DESCRIPTORES: calidad de vida; trasplante de médula ósea; enfermedades autoinmunes; trasplante de células madre hematopoyéticas

QUALIDADE DE VIDA DE PACIENTES COM DOENÇAS AUTO-IMUNES SUBMETIDOS AO TRANSPLANTE DE MEDULA ÓSSEA: UM ESTUDO LONGITUDINAL

O objetivo deste estudo foi avaliar a qualidade de vida de pacientes com doenças auto-imunes (DAI), submetidos ao Transplante de Medula Óssea (TMO), em dois momentos distintos: na admissão do paciente e por ocasião da alta hospitalar (30 dias após o transplante). Foram selecionados pacientes atendidos na unidade de TMO, maiores de 18 anos, que apresentaram condições e disponibilidade para colaborar voluntariamente. Para a coleta de dados utilizou-se roteiro de entrevista semi-estruturada e o Questionário de Avaliação de Qualidade de Vida - SF-36. A amostra foi composta por 19 pacientes atendidos em um hospital-escola do interior do Estado de São Paulo, Brasil. Os dados obtidos sugerem deprecição da qualidade de vida desses pacientes antes da realização do transplante, acompanhada da progressão de suas enfermidades. Imediatamente após o transplante já se percebe melhora da capacidade para realizar atividades do cotidiano e a possibilidade renovada de traçar planos futuros.

DESCRIPTORES: qualidade de vida; transplante de medula óssea; doenças auto-imunes; transplante de célula-tronco hematopoéticas

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INTRODUCTION

Autoimmune diseases (AID) constitute a heterogeneous group of pathologies with variable presentation and severity, treated with anti-inflammatory drugs, immunosuppressors and immunomodulators, with satisfactory results in the majority of patients⁽¹⁾. However, advancements in the AID pharmacobiological therapies have not prevented that a subpopulation of patients with progressive forms of these diseases has a bad prognosis. The low quality and expectancy of life of these patients justify the use of aggressive therapies like high dosage chemotherapy, with or without bone marrow transplantation (BMT)⁽²⁾.

In this scenario, autologous BMT is presented as a potential treatment for diseases like multiple sclerosis⁽³⁻⁴⁾, systemic lupus erythematosus⁽⁵⁾ and type 1 diabetes mellitus⁽⁶⁾.

Nevertheless, BMT is not a definitive solution. It is an aggressive procedure, which can either recover patients' life or lead them to death. This paradox basically occurs because the immunosuppression induced by the pre-BMT regime turn patients temporarily vulnerable to complications that cause risks, not only to their physical integrity but also to their life⁽⁷⁾.

Because of these factors, quality of life (QoL) has been shown as an important criterion in the effectiveness evaluation of certain interventions in the health area. This study used the concept of quality of life related to health. It refers to the perceptions people hold of their health, based on subjective evaluation of their health condition and treatments they are submitted to. To analyze the chronic impact of chronic diseases and interventions in people's daily life, it is necessary to evaluate indicators of physical functioning, social aspects, emotional and mental state, repercussion of symptoms and individual perception of wellbeing⁽⁸⁾.

OBJECTIVE

This study aimed to evaluate the health-related quality of life of patients with autoimmune diseases who were submitted to BMT in two different moments: when the patient is admitted to the hospital and at discharge (around 30 days after the marrow infusion). This evaluation aimed to: 1) understand the meaning of quality of life for patients with AIDs through semi-structured interviews (qualitative approach); 2) evaluate the health-related quality of life (through SF-

36), 3) and establish connections between data obtained through the instruments.

JUSTIFICATION

In the last decades, the scientific literature has focused its attention on aspects of health-related quality of life in individuals with chronic health conditions.

Because BMT is an innovation in AID treatments, studies aimed at evaluating not only its technical effectiveness but also the impact it causes on patients' life are essential. The majority of studies has focused only on its clinical aspect and because of this, evaluating the emotional and psychosocial aspects involved in the treatment of an autoimmune disease is important.

Specifically, if adequately measured, the health-related quality of life makes it possible to evaluate therapeutic intervention effects, rethinking some modalities, considering their effects on the patient's life in the medium and long run⁽⁹⁾.

This study is inserted in the scenario in which Brazil stands out as pioneer in the application of BMT in some of these diseases and focuses on results obtained in the Bone Marrow Transplant Unit (BMTU) at the Hospital das Clínicas, Medical School at Ribeirão Preto (HCFMRP) – the only public health service in the country that performs this therapeutic.

METHOD

The quantitative method is evidenced by previous and technical hypotheses of systematic verification, in the search for causal explanations of the study phenomena⁽¹⁰⁾. This method aims to know and control variables, eliminating confusing factors. It is concerned with validity and reliability, with a view to producing theoretical generalizations. In the health context, this model is frequently related to epidemiological studies, leaving concerns related to implicit subjective factors for the human areas to study⁽¹¹⁾.

In the context of the qualitative methodology applied to health, the concept brought from the human sciences is used, according to which one does not attempt to study the phenomenon per se, but to understand its individual or collective meaning in people's life. Thus, it is essential to know what the phenomena of the disease and life in general represent to them⁽¹²⁾.

This study aimed to integrate the advantages of both the quantitative and qualitative methods. This integration was possible through the triangulation of data, that is, jointly applying theory and technique, as well as establishing connections between data obtained through the instruments used⁽¹⁰⁾.

The project was approved by the service coordination and Research Ethics Committee at the Hospital das Clínicas, FMRP-USP (process HCRP number 9613/2003).

The sample was composed of 19 patients with autoimmune diseases, both genders, submitted to BMT at the BMTU, HC-FMRP-USP. All patients who met the inclusion criteria and were attended at the unit between December 2003 and December 2005 were included in the study. The selection criteria were: AID diagnosis; at least 18 years of age; under treatment in pre and post BMT at the BMTU in the period delimited for evaluation; present conditions and availability to voluntarily collaborate with the research and cognitive abilities and other basic mental functions.

Table 1 presents a characterization of patients who participated in the investigation according to their sociodemographic profile.

Table 1 – Distribution of patients submitted to BMT by the sample's sociodemographic profile, Ribeirão Preto, SP, 2003-2005

Participant	Age	Marital status	Profession/O- ccupation	Diagnosis*	Length of diagnosis (years)
Neiva	41	Married	Teacher	TA	13
Saulo	38	Married	Business Administrator	MS	6
Domingos	52	Married	Engineer	MS	8
Sílvio	39	Married	Physiotherapist	P	5
Álvaro	50	Married	Physician	MS	10
Roberta	44	Married	Events Promoter	SLE	11
Leonardo	24	Cohabitant	Painter	D	4 months
Silvana	42	Married	Business person	MS	8
Marta	41	Divorced	Merchant	MS	10
Alexandre	27	Married	Nursing Auxiliary	D	3 months
Renata	37	Married	Teacher	MS	7
Osvaldo	51	Married	Autonomous worker	MS	8
Solange	26	Single	Educator	P	7
Leila	30	Cohabitant	Biologist	MS	9
Soraya	43	Divorced	Housewife	MS	7
Marcela	48	Married	Secretary	MS	10
Roberval	54	Married	Merchant	MS	5
Clarissa	36	Married	Secretary	ME	7
Lícia	32	Single	Architect	ME	6

TA (Takayasu's Arteritis); P (Pemphigus); EM (Multiple sclerosis); SLE (Systemic Lupus Erymatosus); D (type 1 Diabetes Mellitus)

It is observed in Table 1 that, among the 19 participants, 11 were female. The sample's average age was 39.7 years (se= 9.04), ranging from 26 to 54 years. Patients were mostly married and had remunerated activities that varied according to the level of qualification and required education, while 10 participants had a higher education degree. It is also observed that the predominant primary disease in this sample was Multiple Sclerosis (13 patients) and that diagnosis time varied from 3 months to 13 years (X=7.3 years; se=3.2). All participants are referred to by fictitious names.

The BMTU – HC-FMRP-USP was created in 1992. It is a facility with seven beds and counts on a multiprofessional team composed of physicians, nurses, nursing auxiliaries, social workers, physiotherapists, nutritionists, psychologists, occupational therapists and dental surgeons. The BMT in AID initiated its activities in June 2001 and, on the average, two transplantations are performed per month.

The participation of patients in the study was voluntary and there was no refusal. Five participants died between 7 and 15 days after the transplantation.

Instruments

Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36)

The SF-36 is a multidimensional instrument for generical evaluation of the perceived health state or, as it has been called more recently, the health-related quality of life, of easy administration and understanding, originally created in English⁽¹³⁾, translated and validated in Brazil⁽⁶⁾. It is composed of 36 items, which evaluate two components: the physical health component (PHC) and the mental health component (MHC). The PHC presents the following dimensions: Physical Functioning (evaluates whether there are physical activities and limitations); Role Limitations due to Physical Problems (evaluates physical limitations and how much they affect the realization of work and daily tasks); Bodily Pain (evaluates the extension and interference of physical pain in daily activities); General Health Perceptions (it refers to the subjective perception of the general health state). The MHC is constituted of the following dimensions: Social Functioning (evaluates how frequently social activities are affected due to physical

or emotional problems); Vitality (evaluates feelings of tiredness and exhaustion and their persistence over time); Role Limitations due to Emotional Problems (evaluates limitations to work or perform other activities due to emotional problems); General Mental Health (evaluates feelings of anxiety, depression, altered behavior, emotional lack of control and their persistence over time). The results of each dimension varied from 0 to 100, in which zero corresponds to the worst health state and 100 to the best health state^(8,13).

Semi-structured Interviews

Semi-structured interviews were used, based on the researchers' practical experience. They aimed to characterize the subjects regarding their age, marital status, education, occupation, length of diagnosis and identify physical changes, as well as changes in social relations after the appearance of the autoimmune disease in patients' life. This identification is important because the SF 36 does not permit specifying these changes. In addition, the interview allows one to know patients' perspectives in relation to the BMT, expected difficulties (pre-BMT) and those really faced (post-BMT), as well as their expectations and future plans.

Data Collection

The instruments were applied in the pre-BMT, upon the patients' admission to the hospital, in the BMTU nursing ward. Post-BMT data were collected during follow-ups, around 30 days after the transplantation, at the BMTU outpatient clinic or the Support Group for Bone Marrow Transplanted (SGBMT) Patients.

Interviews were audio recorded after participants' consent. A previously established semi-structured script was followed and applied individually and face-to-face.

Data analysis

Interviews were fully transcribed and qualitative analysis was used, aiming to identify the patients' concepts, beliefs, values, motivations and attitudes in relation to their experience with the disease and transplantation. Thematic content analysis was used. It consists of: pre-analysis (organization of material and systematization of ideas); analytical description (categorization of data in units) and referential interpretation (treatment of data and interpretation based on the literature)⁽¹⁴⁾. The analysis of the SF-36 results followed recommendations from literature⁽⁸⁾. After data collection, the data obtained through this scale were submitted to statistical analysis. The level of significance adopted was $p \leq 0.05$. It was initially verified whether the differences between the moments (pre-BMT and post-BMT) presented normal distribution through Kolmogorov-Smirnov's test. After the normality hypothesis was not rejected, the two moments were then compared, aiming to detect significant differences between the obtained data, through Wilcoxon's non-parametric test for paired samples.

RESULTS

The results of 14 subjects evaluated in the pre and post BMT phases were compared. The results of the remaining subjects, who died, were excluded from the analysis since the objective of the study was to compare data obtained in the two moments of treatment.

Health-related quality of life

The average results from the SF-36 scale in the evaluation of the pre and post transplantation stages were systematized in Table 2.

Table 2 – Average results obtained through the application of SF-36 in the sample of patients who survived the BMT. Ribeirão Preto, SP, 2003-2005

Component	Component	Moments				p*
		PRE-BMT		POST-BMT		
		Average	SE	Average	SE	
Physical Component	Physical Functioning	24.29	31.92	32.14	34.57	0.09
	Role Limitations due to Physical Problems	23.21	24.93	30.36	35.60	0.54
	Bodily Pain	67.29	28.53	62.00	29.44	0.42
Mental Component	General Health Perceptions	67.14	20.03	71.57	15.09	0.41
	Vitality	67.14	19.88	59.29	18.59	0.24
	Social Functioning	64.25	28.95	63.39	30.41	0.79
	Role Limitations due to Emotional Problems	59.50	45.66	59.57	43.74	0.88
	General Mental Health	76.00	27.08	71.71	16.64	0.40

* $p \leq 0.05$

According to the statistical analysis, there was no significant alteration in any of the quality of life components evaluated by this instrument. On the other hand, the level of significance in the Physical Functioning component is close to the adopted ($p \leq 0.05$), which shows a tendency of significantly higher post BMT than pre BMT values.

Pre BMT interview

The analysis of interviews revealed not only aspects of these patients' history of life, but also difficulties they have faced over many years of experience with chronic diseases and their progressive and disabling course.

Interviews carried out in the pre transplantation phase allowed researchers to obtain data on the participants' life history, experience with the disease and expectations regarding the BMT.

Long experience with the disease and dependency on health services: Among the 14 patients who survived the BMT, 12 had been diagnosed quite some time ago. They had already experienced several treatments and a long peregrination through health services. In some cases, no treatment had achieved the desired effect. It was noticed that these patients invariably reached the transplantation reporting tiredness after successive unsuccessful treatment attempts: *The decision was to try all immunosuppressors and they didn't work anymore. I'd have pain all the time, never woke up or opened my eyes without pain. So the pain, is like, my constant companion? No! I think like, it's an aggressive treatment? Yeah! Unfortunately, for the good cells too. But the disease is very aggressive, so we'll have to use heavy weapons.* (Neiva, 41)

Routine limitations and change of life: The disease for these patients is a factor that triggered several changes in their lives. So, difficulties emerge in the performance of daily tasks. Limitations due to progressive loss of abilities make them give up their professional activity because they are not able to anymore, or even retire early. From the psychological point of view, discouragement and negative feelings gradually escalate and are intensified by dependency on other people to perform daily tasks. On the other hand, in some cases, the disease appears as an opportunity to reflect on life, leading to a re-evaluation of beliefs and values and to a more accurate perception of their human condition: *It helped to face it more easily, with less fear. I was afraid of everything. Today I'm*

self sure. I used to be a person who'd not go anywhere 'cause I'd get sick, I'd stumble. Now, I have my difficulties, so I have to adapt to take care of my problems. (Soraya, 43)

Some reports related to the occurred changes deserve to be highlighted in the analysis of the interviews. All patients report profound changes in their daily routine with gradual aggravation of the disease: *Today, because of this physical aspect, I'm very dependent on everything, you know? For little things, like getting a glass of water, and dependency for major things like taking a shower, see? So, I see myself, sometimes, really upset, more anxious, more annoying, more irritated, just because I can't do things by myself.* (Álvaro, 50)

In fact, the most noticeable changes are the physical and bodily changes. However, the perception of change, many times subtle, in their life style and on how they relate with themselves, with the world and people, as well as the way they deal with problems, were also recurrent in their reports: *I'm learning how to deal with my limitations. Everyday I have to learn a little, because the disease progresses a little everyday. As I told you before, driving was an automatic thing and I haven't driven for more than two years now, so I'm adapting, you know?* (Roberval, 54)

Family reorganization: With respect to the potential changes perceived in the interaction with family and friends, three aspects can be highlighted, as follows:

- The perception that the family has joined after the disease: *The family started to get a little closer. They started to pay more attention to my things. So, I guess it is... well, good, beneficial, because it is something that... if weren't the disease, maybe I'd have to reprehend them for something.* (Álvaro, 50)

- The perception that friends got distant: *Many people got away from me. In the beginning it'd hurt and I'd cry. I used to be around lots of people when I got worse. I thought like: Wow! Now that I can't work anymore people will come and see me, they'll call to know about me. And that didn't happen. So, in the beginning it surprised me a lot. Then, I understood that each person reacts in a different way and who ended up by my side were people I really was closer to.* (Neiva, 41)

- The perception that the patient distanced him(er)self from family and friends: *I got more retired, I don't want to get close to people, think they'll have prejudice, I don't know. I ran away, but it's all in my head.* (Lícia, 32)

Changing the project of life: In this context with so many losses, for patients, stem cell transplantation entails an expectation of recovering the life they had before the disease and resume their plans and project of life they had left behind. Although

many of these patients are aware that the procedure is not a promise of cure, but an attempt to interrupt the progressive course of the disease. They affirm that they will be satisfied if they can achieve this goal. Their reports implicitly - and sometimes explicitly - contain the hope that this innovating treatment will be the definitive answer to their problems: *I want a new life! Better quality of life! If my hair will grow again or not, it's up to destiny. If I'm going to get a big belly or not, it's up to time. But I'll tell you, I'll be happy with my family. I think this is the least you can do!* (Saulo, 38)

Post BMT Interview

Redimensioning their expectations: The analysis of the post transplantation interviews point to an intense involvement of patients in the redimensioning of their own expectations with regard to the procedure result. In this perspective, some show a perception of improvement, others feel frustrated about the maintenance of their previous physical condition: 1a) *I have noticed here in my legs... Before, I didn't have the strength, I'd fall. Now I manage to stand! And my spine also, it had a tendency to bend, and now it doesn't. Only when I'm too tired or the weather is too hot* (Soraya, 43); 1b) *It's difficult to see any improvement, you know? Because my legs still hurt a lot, but... It's a treatment I didn't think would take this long, you know? I wasn't prepared for this.* (Silvana, 42)

Continuation of limitations: The dependency on others to perform simple daily tasks stood out not only in the post BMT interviews, but also in the interviews carried out before the transplantation. This was one of the most inconvenient factors mentioned by the study participants, which is still limiting their lives post BMT: *What bothers me most is the possibility of being a burden to others. It bothers me a lot. And people getting trapped with my problem. It makes me very upset.* (Roberval, 54)

Devising the future: In relation to future expectations, all patients report the expectation of improvement. They actually nourished the desire that the treatment would really cure them and allow them to resume their lives from where it had been interrupted: *I'm not someone who wants to be in bed all day, expecting people will feed me... I'm not going to try to kill myself because of this, but I think I still have potential to do a lot, so...I thought it wouldn't hurt to lose movements, but I was ok then. Now my mind is faulting, so let's start moving because it's not working this way* (anxious laugh). (Silvana, 42)

DISCUSSION

In general, retrospection suggests these patients' quality of life is continuously and constantly reduced as the disease insidiously progresses. In this devastating scenario, the transplant is presented as a heroic possibility, so that they would recover not only their movements but also the normal life they had lost.

In summary, in the immediate post BMT, despite the relief they felt for leaving the nursing ward and the hospital environment, their quality of life seemed to be harmed in several aspects.

In the SF-36 evaluation, data suggest patients have a perception of improvement after the procedure in relation to the capacity to perform daily tasks.

It could be perceived in the data analysis that patients presented a good psychosocial adaptation before the disease, that they had a productive life and satisfactory performed their social roles, professional activities and daily life. They were mostly people with good or at least average cultural and economic level, which shows, from the evolutive point of view, that they were autonomous, able to make their own decisions and execute tasks according to what is expected from adult people. In this context, the loss of their health condition led to harmed adaptative capacity and daily organization, coupled to a faulty social support network, leading to feelings of deception, anger, denial and frustration, which put people face-to-face with their own weakness in the face of adverse events, which they cannot control. Despite the marking difficulties caused by the disease, they show ability to overcome challenges, common daily preoccupations caused by the disease and preservation of affective involvement with family and friends.

The disease implied a broad range of symptoms that progressively aggravates. It can be perceived that the main complaints are related to the loss of physical functioning, which prevents them from exerting their routines with the same ability and dedication they were used to. In this sense, the perception of difficulties and limitations in simple daily

tasks, the impossibility of continuing to exert their regular professional activity, exposure to continuous pain and perceived changes in their interpersonal relationships are highlighted.

On the other hand, new possibilities are noticed, as they reflect on the meaning of their lives, values, beliefs and projects. Thus, the diagnosis of an autoimmune disease, despite the hope for cure expressed by some patients, substantially interferes in their quality of life. In this study, it appears harmed, especially in the Physical Functioning and Role Limitations due to Physical Problems. Differently from what is appointed in literature⁽¹⁵⁾, in this study, patients showed themselves very determined regarding the transplantation, always characterizing it as a salvation-treatment and disconsidering the equally viable possibility of threat-treatment. It can be due to the fact that these patients have lived with their diseases for a very long time, have suffered a considerable reduction in their quality of life as a consequence of the disease progression, and have already tried several treatments with no satisfactory results. And especially because they felt they were at the limit of their strength, nearing physical and mental exhaustion, which makes them reveal they are very "tired" of feeling so many limitations in their lives.

Therefore, the transplantation appears as a redemptive possibility, a hope for cure, and for recovery of their so compromised quality of life, corroborating with findings of some authors⁽¹⁶⁾, who appoint that this expectation encourages them to decide in favor of the BMT.

When patients leave the nursing ward after transplantation, they present indices of quality of life very similar to those they had previously to the surgery, so there is no significant statistical difference between the two phases of the procedure. This result

per se can be seen as positive if we consider the BMT's tremendous consequences. Nevertheless, the data obtained through interviews analysis appoint to a perception of improvement of Role Limitations due to Physical Problems and Physical Functioning right after the hospital discharge. The majority of patients showed renewed disposition to perform daily activities, even against medical recommendations, which indicates improved emotional state. Thus, despite feelings of weakness and frustration experienced by patients with autoimmune diseases, there is a possibility that patients will feel capable of dealing with challenges and overcoming adverse conditions, seeking not to restrict themselves to the limitations of the chronic condition, which is experienced as feelings of capability and power in the face of life⁽¹⁷⁾.

A fact to be considered when one refers to quality of life of these patients is the change in life styles. Patients recover quality of life previous to the procedure, but not the *same quality of life*, and changes like better appreciation of life and search for closer affective interpersonal relationships⁽¹⁸⁾ are common. These changes could be verified through interviews, in which the majority appointed their own life as the most precious thing.

CONCLUSIONS

It can be concluded that, when applied as a therapeutic technique for autoimmune diseases, after leaving hospital, BMT contributes to a perception of improved capacity to perform everyday activities. Patients feel encouraged by the possibility of reorganizing their professional life, resuming their plans and reliving their dreams interrupted for so long because of the disease.

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