

## Quality of life after bone marrow transplant: comparison between evaluation of children and mothers

### Qualidade de vida pós-transplante de medula óssea: comparação entre avaliação das crianças e das mães

### Calidad de vida post-trasplante de médula ósea: comparación entre la evaluación de los niños y sus madres

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This study aimed to evaluate the quality of life of children submitted to bone marrow transplantation and compare the results of self-assessment with the hetero-evaluation carried out by the mothers. The sample was composed by 14 participants, seven mothers and their children. The Pediatric Quality of Life Questionnaire PedsQL™. The results indicate significant differences in the values of mothers and children evaluation, and mothers overestimated their children QV. This indicator is important because it suggests the need to implement interventions with the pair, in order to facilitate dialogue and increase understanding of the emotional experiences of children by mothers.

**Descriptors:** Quality of life; Child; Mothers; Bone marrow transplantation.

Este estudo teve por objetivo avaliar a qualidade de vida de crianças submetidas ao transplante de medula óssea e comparar os resultados da autoavaliação com o heteroavaliação realizada pelas mães. A amostra foi composta por 14 participantes, sete mães e seus respectivos filhos. Utilizou-se o Questionário Pediátrico de Qualidade de Vida PedsQL™. Os resultados indicam diferença significativa nos valores da avaliação das mães e crianças, sendo que mães superestimaram a QV dos filhos. Este indicador é importante porque sugere necessidade de implementar intervenções com as díades, visando facilitar o diálogo e ampliar a compreensão das vivências emocionais das crianças pelas mães.

**Descritores:** Qualidade de vida; Criança; Mães; Transplante de Medula Óssea.

Este estudio tuvo como objetivo evaluar la calidad de vida de los niños sometidos a trasplante de médula ósea y comparar los resultados de la autoevaluación con la heteroevaluación realizada por las madres. La muestra consistió de 14 participantes, siete madres y sus respectivos hijos. Se usó el cuestionario de calidad de vida pediátrica de PedsQL™. Los resultados indican una diferencia significativa en los valores de la evaluación de madres y niños, y las madres sobrestimaron la CV de sus hijos. Este indicador es importante porque sugiere la necesidad de implementar intervenciones con el par, con el objetivo de facilitar el diálogo y ampliar la comprensión de las experiencias emocionales de los niños por las madres.

**Descritores:** Qualidade de vida; Criança; Mães; Transplante de Medula Óssea.

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## INTRODUCTION

**B**one marrow transplantation (BMT) is a complex medical procedure, whose basic principle is to destroy the patient's sick marrow and transfer normal progenitor cells to the individual affected by solid and hematologic cancers, such as leukemias and lymphomas, and genetic and immunological diseases. The objective is the reconstitution of the sick hematopoietic and immune systems, once the graft will take over the production of blood cells and contribute to the destruction of cytotoxic cells which still remained in the body of the receptor<sup>1</sup>. It is indicated for those patients who have obtained little response to the conventional biomedical treatment.

During the transplant process, the children face numerous challenges in hospitalization, such as the requirement to remain in protective isolation and adaptation to a rigid scheme of medical routines, in addition to the reactions and side effects resulting from the high toxicity of the treatment. The expectation around what can happen, from pain to the changes in daily life, that cause suffering by anticipation and, consequently, fragilizes children and their family<sup>2</sup>.

Currently, the BMT is considered the most appropriate and successful therapy in the treatment of diseases that some time ago were fatal, such as leukemia and other hematologic neoplasms. However, it is an extensive, aggressive prolonged and complex process and prone to complications that weaken, leave sequels or have fatal consequences. In that long and tortuous route, the children face situations and complications that involve pain and physical and psychological suffering<sup>2</sup>.

Radiotherapy and chemotherapy result in significant and debilitating side effects. Complications arising from infectious are possible and not very rare. Children daily lives are controlled by external factors. The acts of eating, sleeping and even get dressed are organized on the basis of medical procedures and strict requirements of care<sup>2</sup>.

The child submitted to BMT can have a feeling of not possessing their body and the

control of their routine, since the continuity of their life, of their social and affective bonds were abruptly interrupted<sup>3</sup>. At the same time, the family is also affected by many negative feelings, aggravated by the stress produced by the rupture of the routine, changes in family roles, high expenses and uncertainties in relation to the future, besides the expectations towards the treatment, its adverse effects and the time that is spent on successive trips to the hospital<sup>4</sup>.

The hospitalized child usually experiences insecurity, discomfort and psychological distress due since they are far from their relatives and their home, school friends, restriction to bed and the real danger of death, and they will look for support in the family to face this new reality<sup>5</sup>.

Therefore, perceiving that they are seriously ill and needing a treatment of such complexity constitutes an enormous challenge. They need to develop a new way of guiding their lives, acquiring new knowledge and discovering new ways of being and making their existences, while learning to live with the disease in an unfamiliar and frightening environment.

The moments of uncertainty that are experienced in this phase mean that surviving the disease and treatment is living one day at a time, facing the challenges and achievements, the daily losses and gains, in an incessant movement to seek new adaptive perspectives. The effectiveness of the adjustment to the new reality depends on the family support and the interventions received from the health team, which can facilitate coping with this difficult period<sup>6</sup>.

Relatives and patients have their suffering intensified, especially because, when they enter the TMO unit, they have already undergone several services and a stressful routine of examinations, treatments, and medical consultations, searching health devices that can offer real healing possibilities.

During the completion of the BMT, the child faces several stressful events: the toxic effects of the chemotherapy sessions, the various implications that the treatment infringes on their autonomy and the

possibility of suffering complications resulting from the procedure. These vital events, together with the imminent risk of life loss, can result in impairments for the patients and their family quality of life (QOL)<sup>1</sup>.

QoL indicators have been considered essential to assess the impact of the disease and the treatment on the patient's life. They have also been used to establish indicators of the illness severity and progression, as well as to create strategies to minimize the disorders caused by the treatment<sup>7</sup>.

Recently, two trends<sup>1-7</sup> are identified: QoL as a generic concept and health-related QoL (HRQoL). The second term is used as a concept that specifically refers to dysfunctions or health problems, including the assessment of aspects directly related to diseases and health interventions, such as limitations or disabilities and their effects on the well-being perception<sup>7</sup>.

Assessing the HRQoL of children after treatment is crucial to subsidize health actions. Recently, there has been a concern to analyze the concordance of HRQoL assessed by the child and evaluated by the parents. The importance of this type of measurement is to promote actions that are actually more effective for the children's physical and mental health, according to their own needs, not perceived or experienced by the parents, who end up being their children "spokesmen". Although there is no convergent outcome, in all studies appear divergences between self and hetero-evaluation<sup>8-16</sup>.

The results of the HRQoL, both self and hetero-evaluated, are very different, depending on the context in which the study was conducted. Two articles on the theme were found in Portuguese, one of the instrument validation in the Brazilian scenario<sup>9</sup> and the other in the Portuguese context, and this is a descriptive study with children with cancer between eight and 17 years old; There was a significant difference between the children's perception of their QoL (66,0±13.3) and that of their parents (60,3±15.0)<sup>17</sup>.

This study aimed to evaluate the quality of life of children undergoing bone marrow transplantation and compare the results of

their self-assessment with the hetero-evaluation performed by their mothers.

## METHOD

It is a descriptive and exploratory cross section study. We included all children who performed the BMT and were in post discharged phase (up to a week out from the hospital), from January to December, 2015, and their respective mothers.

The participants were in outpatient follow-up in the BMT unit from a tertiary hospital in the State of São Paulo in Brazil.

Inclusion criteria were: child just submitted to a transplant between eight and 11 years old, out of the hospital with outpatient follow-up and available, with their mother, to cooperate voluntarily with the research. We evaluated all children who were discharged from the ward of BMT unit.

The instrument used was the *Pediatric Quality of Life Cancer Module* (PedsQL™). This is an instrument validated for Brazil to evaluate children and adolescents with cancer, able to assess how the disease and the therapeutic method adopted interfere in the children's HRQoL<sup>18</sup>.

Structurally, it consists of 27 items, distributed in eight subscales: pain and injuries (two items), nausea (five), anxiety due to the procedure (three), anxiety due to the treatment (three), concerns (three), cognitive difficulties (five), perception of the physical appearance (three) and communication (three). *Likert* type scale consists of five response options: "never", "almost never", "sometimes", "often", "almost always"<sup>18</sup>.

The PedsQL™ was applied individually. The researcher read the questions to the child in full and literally (for example: I feel pain, I hurt my joints and muscles). The mothers also completed the instrument, composed of the same issues, but by making references to their children (for example: My son/My daughter has pain or hurts the joints and muscles).

The data were collected in a hospital preserved environment, wherever possible in a reserved room, safeguarding the principles of comfort and privacy, for approximately 20 minutes.

Data were analyzed according to the recommendations of the instrument. After the application we assigned a score for each question that later was transformed into a 0-100 scale, where zero corresponds to a worse state of health and 100 to a better one, with each dimension analysed separately. The values obtained with the children were compared with those of their mothers using the Mann-Whitney test. The level of significance was  $p \leq 0.05$ .

The project was approved by the Committee of Ethics in Research (CAEE nº 23198513.3.0000.5407).

**RESULTS**

The sample was composed by 14 participants, seven children and their mothers. There is little variation in the age of the participants, being the diagnosis the biggest differentiator. All mothers were full-time caretakers of their children during the Bone Marrow Transplant.

**Table 1.** Characterization of children after BMT. Ribeirão Preto, SP, Brazil, 2016.

| Sex | Age* | Diagnosis                    | Idade da mãe |
|-----|------|------------------------------|--------------|
| F   | 10   | Sickle Cell Anemia           | 31           |
| F   | 10   | Severe Aplastic Anemia       | 33           |
| M   | 8    | Acute Lymphoblastic Leukemia | 39           |
| M   | 10   | Severe Aplastic Anemia       | 32           |
| M   | 9    | Sickle Cell Anemia           | 38           |
| M   | 10   | Severe Aplastic Anemia       | 32           |
| F   | 10   | Sickle Cell Anemia           | 33           |

\* Age in years at the time of collection

The results obtained in the different domains of HRQoL assessment by the PedsQL™, from the perspective of children

and mothers, are organized in Table 2, which allows to compare the self and hetero-evaluation.

**Table 2.** Comparison between the HRQOL self and the hetero-evaluation of children submitted to BMT. Ribeirão Preto, SP, Brazil, 2016.

| Domain              | Children    |             | Mothers     |             | P           |
|---------------------|-------------|-------------|-------------|-------------|-------------|
|                     | A           | SD          | A           | SD          |             |
| Pain                | 70,4        | 22,1        | 97,9        | 4,6         | 0,03*       |
| Nausea              | 70,8        | 22,6        | 79,1        | 21,8        | 0,42        |
| Anxiety procedure   | 72,0        | 23,3        | 48,5        | 32,0        | 0,49        |
| Anxiety treatment   | 76,0        | 28,5        | 84,6        | 15,4        | 0,95        |
| Concerns            | 64,3        | 30,7        | 82,0        | 11,5        | 0,63        |
| Cognitive functions | 66,6        | 30,7        | 70,8        | 28,1        | 0,81        |
| Appearance          | 66,6        | 28,3        | 84,7        | 13,1        | 0,56        |
| Communication       | 68,0        | 45,2        | 67,9        | 24,2        | 0,64        |
| <b>Total</b>        | <b>69,3</b> | <b>13,4</b> | <b>76,9</b> | <b>13,7</b> | <b>0,26</b> |

A = average, SD = standard deviation

\* Statistically significant difference

In general, the child's self-evaluation (69.3±13.4) about their HRQoL was worse than estimated by the mothers (76.9±13.7). we observed statistically significant difference on the values of evaluation of mothers and children in Pain ( $p=0.03$ ), and mothers have overestimated the absence of pain in children.

The PedsQL™ domains, from the perspective of the children, were ranked as follows, in descending order of preservation: (1) Anxiety with treatment, (2) Anxiety with procedure, (3) Nausea, (4) [lack of] Pain, (5) Communication, (6) Cognitive functions (7)

Appearance, (8) Concerns. From the perspective of mothers: (1) [lack of] Pain, (2), (3) Appearance Anxiety with treatment, (4) Concerns, (5) Nausea, (6) Cognitive functions, (7) Communication (8) and Anxiety with procedure.

Analyzing the PedsQL pains domain™, it calls the attention the difference statistically significant ( $p \leq 0.05$ ) between the frequency in which the child reports pain (70.4 ± 22.1) and the frequency in which the mother believes their children experience painful stimuli (97.9 ± 4.6).

All of the mothers endorsed items which indicate that the child feels pain in the joints and muscles, while the responses of the children are divided on other gradations, three of them reported pain “often” and “not very often”.

The only domain in which mothers underestimate the responses of their children is Anxiety with the procedures, which refers to the difficulties to undergo interventions involving needles, injections and tests. We highlight the fact that it was the domain with the lowest average in the mothers’ estimate ( $48.5 \pm 32.0$ ) and the second best rated by children ( $72.0 \pm 23.3$ ). The children’s answers focus on “never” and “hardly ever” experience problems with these procedures. Mothers believe that the children feel anxious “very often” and “not very often” with these invasive procedures.

The HRQoL component in which both groups were nearee was *Communication*. This domain of the PedsQL™ is understood as the ease of talking – with the health team and people in general-about the disease and about how they feel regarding their condition and treatment. However, in the *ranking* of the domains, Communication ranked fifth in the perception of mothers and in penultimate (seventh) place in the self-assessment of their children, suggesting that there are difficulties in establishing dialogue on such crucial issues for the treatment.

## DISCUSSION

The results show that the self-evaluation of the children about their HRQoL was worse than the estimated by the mothers. These data corroborate other research, which in addition to show differences between the two scores, signals a trend of better assessment by parents than by their own children, that is a trend of the parents in transmitting their own HRQoL to their children QVRS<sup>8,12,14</sup>.

In this study there was low-scoring, in particular those obtained by children, when compared to those in other countries, as an American study that reported an average score of 73 in the self-evaluation and 74 in the hetero-evaluation<sup>8</sup>. In the Japanese context children averages were 78 and family 75<sup>14</sup>

and in China children scored 84 and parents 80<sup>12</sup>.

The data of the present study are closer to the results found in the Portuguese scenario, in terms of the HRQoL average perceived by the child ( $66.0 \pm 13.3$ ), distant from the parent’s assessment ( $60.3 \pm 15.0$ )<sup>17</sup>. In other words, Portuguese parents report a HRQoL of their children with cancer, more depreciated than Brazilian mothers.

The studies mentioned do not refer to reality of the BMT, which admittedly entails harm in the patient’s and their family QoL immediately after it is carried out<sup>1-19</sup>. This commitment such that the authors have developed a module of the PedsQL™ specific for BMT, taking into consideration the implications and complications of the procedure<sup>20</sup>. This scale is not yet available for use in the Portuguese language.

In the present study, we stand out as more preserved the domain Anxiety with treatment. This result was also found in other studies, related to hope in the procedure resolution<sup>8-17</sup>. Among the least preserved domains appears the dissatisfaction with physical appearance, related to body image changes as a result of the treatment, which are not always considered for the children’s reality. These changes are often taken as exclusive of teenagers and adults, even for the mothers who attributed high score for that component ( $84.7 \pm 13.1$ ), when compared to the children’s answers ( $28.3 \pm 66.6$ ).

Three domains stood out in the results: Pain (mothers underestimate the pain experienced by children), Anxiety with the procedures (mothers overestimate their children’s difficulties about the need for examinations) and Communication (domain in which the scores were very close in both groups). Another study found the tendency parentes have to perceive the pain intensity experienced by children lower<sup>21</sup>, which investigated 251 children (92 with cancer) and their parents, with the same instrument used in this study.

The pain assessment is subjective and can affect different spheres of of the patient’s QoL, and the mother, in particular, is important to manage this symptom, so it is

very importante that she understands the real dimension of the children's pain experience<sup>21</sup>.

The health professional needs to be aware of the psychological aspects involving the physiological processes in the manifestation of pain. The assistance should be based on the evaluation of the clinical history informed by the patient himself, personality characteristics, beliefs about pain, functional limitations and strategies to deal with a painful experience. It is known that psychological factors have a powerful influence in the treatment of patients with chronic pain.

As to the difficulties in relation to procedures considered as invasive (domain Anxiety with the procedure), a study showed that the feeling of lack of control, felt by parents on painful interventions affect their QoL and can interfere with the children's perception of the experience in that domain<sup>21</sup>.

About Communication, we can interpret as positive the result obtained, since both the children and mothers showed a similar perception in relation to difficulties and facilities of this process, which is important for the possibility of implement interventions in relation to other disparate domains.

## CONCLUSION

The HRQoL assessment is considered important to drive and humanize oncological treatment. The PedsQL™ results show that there is a disconnect between the perception of children and their mothers HRQoL.

The medical team needs to be especially mindful of the maternal perception of the child's absence of pain, in comparison with the assessment of the painful procedures experience after BMT from the perspective of the children.

The fact that the mothers underestimate their children lack of pain can lead them to an aggressive behavior, apparently difficult to understand, in particular towards the professionals who perform invasive and painful procedures.

This research presents limitations, such as a limited sample and cross design; However, as a first exploratory study in the Brazilian context with children with BMT,

offers relevant results for future research with more robust samples and longitudinal design.

About the presence and intensity of pain, it is necessary to carry out a joint assessment of the mother-children pair, with the use of specific instruments, in order to obtain a more accurate dimension of this subjective construct.

The results suggest that the health team needs to implement interventions that promote rapprochement and dialogue between mothers and children, so that they can be sensitized to meet the real needs experienced by children.

So, the professionals can help mothers to work more effectively to maintain the HRQoL of children and their own, since both are interrelated.

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**CONTRIBUTIONS**

**Érika Arantes de Oliveira-Cardoso** contributed in conception, design, analysis and interpretation of data, and writing. **Juliana Tomé Garcia e Ana Luisa Carvalho Guimarães** worked in the analysis and interpretation of data, and writing. **Maria Laura de Paula Lopes Pereira e Jorge Henrique dos Santos** participated in data collection, analysis and interpretation of data, and writing. **Manoel Antônio dos Santos** contributed to the conception, design, writing, and critical review.

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