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## ORGAN AND TISSUE TRANSPLANTATION: RESPONSIBILITIES OF NURSES

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**ABSTRACT:** In Brazil, more than 30,000 patients are awaiting organ transplantation. The complexity of this therapeutic treatment requires specialized training and constant involvement from health care providers involved in care for these patients. In everyday practice, nurses are challenged to provide high-quality care to patients and families. In view of the need to define the nurse's role in the donation and transplantation process and the importance of disclosure in this field, we elaborated the present narrative review to discuss the role and responsibilities of the nurse working in an organ and tissue transplantation program. The literature found was read, summarized and organized into five thematic categories, namely: definition of the nurse's role in transplantation, the difference between the nurse practitioner and coordinator, legal and ethical aspects; research and information on transplant nursing and education on transplantation. It is concluded that the nurse needs knowledge about the principles of good practices and have resources available to assess the merits, risks and social issues related to transplantation.

**DESCRIPTORS:** Organ transplantation. Nurse's role. Nursing care.

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## TRANSPLANTE DE ÓRGÃOS E TECIDOS: RESPONSABILIDADES DO ENFERMEIRO

**RESUMO:** No Brasil, mais de 30.000 pacientes aguardam em fila de espera para a realização de transplantes de órgãos. A complexidade desta modalidade terapêutica exige preparo especializado e constante da equipe de profissionais de saúde envolvidos no cuidado do paciente. No cotidiano da prática, o enfermeiro é desafiado a prover assistência com qualidade aos pacientes e familiares. Frente à necessidade de definir o papel do enfermeiro no processo de doação e transplantes e a relevância de divulgação desta área de atuação, elaborou-se a presente revisão narrativa que teve como objetivo tecer considerações sobre o papel e as responsabilidades do enfermeiro que atua em programa de transplantes de órgãos e tecidos. Os textos encontrados foram lidos, organizados e sintetizados em cinco categorias temáticas, a saber: definição do papel do enfermeiro no transplante, diferença entre o enfermeiro clínico e o enfermeiro coordenador de transplante, aspectos legais e éticos, pesquisa e informação e educação em transplantes. Conclui-se que o enfermeiro deve ter conhecimento dos princípios de boas práticas e ter recursos disponíveis para avaliar o mérito, riscos e questões sociais relacionadas aos transplantes.

**DESCRIPTORES:** Transplante de órgãos. Papel do profissional de enfermagem. Cuidados de enfermagem.

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## TRASPLANTE DE ÓRGANOS Y TEJIDOS: RESPONSABILIDADES DE LAS ENFERMERAS

**RESUMEN:** En Brasil más de 30.000 pacientes están esperando en fila para la realización de trasplantes de órganos. La complejidad de esta modalidad terapéutica requiere una formación especializada y un equipo permanente de profesionales de salud familiarizados con la atención y el cuidado de los pacientes. En la práctica todos los días, las enfermeras tienen el reto de brindar atención de calidad a los pacientes y familias. Frente a la necesidad de definir el papel de la enfermera en el proceso de donación y trasplante y la importancia de la divulgación en este campo, se ha elaborado esta revisión narrativa destinado a hacer consideraciones sobre el papel y las responsabilidades de la enfermera que trabaja en el programa de trasplante órganos y tejidos. Los textos encontrados fueron leídos, resumidos y organizados en cinco categorías temáticas, a saber: la definición del papel de las enfermeras en el trasplante, la diferencia entre la enfermera de la clínica y el coordinador de trasplantes en enfermería, aspectos éticos y legales, la investigación y la información y la educación en los trasplantes. Se concluye que la enfermera debe tener conocimiento de los principios de buenas prácticas y disponer de recursos para evaluar los méritos, los riesgos y los problemas sociales relacionados con el trasplante.

**DESCRIPTORES:** Trasplante de órganos. Rol de la enfermera. Atención de enfermería.

## INTRODUCTION

Solid organ transplantation is a treatment option to improve the quality of life of people at any age suffering from irreversible and end-stage chronic conditions. Ever since the first successful transplant in 1954, solid organ transplants have constantly advanced in the treatment of kidney, pancreas, liver, heart, lung and intestinal diseases.<sup>1</sup>

Transplant figures continue increasing around the world. In Brazil, since 1964, when the first kidney transplant took place, more than 75,600 solid organ transplants have been executed. A single waiting list system is adopted, which guarantees equal access to this treatment modality. According to the Brazilian Transplantation Register, about 30,547 people are awaiting organ transplantation in 2012, while only 3,703 transplants took place in the first semester.<sup>2</sup> Efforts by the National Transplantation System should be highlighted, in the attempt to increase surgery rates in the Brazilian population that needs transplants.

Despite advances, lack of notification about brain death and errors in organ maintenance for capture continue to impede donation. In that sense, training health professionals involved in the donation process is important with a view to reducing the loss of potential donors, so as to increase the number of donations and decrease the suffering of people on the waiting list.<sup>3,4</sup>

Nurses' contribution to successful transplants is undeniable. Care has become increasingly complex and the post-transplant hospitalization time has been limited. Therefore, nurses need to deliver high-level care to transplantation candidates and recipients as well as their relatives or caregivers, which permits continued treatment beyond the hospital environment.<sup>1,5</sup>

Nurses play distinguished roles and functions according to their professional background, function at the institution and care scenario. In the Brazilian context, few higher education institutions offer education in this knowledge area. Nurses involved in transplantation need to continuously examine their professional practice, seeking ways to improve the nursing care delivered to these clients.<sup>5-8</sup>

In general, some Brazilian higher education

institutions offer specialization or training courses, located in state capitals. Undergraduate nursing programs in the country include themes related to the donation and transplantation process into the course programs of medical-surgical nursing or ethics and bioethics subjects. Other institutions provide nursing students with information about the donation-transplantation process through student league activities.<sup>9</sup>

In the report by the Brazilian Federal Court of Auditors, the complexity of transplants is highlighted, demanding human resources dedicated to this activity, adequate training and periodical recycling. The adopted training strategies have shown to be insufficient to solve existing gaps, starting with the first phase of the process, which ranges from the brain death diagnosis to the family's approach, until the execution of the transplant, involving care for the recipient in hospital. This situation is understandable as, in Brazil, higher education institutions that offer a specific subject on donation and transplantation in their curriculum are rare.<sup>10</sup>

Brazilian professionals working in the transplantation area get support from the Brazilian Association of Organ Transplantation, which has made efforts to train human resources in the field of transplantation across the national territory. No specific orientation towards nursing training is present though. Around the world, associations exist that focus on different transplant areas. In nursing, the International Transplant Nurses Society (ITNS) and the Transplant Nurses Association (TNA) should be highlighted, which offer different resources and educational programs to educate and train nurses for the donation-transplantation process.

In view of the need to define nurses' role in the donation and transplantation process and the relevance of disclosure about this activity area, this study was elaborated to discuss the role and responsibilities of nurses involved in organ and tissue transplantation programs. Therefore, a narrative review was developed,<sup>11</sup> based on Brazilian and international literature.

## DEVELOPMENT

To reach the intended objective, the source of bibliographic or electronic information com-

prised well-known publications (textbooks in the transplantation area), materials from the Brazilian Association of Organ Transplantation (ABTO) and from the International Transplant Nurses Society (ITNS), as well as articles found in Latin and North American databases and the legislation in force. The texts found were read, organized and summarized in five thematic categories, which were: (1) definition of the nurse's role in transplantation, (2) the difference between the nurse practitioner and coordinator, (3) legal and ethical aspects, (4) research and information and (5) education on transplantation.

### **Definition of the nurse's role in transplantation**

Collaborative care delivery as a member of the multidisciplinary expert team is one of the roles of nurses in transplantation programs. Hence, these professionals are constantly challenged to deliver high-quality care to transplantation patients, but the reality at health services shows limited human, material and even financial resources.<sup>1,5,12</sup>

Transplant nurses provide specialized care in health protection, promotion and rehabilitation for candidates, recipients and their relatives, as well as live donors and their relatives over the life cycle. This care includes the prevention, detection, treatment and rehabilitation of patients with health problems related to existing diseases before the organ transplantation or comorbidities associated with post-transplantation treatment.<sup>1,7</sup>

The Federal Nursing Council recommends the following for nurses responsible for the organ transplantation process: planning, execution, coordination, supervision and evaluation of nursing procedures delivered to the donor, as well as the planning and execution of actions to optimize the donation and capture of organs and tissue for the sake of transplantation. Nurses responsible for care delivery to transplant candidates and recipients are responsible for applying nursing care systematization in all phases of the organ and tissue transplantation process, to the recipient and family, including pre and post-transplant (outpatient) follow-up and the transplant (in hospital).<sup>13</sup>

Therefore, nurses need knowledge on immunology and pharmacology for transplantation, on infectious diseases and on the psychological entailments of care with regard to the morbidity and mortality these clients are confronted with.<sup>5,14-15</sup>

In the community, transplant nurses also promote support and education with a view to organ donation. These professionals should deliver evidence-based care in all phases of the transplantation process, considering the enhancement of individual health, functional skills and quality of life at all ages. Evidence-based care is aimed at integrating research into transplant nurses' clinical practice, so as to deeper explore knowledge to improve professional practice, contributing to the quality of care delivery.<sup>16-17</sup>

The key elements of nurses' activities include: patient education; implementation of interventions to maintain or improve physiological, psychological and social health; use of interventions to facilitate and promote behavioral changes and treatment adherence in view of complex and extended therapies; as well as support for patients and relatives in care planning, execution and assessment; and promotion of support system with a view to achieving the best organ transplantation results.<sup>14-15,18</sup>

Nurses' role also includes strategies to improve the systems in which transplant care is provided. Therefore, quality control of care delivery is needed, as well as cooperation among the professionals involved, implementation of health education strategies, research originating in problems deriving from clinical practice, and the organization and registration of care delivery.<sup>14-15,17</sup>

Organ transplant nurses should focus their actions on health education, patient safety and care effectiveness.<sup>1,19</sup>

### **The difference between the nurse practitioner and coordinator in transplantation**

What nurses' activities is concerned, in Brazilian professional practice, the nurse practitioner and the transplant coordinator stand out. The former is responsible for care promotion to candidates and recipients, to live and deceased

organ donors, and to their relatives or caregivers. The function of the transplant coordinator is to manage the transplantation program, coordinating the different phases of the long-term perioperative period and promoting care delivery to candidates and recipients when necessary. No Brazilian studies exist that clearly address this definition, but it is based on the professional experience of nurses active in organ donation and transplantation programs and on the adaptation of international literature to the Brazilian reality.<sup>1,5,14-15</sup>

To work in care delivery to these patients, nurse practitioners need specific knowledge and skills, clinical experience and continuing education, with a view to the development of critical thinking and skills for decision making. Among the activities these professionals undertake, evaluation, diagnosis, outcome identification, care planning, implementation of interventions and the assessment of results in organ donation and transplantation are highlighted. These nurses' background should cover behavioral sciences, experiences in the health-disease process, pathology, physiology, psychopathology, epidemiology, infectious diseases, clinical manifestations of acute and chronic illnesses, emergencies, normal health events and diagnosis of health problems.<sup>1,4,14</sup>

The transplant coordinator nurse is the team member responsible for facilitating the transplant process. This person's role can vary across different transplantation programs and regions. This professional's role is to integrate all transplantation team members, acting as a link between patient and team. The main focus of his/her activity is to guarantee the quality of care delivery with professionalism, in all phases of the process. Nurses need a specific educational background to work in this area, besides knowledge and clinical experience to play their role and guarantee the continuity of care.<sup>7,13,19-20</sup>

Transplant coordinators need to develop a comprehensive knowledge base to manage the complex issues involved in care. Among the skills needed, the following stand out: Evaluation (signs and symptoms of rejection and infection, transplant-associated complications, pharmacological interactions), communication (with patients and family members, transplant team, health providers

from other hospital sectors, hospital departments, documentation), teaching-learning (learning theories, use of audiovisual material, internet use for the development of educative materials, development of alternative strategies for patients and family members with teaching and learning barriers), organizational (maintain organized and accurate registers, ability to perform different tasks at the same time, time management), screening (evaluation of patient problems by telephone, simultaneous management of patients' problems), administrative (management of medical and paramedical team professionals, budget previews, database management) and problem solving skills (management of competing priorities, proposal and adaptation of solutions in individual situations).<sup>1,7,13,15,21</sup>

When they start working as transplant coordinators, nurses should have a period especially reserved to prepare for this function. Besides knowledge about the organizational structure of the transplant program itself, some background experience is important, besides familiarity with current transplant care protocols, procedures involving candidates and recipients, the main drugs used and treatment targets. When getting acquainted with the complexity of the program, a tutor should be present, that is, an experienced transplant coordinator or team physician who is available for orientations during and after the preparation period to take up this role.<sup>7,15</sup> Knowing large transplantation centers acknowledged for their care quality is another very valuable resource for nurses who are starting transplant coordination activities.

In the international context, an explicit distinction exists between the roles nurses play in transplantation. Transplant coordinators can perform function related to the search for organs (live and deceased donors), administering all aspects of the organ donation process; and to the transplant, providing care to patients on the waiting list (candidates) and transplanted patients (recipients).<sup>1</sup> Differences in the nurses' educational background are observed here, undoubtedly influencing their role in transplants. One example is the nurse's autonomy to change the dose of immunosuppressant drugs, based on blood levels, without the need for previous authorization from the medical team.



In the Brazilian context, transplant coordinators are also allowed to deliver care to hospitalized patients and outpatients although, as a rule, only one professional serves as the coordinator. Internationally, on the other hand, in transplant programs that attend many patients, two or more nurses are needed for the high-quality and efficient coordination of candidates and recipients. It should be highlighted that, independently of the nurse's practice area, the transplant coordinator should guarantee the continuity of care in this complex treatment modality.<sup>14,21-22</sup>

Besides the whole range of knowledge mentioned earlier with regard to nurse practitioners or coordinators' activities, given the complexity of the entire process, the ethical, cultural, religious, family and legal dimensions are extremely important and valuable, besides other dimensions related to these professionals' attitudes. Sensitivity, empathy and humanity are needed to appropriately understand and cope with the conflicts and human suffering the donation-transplantation process generates. This may involve anguish about losing a loved one who has been declared brain dead or the suffering of the transplant candidate or recipient who experiences complications that determine the end of life.<sup>4,21,23</sup>

### Legal and ethical aspects

In 2004, the Federal Nursing Council set rules for nurses' actions in organ and tissue capture and transplantation, defining the need to apply nursing care systematization (NCS) as a requirement. In addition, they need to comply with the requirements the Brazilian National Transplant System (NTS) established to guarantee this treatment form in the context of the Unified Health System (SUS).<sup>13</sup>

In this sense, the importance of promoting nursing care standards for organ transplant care should be highlighted. The aim of this standardization is to improve patient outcomes. Nursing care standards can be established based on common practice, legal precedents, clinical guidelines or protocols by institutions or professional associations.<sup>7</sup>

Another important factor refers to the need for certifications to qualify nursing practice. For organ transplantation, certification could guar-

antee nurses' competency, knowledge and skills to promote high-quality care to organ transplant candidates, recipients and donors. In Brazil, no certification exists for the sake of transplantation. In the United States, the American Board for Transplant Certification regulates the activities of nurses serving as transplant coordinators, nurse practitioners and organ search coordinators.<sup>1</sup> Thus, the researchers believe that implementing certification for Brazilian nurses will lead to the preparation of qualified professionals to work in the donation and transplantation process, with a view to increasing the number of donors and improving care delivery to candidates and organ recipients.

Nurses need to be aware of and systematize standards for the protection of donors, candidates and transplant recipients' health information. In that sense, complying with documentation requirements at local, state and federal level, and even of professional organizations (like the Brazilian Association of Organ Transplantation), is one of the legal aspects nurses need to deal with in their daily professional activity. Registering, documenting and filing any care provided in the donation/transplant process improves communication among health professionals, promotes care continuity, protects patients against damage, reduces the risk of lawsuits and promotes care evaluation and improvements. In addition, records should cover all phases of the transplant process, ranging from the donation to the hospital discharge of transplant recipients.

Decrees 1.262/2006 and 2.600/2009, issued by the Brazilian Ministry of Health, address technical regulations to establish the responsibilities, duties and efficiency and organ and tissue donation potential indicators of Intra-Hospital Committees of Organ and Tissue Donations for Transplantation (CIHDOTT). The same documents discuss the technical regulation of the National Transplantation System and include nurses as members of the specialized organ donation and transplantation teams in Brazil.<sup>24-25</sup>

Nurses' activities in transplantation, in all aspects of their practice, based on ethics and legislation, are fundamental to preserve the autonomy, dignity and rights of all stakeholders involved in this process.<sup>26-27</sup>

Although donation represents a morally good social conduct, some aspects lead to the belief that donation still needs to be incorporated into the common moral code, according to a Brazilian study, including: disbelief in the functioning and structure of the health and resource allocation system, in the trust relation between health professional and patient, in equal and fair access, in donor/recipient confidentiality, in free and informed consent, in respect for autonomy, in the defense of life and in the novel and recent nature of this treatment modality, which is still under construction.<sup>27</sup> These factors negatively affect the number of available donors when considering the demands of candidates on transplant waiting lists.

To work in the complexity of organ transplantation therapeutics, nurses need to incorporate and take actions in the transplantation teams, based on the ethical principles of autonomy, non-maleficence, beneficence and justice. The organ and tissue donation process for transplantation is directly related with people's moral, ethical and religious values, as this makes people think about the notion of finiteness and the relation with the body after death.<sup>28</sup>

In view of the ethical dilemmas deriving from organ transplantation, in many situations, nurses can benefit from public ethical consultations, which may involve health care providers, physicians and members of the patient's family. The aim of this consultation would be to contribute to treatment-related decisions.<sup>7</sup>

### **Research and information on transplants**

Research is considered as the production of new information, in which transplant nurses can use the research results to transfer evidence to their clinical practice.<sup>17</sup> Although, in general, nurses' need for clinical experience in care delivery to these patients is more acknowledge, the need for research cannot be ignored, which can improve care, further better results and support the approach and monitoring of donors, transplant candidates and recipients and their relatives.

A bibliographic review undertaken in 2010, which identified and characterized scientific production on organ donation and transplantation,

included 30 articles, published between 1997 and 2007. The study identified more research on transplantation, mainly kidney and liver transplants, by nurse practitioners affiliated with transplantation centers in the Southeast of the country, the region that joins the largest programs in Brazil. The study did not include dissertations and theses on the theme.<sup>5</sup> Therefore, the researchers searched the Database of Nursing Dissertations and Theses, ABEn Dissertations and Theses (CEPEn) and Graduate Programs in the Virtual Health Library (BVS) in July 2012. In this search, three theses on "organ donation" were identified, as well as 24 dissertations and theses on "transplantation", indicating Brazilian nurses' increasing participation in research.

In view of the above, nurses need to develop research competences, involving attitudes like: use of the best evidence available, including research results to guide decisions in clinical practice; participation in research activities; analysis and critical interpretation of research for practical application; use of research results for the development of patient care policies, procedures and standards of practice. Other research attitudes include: participation in the development and implementation of research protocols; participation in data collection for nursing research, and the establishment of protection for human beings when involved in research. In short, in the donation and transplantation process, nurses should not only use research results critically, but also participate in the development process of new studies.<sup>1,17</sup>

Different approaches can be used in nursing research, involving patients and/or families or professionals. The understanding of a phenomenon or the development of clinical studies can be the focus. Independently of what research is undertaken, transplant nurses should consider the incorporation and development of research skills as part of their continuing education process. These skills comprise knowledge on methodological approaches, skills development for data collection and interpretation, culminating in the publication of the results that were evidenced. This grants visibility to the importance of their work to improve patient care in the donation and transplantation process.

## Education on transplantation

Transplant nursing education consists of three different branches: self-education, education for other health care providers and education for the general public. To teach other people, these nurses should continuously update their knowledge, skills and attitudes, especially in this rich area of constant changes and challenges.<sup>7</sup>

Teaching and learning opportunities for nurses include formal programs, affiliations with professional organizations, participation in conferences, review of papers for publication in scientific journals and information exchange with other professionals in the transplantation area. Continuing education, associated with clinical practice, allows nurses to progress from learning professionals to expert professionals, getting involved in complex decision processes in transplants.<sup>7-8,18</sup>

Nurses are also responsible for educating other health care providers about the donation and transplantation process, particularly new nurses, nursing technicians and auxiliary nurses recently hired as members of the transplantation team, as well as undergraduate nursing students. Due to the growing number of organ recipients in the general population, in addition to enhanced longevity, these professionals should also educate health providers who are not directly involved in transplants, but who can deliver care to recipients in other specialties in the hospital context, or in primary and secondary health care services.<sup>7-8,18</sup>

Educating the public in general is an important task for nurses. Families' refusal to donate organs still contributes to the non-realization of the donor potential, despite the growth in organ donation rates across the country. Hence, nurses can facilitate organ donation by educating the public on the benefits and procedures needed for the organ donation process, on the importance of encouraging individuals to express the desire to donate organs for transplantation or not to their relatives, and mainly by clarifying the concept of brain death to the lay population.<sup>7-8,18</sup>

In hospital, nurses use teaching-learning strategies with candidates and recipients in order to enhance skills for self-care promotion at home, besides preparing patients during the pre-, intra- and post-operative transplant

periods. In this context, teaching can take place amidst different difficulties, as many patients are weakened to participate in educative programs. In these cases, family members benefit from the educative actions the nurses propose. Teaching contents depend on the organ for transplantation, on the patient's skills and on each transplantation program's policies.

## FINAL CONSIDERATIONS

Organ and tissue transplant nurses need comprehensive scientific knowledge. The clinical competences needed go beyond those learned in the undergraduate nursing program. They include the evaluation and management of deceased donors, transplant recipients, potential donors or live donors, teaching and counseling of transplant recipients and live donors related to self-care management, healthy life and a peaceful death when this is imminent.

Competency development to respond to the physiological, pathophysiological and psychosocial needs of patients, family members and communities is essential and includes ageing and end-of-life support skills. In this respect, preparation is fundamental, particularly evaluation, which represents the framework for transplant nurses' practice. One example is these professionals' skills to assess rejection or infection in transplant recipients. Besides preparation for nursing care decision making, nurses' activities should be multiprofessional and multidisciplinary.

Nurses play a crucial role in the establishment of a successful transplantation program. They are vital members of the team that works to deliver care to patients and relatives, through the use of technological, logistic and human resources, with a view to coordination, care, education and research on organ and tissue donation and transplantation. Therefore, nurses need knowledge on the principles of good ethical principles and have resources available to assess the merit, risks and social issues related to transplants. The researchers hope that this study will encourage further research on the role and responsibilities of nurses.

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