



3.7.9 Research on Comprehensive Care for Transplanted Children and Adolescents Group*

COMPOSITION

María Jesús Pascou González-Garzón.

Nursing supervisor. Hospital Universitario La Paz

Luz Yadira Bravo Gallego.

Medical Advisor.
FIBHULP

María Teresa Álvarez Gómez. Supervisora de Enfermería de Hospitalización Pediátrica. Hospital Universitario La Paz

Almudena Alonso Márquez. Supervisora de Enfermería Unidad de Hospitalización Pediátrica. Hospital Universitario La Paz

Mercedes Hermosilla Mínguez. Supervisora de Enfer-

mería de Unidad Pediátrica. Hospital Universitario La Paz
Carlos Martín Saborido. Vocal Asesor. Ministerio de Sanidad y Consumo

Paloma Martínez Campos. Enfermera pediátrica en unidad de Reanimación y Anestesia Infantil. FIBHULP

Miriam Muñoz Berges. Enfermera Especialista en Pediatría en Nefrología Infantil. Hospital Universitario La Paz

Antonia Polo Lucero. Enfermera Especialista en Pediatría. Hospital Universitario La Paz

Guillermo Manuel Sibón Sancho. Enfermero. FIBHULP

STRATEGIC OBJECTIVE

Paediatric Solid Organ Transplantation (SOT) and Haematopoietic Stem Cell Transplantation (HSCT) have dramatically changed the life expectancy of many children by providing treatment to them, who would otherwise have not survived. Worldwide, nearly 150,000 SOT1 and 80,000 HSCT are performed annually. Paediatric transplantation constitutes about 10% of the total for SOT and 20% of the total for HSCT. Between 2012 and 2016, 7,741 SOT and 14,717 HSCT were performed on children in the European Union (EU), and the number of PTs performed worldwide continues to increase.

Paediatric SOT & HSCT replaces end-stage disease with a more sustainable chronic disease state, which enables youth to reach adulthood.³ However, although transplantation can improve personal health outcomes, it can also be associated with long-term side effects that require continuous monitoring and care. Post-transplant follow-up care aims to prevent rejection and transplant-related complications, so that each person can achieve a life expectancy and quality of life (QoL) similar to healthy peers.

The “Research on comprehensive care for transplanted children and adolescents” group arises from the need to cover gaps in knowledge about the comprehensive care of children and adolescents who receive transplants in the paediatric age.

The group will be focus on the research of three specific topics:

1. Transition and transfer of adolescents and young adults (AYAs) living with a transplant to adult clinics: clinical and psychosocial impact. Transition is a gradual, multifaceted, active, and purposeful process involving many important steps and key checkpoints. The process comprises three phases⁵: (1) transition planning and preparation, (2) transfer of care, and (3) integration into adult health care. Each of these phases has unique barriers to success and opportunities for improvement.
2. Quality of life (QoL) in paediatric transplant setting: patient reported outcomes and experience measures (PROMs and PREMs).
3. Innovation in health education of transplanted children and adolescents and their parents/caregivers/family: evaluation of programs and validation of tools and questionnaires.

RESEARCH LINES

- Transition and transfer of adolescent and young adult paediatric transplant recipients to adult care: clinical and psychosocial impact.
- Quality of life in paediatric transplantation: outcome measures and patient/family reported experiences (PROMs and PREMs).

- Innovation in health education for transplanted children and adolescents and their parents/caregivers/family: evaluation of programmes and validation of tools and questionnaires.

*Group recently created, december 2022