

FAMILY CRISIS IN THE CONTEXT OF BONE MARROW TRANSPLANTATION: AN INTEGRATIVE REVIEW¹

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This study presents an integrative literature review about the crisis experienced by relatives of bone marrow transplant (BMT) patients. The sample consisted of 25 publications, one of which came from Lilacs and 24 from Medline. The results evidenced that there were no experimental studies and that interventions are aimed at psychological and social aspects. In terms of aspects of family crisis indicated in the articles, all publications discussed the characteristic of the event (diagnosis of the disease and BMT) and the perceived threat; 52% of the articles mention the resources offered as being relevant and 20% mention that past crisis experiences influence the current crisis. Understanding the elements of family crisis and identifying appropriate interventions help nurses in care delivery to BMT patients.

DESCRIPTORS: family; bone marrow transplantation; nursing care

CRISIS DE LA FAMILIA EN EL CONTEXTO DE TRASPLANTE DE MEDULA ÓSEA: UNA REVISIÓN INTEGRADA

Esta revisión integrada de la literatura se trata de la crisis vivenciada por los parientes del paciente con trasplante de médula ósea (TMO). La muestra se constituyó de 25 publicaciones, una de ellas obtenida del Lilacs y 24 del Medline. Los resultados mostraron la inexistencia de estudios experimentales, y que las intervenciones se dirigen a los aspectos psicológicos y sociales. Considerando los aspectos de la crisis familiar apuntados en los artículos, se observó que el 100% mencionó la característica del evento (diagnóstico de la enfermedad y TMO) y la amenaza percibida; el 52% citó como relevantes los recursos ofrecidos y el 20% indicó que experiencias de crisis pasadas influyen la crisis vivenciada. La comprensión de los elementos de la crisis familiar y la identificación de intervenciones apropiadas ayudan al enfermero en la atención a parientes de pacientes sometidos al TMO.

DESCRIPTORES: familia; trasplante de médula ósea; atención en enfermería

A CRISE FAMILIAR NO CONTEXTO DO TRASPLANTE DE MEDULA ÓSSEA (TMO): UMA REVISÃO INTEGRATIVA

Trata-se de revisão integrativa que aborda a crise vivenciada pelo familiar do paciente com transplante de medula ósea (TMO). Foram selecionados 25 artigos, sendo um da Base Lilacs e 24 d Medline. Os resultados apontaram a inexistência de estudos experimentais e, também, que as intervenções estão voltadas aos aspectos psicológicos e sociais. Considerando os aspectos da crise familiar destacados nos artigos, observou-se que 100% deles abordaram a característica do evento (diagnóstico da doença e TMO) e a ameaça percebida; 52% citaram como relevantes os recursos oferecidos e 20% mencionaram que experiências de crises passadas influenciaram a crise vivenciada. A compreensão dos elementos da crise familiar e a identificação de intervenções apropriadas auxiliam o enfermeiro na assistência aos familiares de pacientes submetidos ao TMO.

DESCRIPTORES: família; transplante de medula ósea; cuidados de enfermagem

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INTRODUCTION

Indication for bone marrow transplantation (BMT) has increased over the last decades, not only for hematologic, but also auto-immune diseases. Moreover, there are studies that highlight its use in cell regeneration of the hematopoietic organ.

BMT is defined as a procedure involving intravenous infusion of stem cells - CD34 (removal of bone marrow from a compatible donor, previously selected) - into a previously conditioned recipient. The aim of this procedure is to reconstitute the hematopoietic organ, which has been debilitated either by infiltration of leukemic cells in the bone marrow or by diseases that harm and change blood-cell production⁽¹⁾. This therapeutic procedure triggers a compromised state of multiple organs and tissues, as well as severe immune depression. This causes higher predisposition to systemic infections and effects due to previous treatments involving chemotherapy, radiotherapy, and use of hepatotoxic and nephrotoxic drugs. Thus, recipient patients need both professional and family support in order to feel secure throughout treatment phases.

In general, hospitals with BMT units allow a family member to accompany the patient throughout the process, from admission to discharge; hence, that person experiences all of the phases and complications involved in the BMT. In such cases, a nursing professional, along with a multidisciplinary team, must provide assistance to both the patient and his or her family.

This study aims to encourage nursing professionals to ponder the emotional crisis that family members of BMT patients may be exposed to. It aims to synthesize the knowledge available in scientific literature concerning family crisis from 1995 to 2005.

The family of the BMT patient

BMT complexity is capable of producing deep psychological effects on patients, family members, and healthcare professionals. Ignoring such factors and simply considering the procedure's technical aspects may bring serious consequences to all involved. Throughout BMT, the patient and his or her family undergo changes in their psychosocial structures. Hence, nursing professionals have an important role in this adaptation so that the best quality of life may be achieved. The family is an ally of the

nursing team in that it provides security and psychological support to the transplant patient during readaptation of the BMT patient to his or her regular social life⁽²⁾.

The primary sources of social support, families have shown changes in terms of demographics and the roles of each element within the family nucleus⁽³⁾. Nursing professionals must take the various family universes into consideration: legal (blood relatives, adoptive children, spouses); biological (those genetically related to the patient - children, parents); social (groups of close friends from the patient's social life); psychological (people who are intimately important to the patient, such as people who co-habit - monasteries, convents, fraternities, and boarding houses; and alternative families, as in the case of homosexuals)⁽²⁾. A family may also be formed by people related by marriage or blood who have a relationship that follows rules that are specific to them. Such rules determine the functions and distribution of roles within the group, all of which share the same system of beliefs and loyalties⁽²⁾.

Not always are family members ready to deal with the situations imposed by BMT. Many times they may not be prepared, know how to ask for help, or simply stand by a loved one. BMT treatment may exceed the patient's or family's adaptation and coping abilities. The treatment necessitates the restructuring of family routines. This is caused by factors such as role changes and the search for financial and emotional resources.

Various models of family crisis are stated in the literature. The model chosen for the present study indicates four factors influencing the family's ability to deal with and adapt to a crisis: characteristic of the event, perceived threat, evaluation of family resources, and former crisis experience⁽⁴⁾. This analytic model provides the basis for evaluating both the meaning that the crisis has to the family and the family's capacity to adapt to the situation. Moreover, it allows for the identification of family strengths and weaknesses. This makes possible the application of nursing intervention strategies to the situation.

The present study was developed with the aim of obtaining knowledge about the family crisis phenomenon. If the BMT patient's family receives emotional and social support, the patient will obtain, in addition to knowledge of the situation, better care and support from the family during treatment.

RESEARCH OUTLINE

The present study is an integrative literature review that aims to gather and synthesize pre-existing knowledge about the proposed theme⁽⁵⁾.

Integrative reviews, when critically developed, have the same standards of primary research in terms of clarity and rigor. It is an appropriate strategy for situations in which studies covering a particular subject are insufficient for meta-analysis research to be conducted⁽⁶⁾.

The stages in performing an integrative review are: a) identifying the theme or question of the integrative review: consists of determining the guiding theme of the research in a clear and specific manner, with clinical and theoretical reasoning by the researcher, and then choosing the key words that will be used in the literature search; b) sampling or searching the literature: begin the search in the selected databases to obtain the studies that will be included and analyzed; study selections must be made according to certain criteria in order to obtain internal validity of the review, and such criteria must be clearly and concisely stated in the text; c) studying categorization: consists of defining the information to be extracted from selected studies, using a previously created instrument; d) evaluating studies included in the integrative review: the selected studies must be submitted to critical evaluation, taking into consideration the researcher's clinical experience; e) interpreting results: discuss the analyzed data and compare to pre-existent theoretical knowledge; f) synthesizing knowledge evidenced in the analyzed articles or presentation of the integrative review: synthesis of the evidence obtained in the analyzed articles, based on a critical method⁽⁵⁻⁶⁾.

The guiding question of the present study is: how have nursing professionals approached the family crisis theme in BMT?

The LILACS and Pub Med databases were used which have broad coverage of scientific journals in the area of healthcare. Consulting such a large base ensured compliance with the literature recommendation of searching for publications in different sources⁽⁷⁾. The articles were identified in the journal section of the Central Library of the University of São Paulo - Ribeirão Preto Campus. Articles that were not located in this section were requested through the university's Bibliographic Commuting Program (COMUT).

Inclusion criteria for the articles were: journals had to be indexed in the LILACS and MEDLINE databases; published in either English, Spanish, or Portuguese; published during the period from January 1990 to May 2005; applied to human beings independent of color, ethnic group, or religious beliefs; used the descriptors "bmt", "family", "bone marrow transplantation", and "family", respectively in the three languages; approached the subject of assistance to the families of BMT patients.

Once the study sample had been established, the next step was to read the articles with the aim of identifying relevant data in the data collection instrument. Certain methodological steps were followed to assure higher study reliability: identification of the publication; method used in the publication; methodological problems identified in the development of the investigation; level of evidence in the articles; nursing care strategies and the model of crisis used in the study.

In order to analyze the methodology used in the studies, publications were identified by the following items: journal name, volume, number, page number, year/month of publication, authors, title, type of study, subjects⁽⁸⁾. To analyze evidence found in the articles, a 6-level classification was done (1-evidence obtained from meta-analysis results of randomized clinical trials; 2-evidence obtained in an experimental-design study; 3-evidence obtained in quasi-experimental research; 4-evidence from descriptive studies or a qualitative method approach; 5-evidence from case or experience reports; and 6-evidence collected based on the opinions of experts or lawmakers⁽⁹⁻¹⁰⁾. To identify the crisis concept used in the studies, they were analyzed following the family crisis model (4): characteristic of events, perceived threat to family relationships in terms of their status and goals, evaluation of family resources, and past crisis experience. Nursing interventions identified within the text were associated with the interventions proposed by the Nursing Intervention Classification (NIC)⁽¹¹⁾ for nursing diagnoses: "**Interrupted family processes**" and "**Compromised family coping**". Such nursing diagnoses were chosen because they represent the studied family crisis framework.

RESULTS AND DISCUSSION

The final sample was reached after initially analyzing 807 studies obtained from the Medline

database. Among these, 783 studies were about medical aspects of BMT and 24 covered family crisis, the theme proposed for the present study, though using a different term. Two additional studies from Lilacs were considered, of which one was a master's dissertation and was included in the sample. Thus 24 (96%) of the analyzed studies were extracted from the Medline database and one (4%) from the Lilacs database.

As for the journals' country of origin, it was observed that 18 (72%) were from the United States, one (4%) from Greece, one (4%) from Canada, one (4%) from Poland, and one (4%) from Brazil. It was impossible to determine the origins of three journals (Clinical Transplant, Support Care Cancer and Psychother Psychosom). The journal with the highest incidence of publication was Oncology Nursing Forum (20%), followed by Cancer Nursing (12%), Social Science Medicine (8%), Canadian Journal Psychiatry (8%), and Yale Journal Biological Medicine (8%). The other journals had only one publication each.

Regarding year of publication, studies showed higher incidence in the years 1990 (16%), 1996 (20%), and 1999 (16%), as shown in Figure 1:

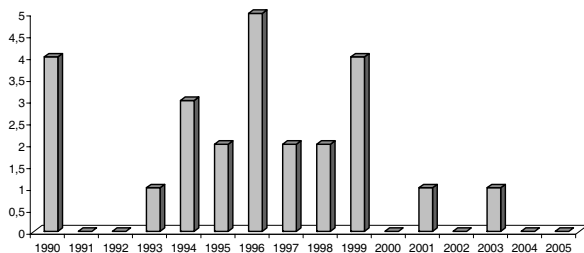


Figure 1 - Study distribution by year of publication

Concerning the **authors of the studies**, it was observed that 12 studies (48%) were developed by nurses, six (24%) by other professionals, and seven (28%) did not specify their authors' professions. These findings indicate the multifaceted nature of the theme, which is of interest to various healthcare professionals. Furthermore, it was observed that most were clinical experts or professionals with graduate degrees. The authors are employed at universities, hospitals, and supporting institutions.

Regarding the **research outline**, all analyzed studies are non-experimental, of which 7 (28%) are ex-post-facto and 19 (72%) are descriptive (case reports, experience reports, literature reviews). Therefore, it was observed that the production of experimental studies remains scarce for this theme

and requires greater attention from researchers. The literature states that the best clinical evidence is obtained by experimental clinical studies, taking into consideration accuracy, precision, and practical applicability⁽¹²⁾.

As to the **evidence levels**⁽⁹⁾, most studies show level four (64%), followed by levels six (28%) and five (8%). Such results demonstrate that the studies do not indicate strong clinical evidence. Nevertheless, the evidence found in the studies emphasizes the importance of clear and effective communication between family members, healthcare teams, and patients in order to minimize anxiety and depression. Factors which may enhance emotional support are: certain family types with specific characteristics, family cohesion, few conflicts within the family, cultural and intellectual elements, and religion. Support groups and networks minimize anxiety, anguish, and depression experienced by patients and their families.

Most articles portray the impact of BMT on patients and their families taking into consideration factors that generate stress, depression, anguish, and strategies used to help them cope with that situation.

Family crisis was approached by the authors when they highlighted the impact of factors such as diagnosing the disease, choosing treatment (BMT), complications involved, and which of these factors influenced the every-day lives of the families. The authors state that patients as well as their relatives may develop anguish, depression, and anxiety during the various treatment phases. Nonetheless, when healthcare professionals communicate with patients and their families in a clear and effective way, respecting their religious beliefs, symptom consequences can be minimized.

As to the findings about **family crisis** analyzed according to the selected model, it can be affirmed that event characterization (disease diagnosis and BMT) and perceived threat (moving to another city, treatment, separation, complications and changes in family roles) were reported in all the articles. Such aspects are relevant for proposing interventions to minimize consequences brought about by the situation.

Statements about family resources were observed in 52% of the articles. According to the studied authors, resources (housing in support homes, possible help for transportation, food, and medication) offered to the families influence results. The influence of former crisis experience, stated in 20% of the

articles, may lead to either positive or negative coping in the current situation. Thus, nursing professionals must intervene in situations that generate anxiety, stress, and depression so that a positive solution is achieved, which would contribute to patients' treatment.

All analyzed articles state that patients and their families must be informed about the therapy as of the moment of diagnosis. The authors also emphasize the need to explain the importance of keeping the patient isolated during treatment, as well as to provide additional information about the possible complications, prognosis, and how treatment will be done. Nursing professionals have a fundamental role in helping family members adapt to the new situation and to deal with the various treatment stages, as well as to minimize the consequences of stress factors due to the complexity of treatment⁽¹³⁾.

BMT causes a rupture in family dynamics with harsh changes, causing particularly a decline in economic status⁽¹⁴⁾ and role changes, and initiates the search for treatment centers (which usually are distant from their home town). Such situations are stress generators⁽¹⁵⁾. Sixty-four percent of the analyzed articles defined BMT as a complex treatment requiring that nursing professionals provide assistance to patients as well as their families. Situations that generate stress, anxiety, or anguish take place as of the medical diagnosis and continue throughout the various treatment stages; such as selecting donors, preparing for transplantation, the transplantation itself, and possible complications. These difficulties continue throughout the whole process until discharged from hospital and forwarded to out-clinic follow-up. At such moments, both emotional and social supports are relevant because it is through acquired knowledge that family members can positively cope with this situation.

Both psychosocial and psychoemotional aspects interfere with treatment in a positive or negative way, depending on how one deals with situations that generate stress and anxiety. Examples of such situations include: fear of death, reduction in financial resources, and witnessing complications and changes in the patient's conditions. The nurse is able to evaluate the family's emotional status⁽¹⁶⁾ as well as to develop coping techniques, thus helping them deal with the situation in the best possible way⁽¹⁷⁾.

The articles highlight that the **proposed interventions** must meet the Nursing Intervention

Classification (NIC). Most articles (64%) state that emotional support is relevant to minimize the psychological consequences brought about by BMT, and that the nurse has a fundamental role in that process. Other points that were highlighted as important to positive coping are: family support (36%), financial aid (24%), support groups (32%), ways of coping (40%), anxiety reduction (28%), family process maintenance (16%), and role performance reorganization (12%).

According to 16% of the articles, it is important to create explanatory handouts with information about the treatment, complications, recommendations, and support institutions that offer housing, feeding, transportation, and medication. City guides and schedules for public transportation are also relevant and make it easier for family members to adapt to the new situation, reducing stress.

Taking the results into consideration, a synthesis of the main findings concerning family crisis in the BMT context is presented:

- the analyzed articles were indexed mostly (96%) in MEDLINE database, not observing double citation of articles, i.e., in both databases;
- most journals (72%) are from the United States;
- nursing professionals (48%) were those who most published articles about the proposed theme;
- most authors hold clinical expertise or graduate titles, and work at universities, hospitals, and support institutions;
- 76% of the articles were developed by more than one author;
- 36% of the articles were published in specific nursing journals;
- most articles reported on the impact of BMT on patients and their families, taking into consideration factors that generate stress, depression, anguish, and the strategies used to cope with the situation;
- all studies presented non-experimental designs, distributed into 7 (28%) ex-post-facto and 19 (72%) descriptive (case report, experience report, literature review); clinical evidence ranged between levels 4(64%), 5 (4%), and 6 (28%);
- evidence from nursing studies are still of low consistency; the family crisis terms "event characterization" and "perceived threat" were observed in all the analyzed articles;
- nursing interventions approach mainly emotional support as relevant to minimize the consequences of BMT.

FINAL CONSIDERATIONS

It is understood that the family crisis generated by bone marrow transplantation can lead family members to experience anxiety and depressive episodes. Such factors are no help in patients' treatment and or to family members' coping with the situation. Nursing care should not focus only on the biological aspects of BMT, Psychosocial aspects require nursing interventions for both patients and their families, helping them cope with and adapt to the crisis.

It is worth noting that on one hand the behavior of family members may interfere in the immunologically compromised patient's conditions. Yet on the other hand, deterioration of family structure occurs concomitantly with the most severe complications after BMT. It cannot be affirmed that

inadequate family coping is the cause for onset or worsening of the patient's conditions. This hypothesis needs further investigation, as recommended by the authors.

Attention to socioeconomic factors, perceived threat to family relationships and structure, along with the need to clarify all the factors involved in this therapeutic procedure, meet the characteristics described in the family crisis model used in this study.

Care to BMT patients' families is a challenge for the whole multiprofessional team. However, when these people's needs are understood, one can help them cope effectively and positively with the crisis situation brought about by the treatment, minimizing emotional consequences such as depression, stress, and anxiety.

Further studies are needed in order to evaluate the response of family members to different strategies.

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