

Nurses' competences in the critical care of children undergoing hematopoietic stem cell transplantation

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ABSTRACT

This is a descriptive study, with qualitative data analysis, in order to identify and analyze the experiences and competencies required by nurses in the care of transplanted child, who demand critical care. Nine nurses were interviewed. We analyzed the data according to the procedures for qualitative content analysis, and then we elaborated the following themes: Critical care to the transplanted child: a double challenge for the nurse; Nurses' competences for the care towards the critically ill child submitted to hematopoietic stem cell transplantation (HSCT). The identified competencies based on scientific knowledge, skills and natural abilities and relate to specific knowledge about pediatric HSCT; technical-scientific, interactive and communication skills; management of material resources and equipment; emotional control, empathy and leadership. Such competences help in the construction of a specific profile for the care offered to this clientele, with a view to therapeutic success.

Descriptors: Pediatric Nursing; Critical Care; Hematopoietic Stem Cell Transplantation; Professional Competence; Nurses.

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INTRODUCTION

Hematopoietic stem cell transplantation (HSCT) is an important therapeutic option for children with oncological, hematological and immunological diseases⁽¹⁻²⁾. There are basically three types of transplantation: autologous, syngeneic and allogeneic, named according to the stem cells origin, that is, if they come from the patient, from an identical twin or a relative donor or not⁽³⁾. It is a prolonged therapeutic modality, with high specificity and complexity, with a significant mortality rate⁽²⁾. It requires an exclusive hospital unit and multidisciplinary team trained to assist the transplanted child⁽⁴⁾.

HSCT may be the only possibility of cure for children with severe diseases. However, the procedure relates to complications and depends on the clinical picture prior to transplantation. Critical care is intended for children who become clinically unstable during treatment or related to it, some of whom will experience impairment of vital organs, systemic infections, and Graft-versus-Host Disease (GVHD), and thus benefit of pediatric intensive care units (Pediatric ICU)⁽⁵⁾.

Nursing work in a HSCT unit encompasses specific technical competencies, technical-scientific resources and communication elements that contribute to therapeutic success. In addition, the humanized, safe and individualized care towards the child and the family should be a priority^(2,6). The nurse must systematize and individualize the care to the client in all transplantation stages, from the indication, hospital admission to outpatient follow-up, differentiating each phase and intervening adequately in each of them^(2,7).

In the literature related to pediatric nursing and HSCT, publications focused on infection prevention, catheter care, post-transplant complications, and the quality of life of children undergoing HSCT are prevalent^(2-3,5). There is no mention of skills related to nurses' training in this area, especially with critical pediatric patients. Thus, the guiding question of the study was: "What are the necessary nursing competencies in the care of children undergoing HSCT and the specificities of this care in critical situations, from the point of view of nurses?" From this perspective, this study aimed to identify and analyze nurses' experiences about the competencies needed to assist the children undergoing HSCT who demand critical care.

METHOD

This is a descriptive study, with qualitative data analysis, performed in Bone Marrow Transplantation and Immunological Therapy Units of a university hospital in a city in the state of São Paulo, Brazil. Both of them performed HSCT in adults and pediatric patients, since the incorporation of beds for this clientele in 2009. However, one of them has a smaller number of pediatric hospitalizations, since autologous HSCT are performed for autoimmune diseases, which have a lower incidence in childhood.

The Research Ethics Committee of the institution where the study was developed approved the research, according to Resolution 466/2012 of the National Health Council⁽⁸⁾ (Protocol No. 166/2016). The Informed Consent was prepared, in clear and accessible language, informing the participants about the objective of the research and procedures for data collection; possible constraints or benefits, guaranteeing total secrecy and respect to the desire to participate or not of the study, voluntarily. Prior to data collection, the Informed Consent was presented, read and discussed with each potential participant. Those who agreed to participate in the study were asked to sign the consent, affirming their participation in the research and allowing the recording of the respective interview.

The participants were nurses with professional experience of at least one year; who had been active in HSCT units in the institution for more than six months and who assisted transplanted children at different stages of treatment. The invitation to the participants to integrate the research was continuous, until the

empirical data set was redundant⁽⁹⁾, proving sufficient to respond to the objective of the research and to the understanding of the studied phenomenon.

Semi-structured, audiotaped interviews were conducted in a single meeting, with an average duration of 23 minutes, to understand participants' experiences about their professional competence for critical care towards children undergoing HSCT. The interviews occurred in June/2016, in the units, in a private space, respecting the schedules previously agreed with each professional, not interfering with the work dynamics.

As an initial approach, respondents were encouraged to tell what they considered critical care for these children. Then, the nurses' competences needed to care for transplanted children requiring critical care were approached. To characterize the participants' profile, we collected age, training time, qualifications and time of experience with HSCT.

The analysis process took place concurrently with the data collection. The interviews were transcribed in full after their completion, preserving the participants' discourses, and submitted to the procedures for qualitative content analysis⁽¹⁰⁾. Initially, the empirical material was read exhaustively, identifying words, phrases and concepts of interest. Then, the data were organized into themes, based on units of meaning previously identified.

To illustrate the themes, we chose to select excerpts from the participants' speeches, which were represented by the letter "E", followed by a sequential number of entry into the study.

RESULTS AND DISCUSSIONS

Nine nurses participated, aged between 31 and 49. Of these, one was male and eight were female, which corroborates the predominantly female historical profile of the profession and current research data on the nursing profile in Brazil⁽¹¹⁾.

As for training, all were graduated more than five years; two had only undergraduate; two held specialization *lato sensu* courses, one of them had a master's degree; three have undergone both *lato sensu* and masters' specialization courses; and one interviewee had *lato sensu* and a doctoral degree. Five participants had professional experience in HSCT units between one and five years; one had professional practice over five years and less than 10 years, and three had more than 10 years of work in the nursing area.

The qualitative analysis of the empirical data allowed us to identify two themes: Critical care to the transplanted child: a double challenge for the nurse; and Nurses' competences for the care towards the critically ill child submitted to HSCT.

Critical care for transplanted children: a double challenge for nurses

Taking care of this clientele represented a double challenge to the nurse, due to the need to deal with both the specificities of being a child and the demands of the patient transplanted in critical care.

The HSCT process was considered critical, regardless of the population and age group, since it is a high-risk treatment that requires differentiated and intensive care. Other participants considered it critical only in

the face of some type of hemodynamic instability with compromised vital functions, as illustrated below:

I think critical care begins at the moment [the child] shows some decompensation ... a fever, which may be simple and punctual, but may also be the beginning, for example, of septicemia. (E2)

I believe critical care is some type of hemodynamic instability or clinical change that requires more care that is specific. (E7)

In this perspective, nurses characterized critical care as requiring rigorous nursing assistance and increased transfusion requirements, monitoring and use of intravenous medication. Most nurses perceived pediatric HSCT as critical and specific care; only one showed difficulty in conceptualizing and/or characterizing critical care in children undergoing HSCT.

HSCT is considered a high-risk therapeutic modality and the patient undergoing this procedure is often compared to the one who needs intensive care, mainly due to the severity and need of technological devices⁽¹²⁾. Despite the advances related to histocompatibility tests and safer conditioning regimen, transplantation still shows high complication rates, with a high mortality rate related to toxicity of the conditioning regimen, immunosuppression and graft-versus-host disease^(1,5). Such complications require ICU admission, increasing mortality, especially when there is prolonged endotracheal intubation⁽¹⁾.

A study points out that the proportion of children undergoing this transplant who needs admission to a pediatric ICU can reach 44%⁽³⁾. The post-transplant phase (up to 100 days after stem cells infusion) is the most at risk, especially in cytopenia periods, when a higher number of adverse events related to HSCT are expected, such as infection, bleeding, anemia, mucositis, interstitial pneumonitis, hemorrhagic cystitis, among others⁽⁵⁾.

Nurses were also asked about the frequency with which they assist children undergoing HSCT who require critical care. The interviewees showed contradictions, accentuated mainly by their critical care concepts, that is, for those who understand that it occurs when the child has some type of hemodynamic instability, the frequency of this type of care is small.

For all nurses in the research, their care experience with children who needed critical care included aspects related to: fear of assisting seriously ill children; difficulty interpreting what the child feels; bonding and emotional involvement with the child/family, which made it difficult for nurses to care for and manage the feelings related to them. All participants voiced emotional difficulties in dealing with the child at imminent risk of death, seeing the patient's suffering, and highlighted the challenge of providing support to the family.

For most of the interviewees, pediatric HSCT should require a specific team, considering the profile and the professional preference. Many of them said that they started taking care of children after admitted to the unit and that previous professional experience was related to the adult population. Only one interviewee mentioned preferring to take care of children. Some nurses pointed out the feeling of pity for the child and/or family.

*I always run away from pediatrics, I do not like taking care of children ... It's not that I don't like it, I feel pity. (E7)
Apart from the critical care, the emotional and psychological part of seeing a child, a mother in this situation, is also difficult. (E2)*

Three nurses mentioned difficulty in assisting children, mainly because of the difficulty of interpreting what they feel, as exemplified below:

The child, depending on the age group, cannot communicate clearly. So you need other resources to identify what it is. Perhaps the critical part moment is assessing an answer to pain or even things related to vital signs changes a bit. (E6)

Some professionals reported safety for critical care for children, despite certain limitations and difficulties.

We feel pity for the child, but I have a good emotional control (...). Sometimes I get shaken, but it stays with me; I don't think I expose the feeling. (E1)

Assisting a respiratory insufficiency, clinical intercurrences, this does not scare me. The suffering they go through is what makes me very uncomfortable. (E3)

Thinking about child care, especially critically ill children, it is complex and requires sensitivity to perceive factors that involve relationships and interrelationships with family, team and child, considering the milestones of child growth and development and their peculiarities⁽⁶⁾. In HSCT units, as well as in pediatric intensive care units, since these places are restricted, of high specificity, with prolonged hospitalizations and use of high technology, close relationships and the creation of close ties between professional-child-family can be seen as limiting and exhausting factors for those who act in this scenario^(13,14). However, positive bonds help care planning and open possibilities of humanized, full and integrated care, allowing better results from a therapeutic point of view.

Children undergoing HSCT have severe clinical conditions that prevent them from playing or performing activities of daily living. They remain in private rooms due to the risk of infection and they coexist with repetitive and painful procedures and with adverse treatment events. There is also emotional sensitivity, sometimes expressed by panic, anxiety and restlessness, a condition that mobilizes technical and emotional resources of nurses⁽¹³⁾. Witnessing these conditions imposed by the children's clinical condition reiterates the double challenge experienced by nurses in the daily life of their practice.

Nurses' competences for the care of critically ill children undergoing HSCT

Participants in this study identified specific skills that support nurses' work in pediatric HSCT, which include the child's singularities and treatment, the availability of technical-scientific resources, communication and interaction elements that guarantee managing the proposed treatment and safe and human care, both of the child and the family, as illustrated below:

I believe that, besides this technical knowledge of the nurse, we need to know about the disease, because they have diseases that are specific to childhood, certain leukemias. We need to know what possible problems this child may have, regarding both the disease and the conditioning they are having. (E3)

We [nurses] must have a bag of critical thinking, scientific reasoning; ability to know parameters of the child's vital signs; discernment of whether this complication is expected, as well as common sense. (E9)

The interviewees cited the need for specific and updated theoretical knowledge, as well as the ability to predict serious clinical situations:

You always have to have the vision of child aggravation; it is like always trying to be one step ahead. Since we are very close to the child, we have, together with the mother, more tools to evaluate a child's change, faster than the doctor, for example. (E7)

The nurse needs to plan, that is, always deal with the forethought, to predict what can happen (...), and relate to the transplantation stages. What complications can that chemotherapeutic cause? (...) What is immunosuppressant? Spinal cord infusion? And after? We have to be backed up and supported every day with planning. (E9)

It is also important that the professional working in a HSCT unit plan the care by means of a systematic and individualized care model that assists the child in all stages of transplantation, differentiating risks, specificities and proposing appropriate interventions in each one⁽²⁾. The ability to observe warning signs, to relate theoretical and practical knowledge, to identify the nursing problem, to plan care, to implement care and to evaluate it are elements that constitute the Systematization of Nursing Care (SNC) and focus attention on the needs of the patient and his/her family⁽¹⁵⁾.

Some nurses also cited the need for training for all nursing staff to improve emergency care and pediatric emergencies:

I think that train the team is very important, update the care and the main transplant intercurrences, aimed at children, because it is different. (E2)

Technical skill in relation to emergency care, to know clearly what is expected for each age group, specific medication doses, to have some understanding about the types of devices for each age, because in a critical child, you know what type of cannula to use, which device, you optimize care. (E6)

A nurse mentioned that, in addition to care planning, nurses must have managerial skills, especially regarding the provision of materials and equipment necessary for critical care. One of them stated that:

The nurse, before an emergency, has to manage the unit in terms of materials, to check if it has everything, to assist the patient's needs in all situations (E7).

It is a nursing working process characteristic the concomitance/complementarity of care and management dimension. For the performance of professional activities, the nurse must constantly articulate both dimensions⁽¹⁶⁾.

Nurses voiced greater confidence regarding technical skills, as these can be learned and absorbed in daily clinical practice, unlike those related to vocational skills and choices, such as: Knowing how to deal with

the pediatric population; psychological and emotional control, sensitivity/empathy and communication with the family, as exemplified below:

Skills to deal with the child, this happens over time; know how to puncture; how to make the child undergo a procedure without much suffering; talk to the child and the mother. (E3)

Competence building is linked to both schooling and informal learning processes that occur at different times and spaces⁽¹⁷⁾. Thus, based on nurses' training and experiences, we identified competencies needed for the care of transplanted children who demand critical care. Figure 1 summarizes the competencies that, according to nurses, are essential for the care of children undergoing HSCT in the context of critical care.

Figure 1: Essential skills for the care of children undergoing HSCT who demand critical care, according to study participants.

Essential skills
1. Knowledge about pediatric HSCT.
2. Technical skills in relation to child care.
3. Knowledge to observe warning signs.
4. Systematization of Nursing Care (SNC).
5. Managerial competence (adequacy of material resources and equipment).
6. Specific knowledge about child growth and development.
7. Offering family support.
8. Psychological and emotional control.
9. Teamwork.
10. Sensitivity and empathy.
11. Leadership.

The competences identified as essential base on knowledge, skills and aptitudes, described in the literature as structuring axes of competence, that is, they refer to personal resources that reflect how tasks are performed⁽¹⁶⁻¹⁸⁾. These axes link to personal experiences, in which the subjects are able to mobilize cognitive resources such as knowledge, practices and information in their workplace, providing them with unique and individual learning moments⁽¹⁶⁻¹⁷⁾.

The acquisition of skills depends on the relation between knowledge and individual experiences⁽¹⁸⁾. Human beings grow through the progressive acquisition of knowledge, which is the result of constant analysis, elaboration and interpretation of experiences. Vocational competences, however, do not seem to be the result of any training, but rather the encounter of experiences with theoretical knowledge. Thus, vocational competences are formed by the continuous self-control that the individual presents in relation to the use of his/her own resources and are developed by knowledge application⁽¹⁸⁾. Therefore, the participants' difficulties refer to their limited vocational competence and not to the lack of scientific knowledge and technical skills to assist the pediatric population. The competencies pointed out by nurses as essential are sometimes more vocational than acquired, such as interpersonal communication, something essential to approach the child, family and health team, as illustrated below:

A skill we need to have, as well as technique and knowledge, is knowing how to approach the child and the

companion adult. In these courses, we learned about it, but I think the greatest experience I've ever had was here in the daily basis, learning from the mothers. (E3)

(...) I think you have to have practice in the ability of interpersonal relationship, empathy. (E6)

Although this study was developed with participants from a single health institution, it can be considered an important initiative, capable of triggering new questions for practice and research that foster reflections on the profile of nurses working in pediatric HSCT. Nurses have different degrees of training and the organization of work occurs by the division of tasks, guaranteeing them the role of knowledge holders and controllers of the working process⁽¹⁶⁾, which justifies the need for skills based on communication and leadership, highlighted by most participants.

Thus, in order to ensure full-time nursing care for children undergoing HSCT in a critical situation, intrinsic and extrinsic resources related to knowledge, skills and aptitudes are required⁽¹⁸⁻¹⁹⁾, that is, the professional's care should base on technical-scientific knowledge, but also consider the child and the family, respecting their own emotional limits and their personal skills to deal with such a peculiar public in situations of clinical instability.

FINAL CONSIDERATIONS

The results of this study evidenced the double challenge of the nurse who assists transplanted children in a severe clinical situation. Such a challenge refers to care in pediatrics and its specificities, linked to the possibility that the child's condition becomes critical at some point in treatment. Faced with this situation, the nurse must be prepared to deal with it, which highlights the importance of certain competencies for care.

Among the competencies required by nurses in the care of these clients, the following stand out: knowledge domain related to this modality of treatment and to the care peculiar to them; SNC application; leadership; managerial competence; sensitivity; empathy and teamwork. Likewise, competencies related to the pediatric public, such as knowledge about child's growth and development are fundamental; constant support for the family; psychological and emotional control, as well as the recognition of clinical aggravation symptoms.

Therefore, the participants highlighted skills that can be acquired through technical-scientific knowledge, as well as those associated with the professional's accumulated abilities to deal with the needs of the pediatric public and their families, on a context delicate and characterized by the potential clinical lability of the child population. These findings contribute to systematize these professionals' skills and stimulate future research on a topic insufficiently explored in the literature and in pediatric nursing, despite its significant complexity.

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