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**Title of Project:** Improving communication with pediatric patients & families undergoing heart transplantation: an interview-based needs assessment

**Research Question:** How can providers improve communication with patients and families undergoing pediatric heart transplantation?

**Brief Background:** Morgan Stanley Children's Hospital is a high-volume center for pediatric cardiac transplant. In addition to optimizing medical outcomes, our job as providers is to help patients and families navigate this difficult process. Pediatric heart transplantation literature focuses primarily medical outcomes. It is difficult to find studies that even tangentially address this question of improving communication. More research needed on how to best communicate with families to help them navigate a difficult process.

**Brief Literature Review:**

- Bodil Ivarsson et al. Relative's experiences before and after a heart or lung transplantation. *Heart Lung*. May-Jun 2014; 43(3): 198-203.
  - Qualitative, interview-based study of relative's experiences during adult heart or lung transplantation
  - Major finding: great degree of variation in amount of "information and support"
  - Concluded: "Greater awareness about relatives' experiences with identification of appropriate support and information exchange between health care professionals and relatives is important. This awareness could provide benefits for heart or lung transplant patients, families and health care organizations."
- Kaufman, Beth et al. Palliative care in pediatric heart failure and transplantation. *Current Opinion Pediatrics*. October 2019; 31(5): 611-616.
  - Core tenants of palliative care (symptom management, communication of prognosis, and advanced care planning) should be provided by the primary cardiology team, and incorporated into cardiology fellowship training.

**Hypothesis:** There is a mismatch between the expectations of patients/families and the realities of transplant which leads to psychosocial stress and can strain patient-family-provider relationships. Interviewing patients/families about their experience will help highlight opportunities for improved communication.

**Aims:**

1. Conduct semi-structured, individual, in-depth interviews with caregivers and patients undergoing heart transplantation between January-June 2022
2. Identify common themes relevant to clear communication and expectation setting
3. Develop a communication tool to help address the needs identified and standardize the quality of patient-provider communication. (For use in a future pilot intervention.)

**Overall Project Methods:**

- Inclusion Criteria
  - Pediatric patients and/or their caregivers
  - Post-transplantation, pre-discharge

- Admitted to the cardiology floor service (6 Tower)
- Target enrollment:
  - 10-20 patients/caregivers, or until thematic saturation is reached
- Methods:
  - Design semi-structured interview script
  - Conduct & record in-depth interviews
  - Analyze interview text by thematic coding, according to qualitative methods
  - Iterative process of data collection/analysis until no new themes emerge (thematic saturation)\*

\*After each interview, preliminary analysis will be conducted and the script will be modified as needed for future interviews

#### *Draft of Interview Script:*

1. *How can providers improve communication with patients and families undergoing pediatric heart transplantation?*
2. *What do you know now that you wish you knew at the beginning of the process?*
3. *What would you tell a family just being the transplant process?*
4. *Think about a doctor or nurse practitioner you met who was a “good” communicator. Without naming them, what made them a good communicator?*
5. *Think about a doctor or nurse practitioner you met who was a “bad” communicator. Without naming them, what made them a bad communicator?*
6. *Can you describe an example where your expectations of the process were not aligned with the reality?*
7. *As with most medical procedures, heart transplantation is not without significant risks. Do you feel like you were appropriately informed of all the risks involved?*
8. *Would you like to hear worst case scenarios up-front? Or only as they become relevant?*
9. *What topics were not addressed in your “pre-transplant talk” that you wish were addressed?*

#### **Project Goals:**

1. Write qualitative paper for submission to a journal
2. Present findings at a CHONY residency conference
3. Develop communication tool that can be used at CHONY for a future pilot intervention

#### **References:**

1. Bodil Ivarsson et al. Relative’s experiences before and after a heart or lung transplantation. *Heart Lung*. May-Jun 2014; 43(3): 198-203.
2. Kaufman, Beth et al. Palliative care in pediatric heart failure and transplantation. *Current Opinion Pediatrics*. October 2019; 31(5): 611-616.
3. DiCicco-Bloom, Margaret, Crabtree, Benjamin. *The Qualitative Research Interview*. Medical Education. 2006; 40: 314-321.
4. Johnson J. In-depth interviewing. In: Gubrium J, Holstein J, eds. *Handbook of Qualitative Research*. Thousand Oaks, California: Sage 2002;103–19.