

# BMJ Open Mindfulness-based retreat for mothers of paediatric heart transplant recipients: protocol for a pilot intervention study

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## ABSTRACT

**Introduction** Mothers are often the primary caregivers for children requiring heart transplantation. Given that a mother's ability to successfully cope with the demands of her caregiving role may be predictive of positive familial psychosocial outcomes, it is critical that maternal coping is assessed and supported in paediatric healthcare. Mindfulness-based programmes are proposed as one intervention that may enhance quality of life, improve distress tolerance and coping and reduce social isolation in caregiving populations. This pilot study aims to investigate: (1) the implementation success of a mindfulness-based retreat (MBR), and (2) the effectiveness of a MBR at improving quality of life, distress tolerance, coping and perceived social support for mothers of paediatric heart transplant recipients.

**Methods and analysis** A convergent parallel, mixed-method design is proposed for this pilot, exploratory study. Twenty mothers will participate in this pilot MBR held at a resort in Ontario, Canada. Quantitative data will be obtained using five standardised instruments completed at three time points: (T1) 24-hours prior to the intervention, (T2) immediately on completion of the intervention, and (T3) three months post-intervention. Qualitative data will be collected from all participants both through semi-structured focus groups at T2 and individual telephone interviews at T3. Focus groups and individual interviews will be transcribed verbatim for thematic analysis. Quantitative and qualitative data will be merged and compared during interpretation to ensure that the intervention implementation and effectiveness of the MBR retreat are described with comprehensive accuracy. The primary outcomes will be feasibility in relation to implementation effectiveness and participants' perception of social support for efficacy of the MBR intervention.

**Ethics and dissemination** This study received Institutional Research Ethics Board approval from The Hospital for Sick Children (Number: 1000064719). Informed consent will be obtained prior to participant enrolment. Findings will be disseminated via conference presentations and submitted for publication in a peer-reviewed journal.

## INTRODUCTION

From the time of diagnosis, caring for a child with a chronic illness is often a source of persistent stress for a family system.<sup>1–4</sup> Within

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Our mixed-methods study design will allow for a comprehensive understanding of the study phenomena that could not be ascertained by qualitative or quantitative methods alone.
- ⇒ Patient engagement is prioritised throughout this protocol, with the inclusion of a patient partner as a member of the research team to guide decisions concerning intervention design, as well as methodological choices for outcome measures.
- ⇒ The completion of quantitative outcome measures at three time points will allow for intervention efficacy description across five domains of functioning (ie, quality of life, utilisation of mindfulness skills, distress tolerance, coping and perceived social support).
- ⇒ This pilot study is exploratory in nature and designed to assess and inform a richer understanding of the implementation outcomes of this novel mindfulness-based retreat intervention for this clinical population.
- ⇒ This is a single-centre study with a proposed small sample, which may limit the generalisability of the findings.

paediatric heart transplantation, recipients face life-long medical follow-up that includes regular clinical visits; frequent, often invasive, medical tests and procedures; and immunosuppressive drug therapy with many accompanying side effects (eg, high blood pressure, kidney dysfunction, growth delay, infection risks, possible malignancies and cosmetic effects).<sup>5–7</sup> This strict care regimen is disruptive to a family's daily life, their self-care and sleep routine,<sup>8</sup> and places chronic social, psychological and financial strain on family systems.<sup>3,7</sup>

## Impact of paediatric heart transplantation on maternal caregivers

Mothers are most commonly the primary caregivers for paediatric heart transplant recipients.<sup>5</sup> As such, mothers' quality of life is impacted more than any other family member,



by the mounting demands and parenting stressors associated with a child's illness.<sup>5</sup> Previous research on maternal coping in paediatric heart transplantation demonstrates clinically significant levels of psychosocial risk for poor mental health outcomes in 40% of respondents.<sup>3</sup> Additionally, the elevated psychosocial risk and significant emotional impact of transplantation on mothers appears to be enduring,<sup>9 10</sup> with high levels of caregiver burden reported several years post-transplantation.<sup>9</sup> Recent studies have cited the experience of paediatric transplantation as an ongoing source of trauma for parents.<sup>7 11</sup> In a study on parents of heart transplant recipients, (75% of which were mothers), 19% of the participants were found to meet the Diagnostic and Statistical Manual—IV diagnostic criteria for post-traumatic stress disorder (PTSD), amounting to a prevalence rate that is 2.5 times higher than the general population.<sup>7</sup> Untreated symptoms of PTSD are commonly felt within the wider family system as they directly impact parenting capacity, and consequently, child health and development, well-being and adjustment.<sup>12 13</sup>

Increased clinical attention and accessible interventions to support the emotional coping and well-being of mothers may be efficacious to increase maternal coping and instrumental to support paediatric heart transplant recipients' health and well-being. The psychosocial needs of mothers of children with chronic illness are consistently underserved across healthcare settings.<sup>1</sup> Evidence-based interventions to support caregivers in paediatric healthcare are scarce and not prioritised,<sup>14</sup> and existing interventions (eg, weekly support groups and individual counselling) are time-consuming which parents have cited as their primary barrier to participation in such health interventions.<sup>1</sup> To our knowledge, this pilot study will be the first of its kind to specifically target the psychosocial needs of mothers of paediatric heart transplant recipients through an retreat-based mindfulness intervention.

### Mindfulness-based interventions

There is empirical evidence that mindfulness-based interventions (MBIs) significantly reduce psychological distress, anxiety and depressive symptoms, and improve physical and mental health across many populations.<sup>15 16</sup> Mindfulness-based stress reduction is currently the most widely recognised and used MBI for the treatment of PTSD and general stress management.<sup>17–19</sup> MBIs more broadly have been shown to improve mental and physical health in populations of caregivers for children with chronic illnesses.<sup>20 21</sup> MBIs are structured programmes that incorporate tenets of mindful meditation and assume that the cultivation of compassionate and non-judgemental awareness will lead to a reduction in stress, suffering and symptoms of mental illness.<sup>17–19</sup> In MBIs, participants are guided through exercises that develop mindfulness skills through formal practice.<sup>15 16</sup> These supported opportunities to build capacity practicing mindfulness skills increase the likelihood for post-intervention use of these skills as reliable coping tools to minimise distress in

everyday life.<sup>15 16</sup> This exploratory study proposes a novel, 2-day mindfulness-based weekend retreat (MBR) adapted for mothers of paediatric heart transplant recipients. It is recognised that an increased level of social support is derived from the shared experience of MBIs when offered in a retreat format.<sup>15 20</sup> This may provide benefit to the target population of this study as high prevalence of social isolation has been identified among mothers of heart transplant recipients, as well as their shared interest to connect with other mothers in similar positions.<sup>5</sup> MBIs facilitated through a MBR increase the opportunity for social connection among participants because of environmental facilitators such as shared accommodations, meal times and free time. The remote location of the retreat is essential to provide mothers space from their caregiving demands at home to focus both on their own needs and on the mindfulness curriculum. The shared physical space of the retreat is intentional to increase community among participants over the 2-day retreat.

Mindfulness is ideally suited for this population to address the inherent stress they experience through their caregiving roles,<sup>7</sup> and group mindfulness practice has the ability to catalyse community building that is sustained beyond a research setting.<sup>22</sup> Given the applicability of an MBR to meet the needs of mothers of paediatric heart transplant recipients, it is proposed within this pilot study as an intervention with potential to enhance maternal well-being through the development of coping skills, social connectedness and psychological health.<sup>5 15 17 20 21</sup>

### Study aims

To investigate the feasibility and efficacy of this intervention, the research objectives of this pilot study are to: (1) examine implementation outcomes (ie, appropriateness, acceptability, adoption, feasibility, fidelity)<sup>23</sup> of the MBR, and (2) assess the efficacy of the MBR on maternal quality of life, distress tolerance, coping and perceived social support. The primary outcomes will be feasibility in relation to implementation effectiveness and participants' perception of social support for efficacy of the MBR intervention.

## METHODS AND ANALYSIS

### Study design

A convergent parallel, mixed-method design was chosen for this pilot study wherein quantitative and qualitative data will be collected simultaneously and analysed independently, with results merged during the final interpretative phase to address the study's overall purpose.<sup>23</sup> This mixed-methods design will allow for a comprehensive understanding of the study phenomena by incorporating both qualitative description methods to gather a rich account of participant experiences as well as quantitative measures to document the potential changes in participant coping styles, distress tolerance, perceived quality of life and social support.<sup>24</sup> The participant sample size will

be equal across both quantitative and qualitative arms of data collection.

Qualitative research is highly valuable in this area because of the subjective impact of a child's illness on a family, and the individualised nature of each mother's parenting experience through transplantation. Qualitative data will be gathered through participation in a focus group on the final day of the retreat and an individual interview three months post-retreat. Focus groups are an efficient and effective method of qualitative data collection to yield anecdotal information about personal experiences and perceptions.<sup>25 26</sup> Group dialogue with mothers about their experiences of the retreat will offer a reflective opportunity to gather participant insights and to address implementation outcomes (ie, appropriateness, acceptability, adoption, feasibility, fidelity)<sup>27</sup> of this intervention for this clinical population. Fidelity of this intervention will be assessed through the components of treatment fidelity (facilitator factors include design, training and delivery and participant factors include receipt and enactment) put forth by The Treatment Fidelity Workgroup of the National Institutes of Health Behavior Change Consortium.<sup>28</sup> A focus group fits well with the group model of this retreat and is an opportune and feasible way to collect qualitative data from this particular sample, given their geographical diversity. Both the focus group and interview will gather participant feedback of parallel variables.

The quantitative instruments selected (Coping Health Inventory for Parents, Five Facet Mindfulness Questionnaire, Paediatric Quality of Life (PedsQL), Distress Tolerance Scale, Multidimensional Scale of Perceived Social Support) will capture a measurable and generalisable assessment of maternal coping. The focus group and individual interview will highlight detailed and personal perspectives of the mothering experience through paediatric heart transplantation, as well as provide insights to the participant experience of the MBR. Integration of the qualitative and quantitative data will highlight a depth of understanding that could not be obtained by either data separately.

### Patient and public involvement

Caregiver needs and perspectives have been prioritised throughout the MBR pilot study design. At the project's inception, a mother of a paediatric heart transplant recipient was recruited to be a member of the research team as a patient partner (JM). Her lived caregiving experience informed many decisions concerning intervention design as well as methodological choices for outcome measures. The data collection measures identified dually prioritise the need to gather the richest possible data set, with a commitment to refrain from burdening participants with lengthy and arduous measures in consideration of their time.

### Intervention design

The intervention will be a 2-day retreat held over a weekend. The MBR will be hosted at a resort in northern

Ontario, Canada, and will consist of a structured schedule of mindfulness and compassion-based teaching and practices, including formal meditation, circle sharing and deep relaxation.<sup>29</sup> The competencies developed in these exercises will be incorporated into all other retreat activities such as mealtimes, mindful movement (eg, yoga) and walking meditations. Mindfulness talks will be held on each day of the retreat, offering opportunities for participants to learn about and develop mindfulness skills. Each mindfulness talk in the retreat series will build on the content of the previous talk, with the goal of moving participants from introspective personal mindfulness practice to interpersonal community building. Opportunities for guided circle sharing (ie, group practice of mindfulness and interpersonal sharing) and deep relaxation (ie, personal practice bringing mindful attention to the body to relieve stress) will be integrated throughout the retreat.

The MBR will have two primary facilitators who are both mental health professionals (social worker and psychologist) with longstanding personal mindfulness practices. In addition, both facilitators have completed teacher training in mindfulness (Mindful Self-Compassion and Mindfulness-Based Cognitive Therapy), as well as certificates in both Foundations of Applied Mindfulness Meditation and Applied Specialisation in Mindfulness Meditation from the University of Toronto, Canada. Lastly, both facilitators have extensive experience practicing in tertiary care hospitals adapting MBIs to support caregivers in chronic disease populations. The facilitators, alongside the research team's patient partner (JM), adapted the MBR specifically to the paediatric heart transplantation context.

### Sample recruitment

A total of 20 participants will be recruited from The Hospital for Sick Children (SickKids) Labatt Family Heart Centre who meet the following criteria: (1) a mother residing in Ontario who is the primary caregiver of a paediatric heart transplant recipient, who is (2) a minimum of four months post-transplant. Within this study, 'mother' is defined as a female-identifying caregiver to a paediatric heart transplant recipient. Participants are not required to be biologically related to the heart transplant recipient but must be the primary female-identifying caregiver and share residence with the child. Purposive sampling will be used to obtain a sample with maximum variation.<sup>30</sup> Purposive sampling will ensure demographic variation among participants, specifically regarding: the mother's age; their child's age, stage of development and gender; and the family's race, ethnicity, composition and geographical location of residence. Due to resource limitations that prohibit access to language and accessibility services, non-English speaking mothers and those with severe cognitive impairment as determined by a mental health professional will be excluded from participation in this study. Limited resources have also resulted in the restriction for participation in this study to Ontario residents only.



Participant recruitment began in January 2020 and is ongoing. The retreat will be hosted when it is safe to do so according to local COVID-19 public health guidelines. Participant recruitment has involved social work and nursing staff from the Heart Transplant Program at the SickKids Labatt Family Heart Centre, who each received a study description from the research team and were asked to select and refer mothers for eligibility review. If the mother consented to participate in this study, she was then referred to the research team who ensured that all eligibility criteria were met. Written informed consent was obtained from each study participant at that time.

### Sample size

A sample size of 20 participants is adequate to obtain data saturation in qualitative studies<sup>31 32</sup> and aligns with the recommended class size for traditional mindfulness-based stress reduction teaching which informed the overall intervention design.<sup>29</sup> This sample size is also intentional to facilitate social connection within the participant group and to allow for richer discussion within mindfulness practices, such as circle sharing.<sup>29</sup> Mixed-method mindfulness research predominantly describes a sample size ranging from 10 to 20 participants for optimal intervention delivery.<sup>31</sup>

### Data collection

*Quantitative.* Standardised questionnaires will be completed by all study participants at three time-periods: (T1) 24-hours prior to attending the retreat, (T2) 24-hours after attending the retreat and (T3) three months post-retreat. At each time point, the questionnaires will be completed by participants online through Research Electronic Data Capture (REDCap).<sup>33</sup> Paper copies can be mailed to participants on request. The three time points will allow for the comparison of outcomes assessed by pre-intervention and post-intervention measures. The following quantitative measures will be used in this study:

1. *Coping Health Inventory for Parents* is a 45-item scale measuring the demands experienced by parents and caregivers of a child with a chronic health condition.<sup>34</sup> The scale evaluates family integration and cooperation, maintenance of social support, self-esteem and psychological stability and comprehension of the child's medical situation. Reliability has been previously established for this measure.<sup>35</sup>
2. *Five Facet Mindfulness Questionnaire* is a 39-item scale measuring one's propensity to be mindful in their daily life (ie, observing, describing, acting with awareness, non-judging of inner experience and non-reactivity to inner experience).<sup>36</sup> Construct validity has been previously established as well as its use in assessing the utilisation of mindfulness skills.<sup>37</sup>
3. *Paediatric Quality of Life (PedsQL) Family Impact Module* is a 36-item scale measuring the impact of chronic health conditions of children on parents through eight subscales: physical functioning; emotional functioning; social functioning; cognitive functioning; communi-

cation; worry; daily activities; and family relationships. The PedsQL Family Impact Module is a widely used measure for the evaluation of parental quality of life.<sup>38</sup> Internal consistency and reliability have been previously established.<sup>38</sup>

4. *Distress Tolerance Scale* is a 14-item scale measuring distress tolerance across three domains: tolerance of distress, appraisal of being distressed, and emotional regulation.<sup>39</sup> Construct validity of this measure has been previously established.<sup>39</sup>
5. *Multidimensional Scale of Perceived Social Support* is a 12-item scale measuring perceived social support across three groups: family, friends and a significant other.<sup>40</sup> Validity and reliability have been previously demonstrated for this instrument.<sup>40</sup>

Demographic and medical forms will be administered to all participants to collect maternal information (eg, age, race, ethnicity, number of children, annual household income, highest level of education) and child information (eg, date of transplant, underlying diagnosis, age at time of transplant and comorbidities). These forms will be completed by participants using REDCap.<sup>33</sup> Paper copies will be made available on request.

*Qualitative.* Qualitative data will be collected at (T2) on the last day of the retreat intervention and (T3) three months post-intervention. Participants will be divided into two groups of 10 to participate in focus groups on the last day of the retreat, again using purposive selection to ensure maximum variation in focus groups demographics. The focus group will be organised by open-ended questions and probes facilitated by members of the research team with extensive experience in qualitative methodology. Focus group guiding questions will probe several areas around implementation and efficacy of the MBR intervention, including but not limited to: (1) decision-making around attending the retreat (eg, hopes, expectations, worries), (2) experience and acceptability of participating in the retreat (eg, impact on domains of well-being), (3) appropriateness of the retreat content (eg, what components are useful and not useful), (4) feasibility (eg, ease of participation), and (5) post-retreat impressions (eg, would the participant recommend the retreat to other mothers of heart transplant recipients?). While the questions are important, we plan to remain flexible in terms of probing (eg, asking follow-up questions) based on participant answers and interactions. A second researcher will be present to observe each focus group and document topics and concepts discussed by participants. Both focus group discussions will be audio-recorded and transcribed verbatim. A subsequent semi-structured telephone interview will be completed individually with each participant three months post-intervention with transcription and data analysis to follow.

### Data analysis

*Quantitative.* Each standardised instrument will be scored individually, and group data will be summarised by the calculation of means and SD. T1 data will be assessed in

comparison to T2 and T3 data. Notable changes in scores between each time point will be descriptively analysed. Should multiple characteristics present as significantly correlated with the same outcome, repeated measures analysis of variance with post-hoc analysis will be used to discern the aetiology of this correlation. Descriptive statistics will be used to describe and characterise the sample in this pilot.

*Qualitative.* All data will be read and analysed by multiple members of the research team. Deductive thematic analysis will be used, and codes will be determined through line-by-line review of the focus group discussion and individual interviews using NVivo.<sup>41</sup> Through this review process, codes emerging repeatedly in various parts of the transcript will be noted and comparatively analysed by multiple research team members for purposes of consistency.<sup>41</sup>

*Interpretation.* Quantitative and qualitative data will be merged to compare both similarities and differences across findings.<sup>23</sup> The research team will compile quantitative statistical results and compare findings to the qualitative themes present within the focus group and individual interview data. Further analysis will consider how the two sets of data relate, diverge and interconnect to create a comprehensive understanding of the phenomena.

## ETHICS AND DISSEMINATION

This research study has received approval from the SickKids Research Ethics Board (Number: 1000064719). All participants will provide informed written consent prior to their involvement in the study. This research study sample will not include participants incapable of providing informed consent or any participants under the age of 18.

The proposed research will inform a future randomised clinical trial to assess implementation outcomes and intervention effectiveness of an MBR within this population. This pilot study will greatly increase the breadth of knowledge about interventions that may support primary caregivers of paediatric heart transplant recipients. Findings will be translated and disseminated throughout cardiology and transplant communities and communicated to local, provincial and national stakeholders. In addition, findings will be presented at national cardiology and transplant conferences and a manuscript will be submitted for publication in a peer-reviewed journal. Timing for dissemination of results will depend on the scheduled date of the retreat as permitted by provincial COVID-19 gathering restrictions.

All data collected over the course of the research study, including written transcription from the study's qualitative focus group and the subsequent individual telephone interviews, will be de-identified to protect participant confidentiality. Anonymous study identifiers will replace all identifying information present in the transcripts. All identifying information, both paper copy and electronic information, will be kept confidential. Use of data over

the course of the study, and dissemination of results will follow standard practice guidelines as determined by the SickKids Research Institute.

## DISCUSSION

When a child undergoes heart transplantation, the role of the primary caregiver is notably linked to poor mental health outcomes and pervasive, illness-related parenting stress.<sup>7</sup> Previous research has correlated mindfulness-based practices with positive psychosocial outcomes in highly distressed populations,<sup>17 42</sup> and specifically in chronic disease populations, MBIs have demonstratively reduced psychological distress and symptoms of mental illness.<sup>15 16</sup> Aside from the benefits derived from direct participation, there is also potential for MBIs to yield larger systemic rewards. Supporting mothers to improve their coping can increase familial preparedness for post-transplant care management and any potential post-transplant hospitalisations.<sup>6</sup> With the length of hospitalisation contributing the largest percentage of any transplant-associated costs,<sup>6</sup> positive caregiver coping and readiness for discharge could ultimately decrease health-care spending per transplant patient.

This innovative research leverages the MBR as an evidence-based intervention to engage mothers meaningfully by acknowledging the complexity of their role as a caregiver and addressing the impact of chronic stress and high caregiver burden.<sup>5 7 43</sup> While this pilot study is a preliminary step in addressing a wider gap in psychosocial intervention support to caregivers, the potential benefits derived are equally promising for individual patients and caregivers as well as the broader healthcare system.

This research is a necessary first step to advance the field of evidence-informed psychosocial interventions within paediatric cardiology and results will inform future iterations of the intervention across other participant groups. While caregiver experiences are unique, the need for support and disease-specific community building within paediatric healthcare is universal. This promising intervention will serve as a critical template for expansion across other clinical caregiving populations in paediatric solid organ transplant and other chronic illness care programmes. Additionally, meeting the needs of all family members is vital to address family functioning, coping and resilience over the course of a child's chronic illness.

Some study limitations should be considered. This is an exploratory single-centre study with a small sample size, which could potentially limit the generalisability of the results. Exclusion of non-English speaking mothers and mothers residing outside of Ontario is another limitation of the study that was necessary for the delivery of mindfulness teachings in a group retreat-based format, but one that must be noted when considering the demographics of study participants.

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