

## Symposium 3

### How to manage pediatric thoracic organ transplant recipient

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Fri. Jul 9, 2021 4:00 PM - 4:55 PM Track6 (現地会場)

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### [ISPHLT-SY3-3]The role of child life specialists in pediatric heart transplantation in Japan: bridging the gap, serving as a buffer, and offering scaffoldings

○Fumiko Mato (Center for Pediatric Diseases, Osaka University Hospital, Japan)

The revised Japanese Organ Transplant Law took effect in 2010; the pediatric heart transplant team was formed at Osaka University Hospital. Since then, in multidisciplinary collaboration to build the foundation of child- and family-centered care, the Child Life Program for pediatric heart transplant recipients and their families has been developed through the process of creating individualized stepwise plans meeting the unique needs of each child and family while organizing basic guidelines responding to their common needs.

Children and families confront a variety of transplant-specific psychosocial issues in pre-, peri-, and post-transplant phases: uncertainty and unpredictability during extended waiting period, isolation and separation associated with relocation and hospitalization, struggle for control due to restriction on activities, lack of autonomy caused by enforced dependence, concerns about prognosis, fear of life-changing complications, threat to future competence, and identity confusion. In addition to those long-term healthcare needs and hurdles, they potentially need to cope with ethical dilemmas and emotional ambivalence: hopefully waiting for transplant and feeling guilty about waiting for donation.

Child Life Specialists, applying therapeutic values of play as a primary modality in developmentally supportive and psychologically appropriate ways, strive to prevent, minimize, and reduce the adverse effects of potentially stressful or traumatic experiences. Empowering children and families to validate their oscillated, incompatible feelings, Child Life promotes their understanding and coping skills and strategies throughout their transplant journey. Child Life interventions, which involve resilience-focused and relationship-oriented approaches, include therapeutic play, psychological preparation, non-pharmacological approaches to anxiety/stress/pain management, peer-to-peer connection, parental involvement, and sibling support. Those interventions are designed to facilitate positive coping with healthcare encounters.

Introducing the examples of Child Life interventions: 1)meaning-making interventions that incorporate story-based process, and 2)legacy-building activities to validate and celebrate medical, developmental, and psychological milestones, this presentation will address how Child Life helps children cope with psychosocial challenges specific to heart transplantation. The primary focus will be on how children can actively participate in their transplant process when being empowered to maintain self-esteem and hope, enhance a sense of authorship and gratitude, and appreciate the "gift of life" and "life after loss."