

# “We’re Not Really By Ourselves Anymore”: Implementation and Effectiveness of a Mindfulness-Based Retreat for Mothers of Pediatric Heart Transplant Recipients

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## INTRODUCTION

Mothers are often the **primary caregivers** to children requiring heart transplantation (HTx). Their ability to cope with the dynamic health status of their child influences familial, social and health outcomes.<sup>1</sup>

**Mindfulness** is proposed as an evidence-based intervention to **enhance aspects of daily life** in this caregiving population.<sup>2</sup>



## OBJECTIVE

This study explored the **implementation and effectiveness** outcomes of a **mindfulness-based retreat (MBR)** for mothers of pediatric HTx recipients.

## METHODS

**Intervention:** A two-day MBR consisting of mindfulness-based teachings, including mindful meditation, deep relaxation and circle sharing.<sup>3</sup>

**Participants:** Mothers of HTx recipients from the Heart Transplant Program at The Hospital for Sick Children, Toronto, Canada.

**Design:** A convergent parallel mixed methods design using questionnaires and focus groups and interviews over three timepoints.

Assessments		T1	T2	T3
QUANT	Five Facets Mindfulness Questionnaire	X	X	X
	Coping Health Inventory for Parents	X	X	X
	Distress Tolerance Scale	X	X	X
	Multidimensional Scale of Perceived Social Support	X	X	X
	PedsQL™ Family Impact Module	X	X	X
QUAL	Focus Groups		X	
	Individual Interviews			X

**Analysis:** Data were analyzed separately and amalgamated to evaluate implementation and effectiveness outcomes.

## RESULTS

**Sixteen mothers** of pediatric HTx recipients (mean age 9.8 years, range 2-17 years; mean time post-Tx 8.2 years, range 1-16 years) participated.

### Implementation Outcomes

- The MBR demonstrated **high feasibility, fidelity and adoption**.
- Participants reported **high levels of engagement and satisfaction** with the MBR.

### Effectiveness Outcomes

**Significant improvements** were seen at T3 with regards to participants’

- (1) Ability to be **mindful** in daily life,
- (2) Coping through maintaining **family integration**, and
- (3) Perceived **social support** from family members.



### Participants’ Experiences

Qualitative analysis illuminated three themes:

#### Connections

The importance of connecting and sharing stories with other mothers



“I felt **safe**. I felt safe sharing those details that I don't know that I have shared with **anybody**.”

“To hear that their children have gone to high school...it gives you such **hope**.”

#### Reflections

The value of learning mindfulness-based skills and building coping capacity



“The **awareness** of your surroundings...to be **grateful** for the moment...Those were **great lessons**.”

“I do feel like I have planted those couple of seeds that stuck with me.”

#### Wellbeing

The transformative nature of the MBR on maternal health and quality of life



“The retreat gave me a **wakeup call**...Making myself **happy** and better will always be better for my family.”

“If we're good **physically, emotionally, spiritually**, then that's going to help our families too.”

## CONCLUSIONS

Study findings support the MBR as an **effective** and **impactful** intervention that improves **maternal coping, social support and quality of life**, underpinning **family-centred care** within pediatric HTx.

Findings provide the necessary **evidence-base** to inform future investigations examining the **transferability** of the MBR for caregivers and other family members affected by pediatric chronic illness.

### References

1. Cousino MK et al. Psychosocial functioning in pediatric heart transplant recipients and their families. *Pediatric Transplantation*. 2018;22(2):e13110.
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