

Henry Ford Health

## Henry Ford Health Scholarly Commons

---

Surgery Articles

Surgery

---

2-10-2022

### Non-pharmacological interventions engaging organ transplant caregivers: A systematic review

Michelle T. Jesse

Henry Ford Health, MJESSE1@hfhs.org

Kendyll J. Gartrelle

Henry Ford Health, kgartre1@hfhs.org

Heather Bruschwein

Gina Hug

Henry Ford Health, ghug1@hfhs.org

Barbara LeTarte

Henry Ford Health, bletart1@hfhs.org

*See next page for additional authors*

Follow this and additional works at: [https://scholarlycommons.henryford.com/surgery\\_articles](https://scholarlycommons.henryford.com/surgery_articles)

---

#### Recommended Citation

Jesse MT, Gartrelle K, Bruschwein H, Hug G, LeTarte B, Lerret S, and Dew MA. Non-pharmacological interventions engaging organ transplant caregivers: A systematic review. Clin Transplant 2022; e14611.

This Article is brought to you for free and open access by the Surgery at Henry Ford Health Scholarly Commons. It has been accepted for inclusion in Surgery Articles by an authorized administrator of Henry Ford Health Scholarly Commons.

---

**Authors**

Michelle T. Jesse, Kendyll J. Gartrelle, Heather Bruschwein, Gina Hug, Barbara LeTarte, Stacey Lerret, and Mary A. Dew

# Non-pharmacological interventions engaging organ transplant caregivers: A systematic review

Michelle T. Jesse<sup>1,2,3</sup>  | Kendyll Gartrelle<sup>1</sup> | Heather Bruschwein<sup>4</sup>  | Gina Hug<sup>5</sup> | Barbara LeTarte<sup>5</sup> | Stacey Lerret<sup>6</sup> | Mary Amanda Dew<sup>7</sup>

<sup>1</sup> Transplant Institute, Henry Ford Health System, Detroit, Michigan, USA

<sup>2</sup> Center for Health Policy & Health Services Research, Henry Ford Health System, Detroit, Michigan, USA

<sup>3</sup> Academic Internal Medicine, Henry Ford Health System, Detroit, Michigan, USA

<sup>4</sup> Psychiatry and Neurobehavioral Sciences, University of Virginia School of Medicine, Charlottesville, Virginia, USA

<sup>5</sup> Sladen Library, Henry Ford Health System, Detroit, Michigan, USA

<sup>6</sup> Pediatric Gastroenterology, Hepatology and Nutrition, Medical College of Wisconsin, Milwaukee, Wisconsin, USA

<sup>7</sup> Department of Psychiatry, University of Pittsburgh School of Medicine and Medical Center, Pittsburgh, Pennsylvania, USA

## Correspondence

Michelle T. Jesse, PhD, FAST, 2799 West Grand Boulevard, Detroit, MI 48202, USA.  
 Email: [mjesse1@hfhs.org](mailto:mjesse1@hfhs.org)

## Abstract

**Introduction:** Lay-caregivers in organ transplantation (to candidates, recipients, and donors) are essential to pre- and postoperative care, but report significant caregiving-related stressors. This review aims to summarize studies testing nonpharmacological interventions aimed at improving organ transplant caregiver-reported outcomes.

**Methods:** In accordance with PRISMA, we conducted a systematic review (searched PubMed, Embase, Cochrane Central, PsycInfo, and CINAHL, no start-date restriction through 7/1/2021). Quality of comparative studies assessed by ROBS-2 or ROBINS.

**Results:** Twelve studies met inclusion. Study designs, interventions, and outcomes varied. Sample sizes were small across caregivers to adults (nine studies, five with caregiver samples  $n \leq 50$ ) and pediatric patients (three studies, caregiver samples  $n \leq 16$ ). Study designs included seven single-arm interventions, two prepost with comparison cohorts, and three randomized-controlled trials. Eight studies included transplant-specific education as the intervention, an interventional component, or as the comparison group. Outcomes included transplant specific knowledge, mental health, and intervention acceptability. Of the nine prepost caregiver assessments and/or comparison groups, four studies demonstrated no statistically significant intervention effects.

**Conclusion:** Few interventions addressing the needs of organ transplant caregivers have been empirically evaluated. Existing interventions were well-received by caregivers. Given complexities of care in transplantation, research is needed evaluating interventions using rigorous trial methodology with adequate samples.

## KEYWORDS

education, mental health, quality of life (QOL)

## 1 | INTRODUCTION

For many patients with end-stage organ disease, organ transplantation provides an opportunity for extended survival and improved quality of life.<sup>1–3</sup> However, the transplant process (from referral for evaluation to post-transplant) can contribute to a multitude of

burdens for the patients, families, and healthcare providers. Lay or informal caregivers, or individuals who provide support and/or resources although not under any contractual or financial obligation to do so (including partners, parents, adult children, and close friends; henceforth referred to as caregivers), undertake major responsibilities in supporting and assisting patients through the phases of

transplantation. These responsibilities include assisting the patient in managing ongoing and changing medical demands, navigating complex healthcare systems and teams as well as other support networks, and helping the patient manage their emotional adjustment to end-stage organ disease and transplantation.<sup>4-6</sup>

In assuming these responsibilities, transplant caregivers also report significant stressors and caregiver-related burdens across multiple domains, including worry and concern about the patient's well-being, necessary lifestyle adjustments, financial burdens and sacrifices, and their own emotional well-being and quality of life.<sup>7-17</sup> Given the unique burdens in transplantation, caregivers may be at risk for developing clinically significant anxiety, depressive symptoms, and even posttraumatic stress responses.<sup>18-21</sup> At the same time, many transplant caregivers also report psychological benefits and potential personal growth from their role as caregiver.<sup>15,22,23</sup> It is noteworthy that both negative and positive stress responses, such as burden and growth, can co-occur and are part of a complex, dynamic cognitive-emotional process in response to significant stressors.<sup>24,25</sup> Given the challenges of caregiving in transplantation, important questions arise concerning how best to support transplant caregivers and whether interventions are effective at preventing or ameliorating the negative effects and encouraging positive outcomes.

Systematic reviews and meta-analyses on nonpharmacological interventions for caregivers to patients with other chronic diseases, such as cancer and dementia, suggest that multicomponent psychosocial interventions can reduce caregiver burden, and foster mental health and general well-being.<sup>26-30</sup> For example, nonpharmacological dyadic interventions with caregivers and cancer patients have suggested significant positive effects for both caregiver and patient quality of life and relationship functioning.<sup>31</sup> However, whether such strategies would be effective in transplantation caregivers is unclear; multiple authors note the need for targeted interventions for caregivers due to the differences across chronic diseases.<sup>32,33</sup> To our knowledge, there have been no prior efforts to summarize the evidence on nonpharmacological interventions with transplant caregivers. Therefore, we conducted a systematic review of the literature on nonpharmacological interventions where caregivers of organ transplant candidates, recipients, and/or donors participated in any element of the intervention. By conducting this review, we hope to summarize the findings on interventions engaging transplant caregivers and make recommendations regarding necessary next steps in developing and testing interventions.

## 2 | MATERIALS AND METHODS

This systematic review was conducted following Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.<sup>34</sup> Our group designed the protocol, but it was not preregistered.

### 2.1 | Population

The population of interest included lay- or informal-caregivers to organ transplant patient populations. This included individuals  $\geq 18$  years

of age, identified as caregivers or primary support persons for adult or pediatric patients in any phase of the transplant process (evaluation, waitlist, recipient) or living donation (pre- or postdonation). For example, a report of an intervention with caregiver to patients with end-stage renal disease on dialysis but not undergoing evaluation for kidney transplant or listed for kidney transplant would be excluded. Whereas, if the patient population included individuals in the evaluation for transplant or listed, then the report would be included.

### 2.2 | Interventions

Studies evaluating nonpharmacological interventions were included if caregivers participated in or were included in the intervention. Although reports of interventions directed solely to transplant patients have also examined caregiver outcomes, these studies were excluded as they did not actively involve the caregiver in the intervention.<sup>35</sup> Also, reports on development of interventions that utilized caregiver feedback to refine the intervention with no feasibility or pilot testing were excluded. All types of nonpharmacological interventions were eligible, including, for example, caregiver education, emotional support (e.g., support groups), respite/adult day care, psychotherapy, behavioral strategies to build skills, and multicomponent interventions encompassing several of these strategies.<sup>36</sup> We included any interventional study, with the goal of capturing all caregiver studies, regardless of inclusion of a control or comparison cohort. This included controlled trials, quasi-experimental, single-arm pilot studies, etc.

### 2.3 | Outcomes

The primary outcomes for the systematic review included any caregiver-reported outcome measures including, but not limited to, caregiver quality of life (QOL), burden, benefit, knowledge of transplantation, and psychological symptoms or distress. We also explored patient-reported outcomes (e.g., patient health-related quality of life, patient knowledge of transplant) as we were interested in exploring potential dyadic interactions between the caregiver and patient as a result of an intervention.

### 2.4 | Search strategy

A search was developed and performed by two librarians with expertise in systematic reviews (GH & BL). PubMed, Embase, PsycInfo, Cochrane Central Register of Controlled Trials (Central), and Cumulative Index to Nursing & Allied Health Literature (CINAHL) were searched for studies with no first date limitations through July 1, 2021. Specific search terms and strategies are provided in Supplemental Table A. Studies published in a language other than English were excluded. We excluded systematic reviews, meta-analyses, background articles, or literature reviews. Gray literature, including published abstracts in journals and from conference proceedings, was reviewed to ensure all possible content was explored: if a potentially

eligible gray literature source was identified we first attempted to find a corresponding full-text article. If unsuccessful, we attempted to contact the authors by email. If no response was received within three weeks, the source was excluded.

## 2.5 | Abstract reviews and study selection

Following extraction, all abstracts were entered into Rayyan QCRI<sup>37</sup> for deduplication and review. Every abstract was reviewed for inclusion/exclusion by at least two authors (divided among and performed by MTJ, KG, SL, and HB) based upon title and abstract content. If reviewers agreed on inclusion, the abstract was retained for full article review. In the case of disagreements, either the majority decision was retained or if there was no majority, the title and abstract was sent to another coauthor for final decision/majority. Full data extraction from the final set of included articles was performed by one reviewer (KG) and verified by a second reviewer (MTJ). Any disagreements were discussed and, if needed, sent to a third reviewer for final decision.

## 2.6 | Quality assessment of included studies

Consistent with the recommendations outlined by the Cochrane Handbook for Systematic Reviews,<sup>38</sup> potential risk of bias was assessed for studies that included both an intervention and a comparator group. For randomized-controlled trials, we used the Cochrane Risk of Bias Version 2 (RoB 2).<sup>39</sup> Risk of bias is measured across domains including biases in the randomization process, deviations from intended interventions, missing outcome data, outcome measurement, selection of reported results, and overall bias. Risk of bias is rated across each domain as low, some concerns, or high. For nonrandomized trials, we used the Risk of Bias in Non-Randomized Studies–Interventions (ROBINS-I).<sup>40</sup> Risk of bias is measured across domains including baseline confounding, participant selection, classification of the intervention, deviations from intended interventions, missing outcome data, outcome measurement, selection of reported results, and overall bias. Risk of bias is rated across each domain as low, moderate, serious, or critical.<sup>40</sup> Two authors (MTJ and KG) assessed the methodological quality of the studies. Any disagreements were discussed and, if needed, sent to a third reviewer for final decision.

# 3 | RESULTS

## 3.1 | Study selection

The initial search identified 1426 studies, yielding 1346 unique references for title and abstract review (Figure 1). Of these, 1245 studies did not meet inclusion criteria. Full-text reviews (or review of abstracts retained in order to contact the authors to determine if a full-text manuscript had been published), were conducted on the resulting 101 studies, yielding 12 studies<sup>41–52</sup> for the systematic review.

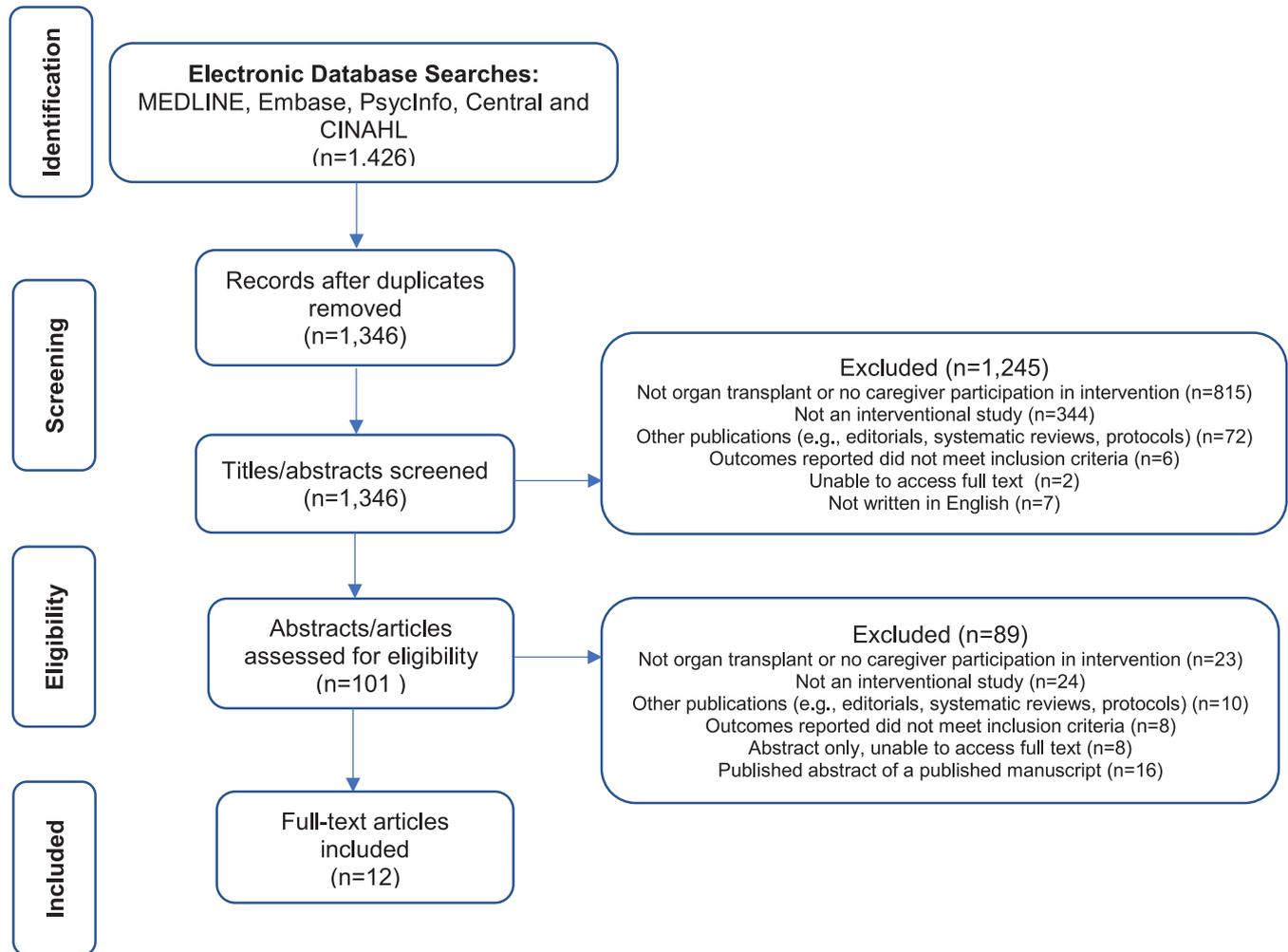
## 3.2 | Study characteristics

Table 1 summarizes key features of the 12 included studies. All, excluding one,<sup>49</sup> were conducted in the United States and published between 2004 and 2021. One study focused solely on caregivers<sup>47</sup> and eleven studies engaged both caregivers and patients.<sup>41–46,48–52</sup> Across all 12 studies, a total of 742 caregivers (7.1% to pediatric patients) and 710 patients (7.4% pediatric) participated in the various interventions. Across studies reporting caregiver sex, 70.5% to 88% of caregivers were female. Nine studies focused on adult transplant populations<sup>43–50,52</sup> and three on pediatric transplant populations.<sup>41,42,50</sup> No studies were identified on caregiving in the context of living donation. The studies represented liver ( $n = 3$ ),<sup>41,43,44</sup> heart ( $n = 2$ ),<sup>42,45</sup> lung ( $n = 2$ ),<sup>46,47</sup> kidney ( $n = 2$ ),<sup>49,52</sup> and combined ( $n = 3$ ) transplant populations.<sup>48,50,51</sup> Studies varied in the time point that interventions were delivered across the organ transplantation process, including delivered at the time of evaluation for listing ( $n = 2$ ),<sup>48,49</sup> patients listed for and awaiting transplantation ( $n = 3$ ),<sup>43,44,46</sup> post-transplantation ( $n = 5$ ),<sup>41,42,45,50,52</sup> and cohorts that included both patients who were listed and those who had received a transplant ( $n = 2$ ).<sup>47,51</sup> Race/ethnicity across studies, when reported, is provided in Supplemental Table B.

With respect to study design, most studies did not include a comparison or control group (prepost single arm or single-arm postassessment only  $n = 7$ ),<sup>41–43,47,48,50,51</sup> intervention and nonrandomized comparison cohort ( $n = 2$ ),<sup>45,46</sup> and randomized controlled trials ( $n = 3$ ).<sup>44,49,52</sup> A variety of nonpharmacological interventions were implemented and evaluated. Eight studies included transplant-specific education as the intervention ( $n = 4$ ),<sup>41–43,48</sup> an interventional component ( $n = 1$ ),<sup>45</sup> the control/comparison group ( $n = 1$ ),<sup>44</sup> or compared two different approaches to education (both the intervention and comparator,  $n = 2$ ).<sup>46,49</sup> Educational interventions varied in length and focus (outlined in Table 1).<sup>41–43,46,48,49</sup> Other types of intervention included mindfulness-based stress reduction ( $n = 2$ ),<sup>47,51</sup> multicomponent interventions comprised of both educational and therapeutic components (telephone delivered self-management training  $n = 1$ , online skills-based workshops  $n = 1$ , and collaborative care model nursing education for self-management and self-efficacy  $n = 1$ ),<sup>44,45,52</sup> and a mobile phone app to assist parental caregivers and adolescents with medication adherence ( $n = 1$ ).<sup>50</sup> Mode of intervention delivery was face-to-face/in-person sessions ( $n = 7$ ),<sup>41–43,46,48,49,51</sup> telephone ( $n = 1$ ),<sup>44</sup> the internet (with both synchronous and asynchronous components,  $n = 1$ ),<sup>45</sup> a DVD ( $n = 1$ ),<sup>47</sup> a mobile app ( $n = 1$ ),<sup>50</sup> and a combination of both face-to-face/in-person sessions and the internet via a WebChat ( $n = 1$ ).<sup>52</sup>

## 3.3 | Quality of evidence

Five studies included an intervention and a comparator group and were reviewed for risk of bias. Bailey et al.,<sup>44</sup> Kayler et al.,<sup>49</sup> and Yan et al.<sup>52</sup> were the only studies to perform a randomized controlled trial and be evaluated by the ROB 2 (Table 2). For Bailey et al.,<sup>44</sup> the overall risk



**FIGURE 1** PRISMA flow diagram of study selection

of bias determined to be high, which was largely due to participants were not blinded after study assignment and it was unclear whether there were deviations from trial context. Yan et al.<sup>52</sup> was also determined to have high overall risk of bias, as there was a lack of information regarding the randomization process and a possibility of bias in the measurement of outcomes due to the knowledge of the intervention by the outcome assessors (participants). The overall risk of bias was determined to be high for Kayler et al.<sup>49</sup> as well, which was mainly attributed to the measurement of results (test-retest bias), as well as the failure to report all results without clear justification. Dew et al.<sup>45</sup> conducted a prepost intervention assessment and included a historical comparison group and Gerity et al.<sup>46</sup> conducted a prepost quality improvement assessment compared to prepost assessment of standard education. Applying the ROBINS-I (Table 3), the overall risk of bias for Dew et al.<sup>45</sup> was rated as serious and for Gerity et al.<sup>46</sup> critical. These risk-of-bias judgments were largely due to intervention participants being unblinded to study intervention, subjective self-report measurements administered by assessors, and authors did not report whether the assessors were aware of the interventions

the participants received. The remaining seven studies were single-arm studies with no comparison groups (not comparative effectiveness studies).

### 3.4 | Synthesis of study results

A variety of caregiver-reported outcomes were assessed. Caregivers reported psychosocial outcomes included health-related quality of life (HrQOL),<sup>45</sup> knowledge of transplant,<sup>46,48,49</sup> mood/depressive symptoms,<sup>45,51</sup> anxiety,<sup>45,47,51</sup> perceived stress,<sup>47,51</sup> uncertainty in caregiving roles,<sup>44</sup> self-efficacy,<sup>44,49</sup> mindfulness awareness,<sup>51</sup> resilience after stressful events,<sup>51</sup> and sleep quality.<sup>51</sup> Additional caregiver outcomes included liver-specific health literacy,<sup>43</sup> kidney-specific health literacy,<sup>52</sup> willingness toward different types of deceased kidney donor options,<sup>49</sup> parental perception of child/adolescent preparedness for transition,<sup>42</sup> caregiver perception of patient adherence,<sup>45</sup> and usability and/or satisfaction with the interventions provided.<sup>41,45,46,48-50</sup> Although two studies included measures of

**TABLE 1** Characteristics of included studies

| Author, Year                          | Design  | Sample Characteristics   | Intervention and length   | Summary of Caregiver Reported Findings   |
|---------------------------------------|---|--|---|--|
| Annunziato et al., 2008 <sup>41</sup> | Pre-post, single arm pilot study (caregiver assessment post-intervention) | Caregivers (n = 16) to pediatric liver recipients within 6 months posttransplant (n = 20, mean patient age 15.80±2.69).  | Four educational sessions (face-to-face), length not reported, first two sessions taught by a transplant team physician or nurse and second two by a psychologist or psychiatrist) facilitating transition of healthcare responsibilities from parent to child.   | Approximately 3-months post-education survey feedback: <ul style="list-style-type: none"> <li>• 70% reported children has tried to take their medication as directed because of education</li> <li>• 90% reported trying to do things discussed in education meetings</li> <li>• 50% reported learning something they did not know before about their child's illness</li> <li>• 50% reported learning something they did not know before about their child's treatment</li> <li>• 70% reported they were more comfortable feeling they know enough to make decisions about giving their children the responsibility to take over their medications</li> </ul> |
| Anton et al., 2019 <sup>42</sup>      | Retrospective chart review of QI project, with pre-post surveys           | Caregivers (n = 12) to pediatric heart transplant recipients (n = 12; mean age 17.42, range 16-22)   | Two sets of 7 educational sessions (2 hours each, face-to-face) occurring over 2 years of clinical care, one for patients and one for caregivers.<br>Educational session content derived from a focus group that included pediatric heart transplant patients and heart transplant nurses, nurse practitioners, physicians, social workers, psychologists, child life specialists, dieticians, and pastoral care providers. | Pre- to post-intervention, no significant changes in parental perception of patient/child <ul style="list-style-type: none"> <li>• Readiness for transition</li> <li>• Understanding of diagnosis</li> <li>• Ability to navigate the health system</li> </ul>  |
| Bababekov et al., 2017 <sup>43</sup>  | Pre-post, single arm pilot study  | Caregivers (n = 48) to adult liver transplant candidates (n = 52)  | Routine transplant education (face-to-face) via 42-slide PowerPoint presentation outlining aspects of liver disease and the transplantation process.  | Pre- to post-intervention small, but significant increase in caregiver REALM-Liver scores  |
| Bailey et al., 2017 <sup>44</sup>     | Randomized controlled trial (pre-post assessments across groups)          | Caregivers to and adult liver transplant candidates across two conditions: self-management telephone (n = 56 caregiver/candidate pairs) and liver disease education (n = 59 caregiver/candidate pairs) | Self-management telephone intervention (coping skills training, symptom management strategies) versus liver disease education.<br>Both interventions delivered for 30-minutes weekly via the telephone over 6-weeks.  | Pre- to 10- or 12-weeks post-intervention, no significant mean change differences between caregiver groups on <ul style="list-style-type: none"> <li>• Perception of illness uncertainty</li> <li>• Uncertainty management</li> <li>• Caregiver self-efficacy to manage patient symptoms</li> <li>• Caregiver reaction to caregiving</li> </ul>  |
| Dew et al., 2004 <sup>45</sup>        | Pre-post design with historical comparison group                          | Caregivers (n = 20) to adult heart transplant recipients (n = 24), and historical cohort caregivers (n = 20) and heart recipients (n = 20)   | Multicomponent internet-based intervention intended for weekly use over a 4-month timeframe (included both synchronous and asynchronous components).  | 93% of caregivers reported website was "very easy" to use.<br>Pre- to post-intervention, greater caregiver website use <ul style="list-style-type: none"> <li>• Associated with significant reduction caregiver anxiety and greater improvement on role functioning related to emotional factors</li> <li>• Not associated with changes in caregiver anger-hostility or depressive symptoms</li> </ul>   |

(Continues)

**TABLE 1** (Continued)

| Author, Year                      | Design   | Sample Characteristics   | Intervention and length  | Summary of Caregiver Reported Findings   |
|-----------------------------------|--|--|--|--|
| Gerity et al., 2018 <sup>46</sup> | Pre-post QI project; between-subjects design (compared to historical control receiving standard education) | Caregivers (n = 17 enhanced education, 19 standard education) to adult lung transplant candidates (n = 18 enhanced education, n = 19 standard)   | Six face presentations (30-45 minutes each, face-to-face), consisting of multiple components (i.e., practice demonstrations, videos, etc.) compared to standard education.   | Post-education, no significant differences in knowledge between enhanced versus standard education   |
| Haines et al., 2014 <sup>47</sup> | Pre-post, single arm pilot study   | Caregivers of adult lung transplant candidates or recipients (n = 28 to recipients, n = 2 to candidates)   | MBSR techniques explained via a DVD, and the techniques were intended to be performed for 5-15 minutes a day over four weeks.  | Pre- to post-intervention, those who watched the entire DVD (versus some or none) reported <ul style="list-style-type: none"> <li>• Significant decreases in perceived stress, state anxiety, and trait anxiety</li> <li>• Those who watched only some or none did not report significant changes in perceived stress, state anxiety, or trait anxiety</li> </ul>  |
| Jesse et al., 2016 <sup>48</sup>  | Post-education survey  | Caregivers (n = 255) to adult transplant candidates (liver n = 112, kidney n = 94, pancreas n = 2, lung n = 1, liver/kidney n = 3, kidney/pancreas n = 3, and other n = 2), and additional social supports (n = 351)                               | One 3-hour transplant lifestyle education session (face-to-face) led by transplant recipients and designed for patients undergoing evaluation for possible transplantation.  | Post-education survey feedback: <ul style="list-style-type: none"> <li>• 92.2% reported adequate or not enough time with the educational session</li> <li>• 94.1% reported information presented was helpful or very helpful in managing the transplant process</li> <li>• 95.3% reported information presented was understandable or very understandable and easy to follow</li> <li>• 92.9% reported program met or exceeded expectations</li> <li>• 82.7% reported mostly or completely confident they could navigate the transplant process with the information provided</li> </ul>   |
| Kayler et al., 2020 <sup>49</sup> | Pilot randomized parallel controlled trial (pre-post assessment between groups)                            | Caregivers to adult kidney transplant candidates across two conditions: animations and standard transplant nurse education (n = 36 caregivers, n = 42 patients) and standard transplant nurse education alone (n = 28 caregivers, n = 38 patients) | Two animation videos (2.16-minute video about KDPI and 2.05-minute video about IRD) and standard transplant nurse education versus the standard transplant nurse education alone. Standard transplant nurse education included fact sheets about KDPI and IRD. | Pre- to immediate post-intervention surveys reported no significant differences between groups in regard to caregiver knowledge of IRD/KDPI, self-efficacy, and IRD/KDPI willingness<br>Post-animation video survey feedback, % responses Agree/Strongly Agree: <ul style="list-style-type: none"> <li>• 100% comfortable using videos; 92% videos acceptable to people of their race/culture; 97% credible; 100% easy to watch; 100% easy to understand; 100% clear; 97% interesting; 97% helps them make better decisions; 69% increased transplant interest; 100% would refer videos to a friend; and 97% would use videos like this in the future</li> </ul> |

(Continues)

**TABLE 1** (Continued)

| Author, Year                          | Design  | Sample Characteristics  | Intervention and length   | Summary of Caregiver Reported Findings   |
|---------------------------------------|---|---|---|--|
| Shellmer et al., 2016 <sup>50</sup>   | Post-field test survey/feedback   | Parental caregivers (n = 9) to adolescent organ transplant recipients (liver n = 4, heart n = 2, lung = 1; age range 11-18)   | Three usability sessions (face-to-face) and a 6-week field test intended to create and refine the multi-component Teen Pocket PATH, a mobile health application to assist adolescent transplant recipients with adherence to medications. | Caregivers reported satisfaction with the prototype, no difficulties with app set-up, and found it useful (no formal analyses provided)  |
| Stonington et al., 2016 <sup>51</sup> | Pre-post, single arm pilot study  | Caregivers (n = 5 to a candidate, n = 13 to a recipient)* to adult transplant candidates (heart n = 6, bone marrow n = 3, liver n = 1) and recipients (heart n = 10, liver n = 5, kidney/pancreas n = 4, bone marrow n = 1) | Six sessions (face-to-face) of a multi-component MBSR class (yoga, mindfulness practice, etc.) led by a SMART-trained facilitator, psychologist, and yoga instructor conducted over 6-weeks.  | Pre- to 6-week post-intervention: <ul style="list-style-type: none"> <li>• Significant reductions in caregiver perceived stress</li> <li>• No significant changes in caregiver depression, emotional resilience, anxiety, sleep quality, positive or negative affect, mindfulness, or HrQOL</li> </ul>   |
| Yan et al., 2021 <sup>52</sup>        | Randomized controlled trial (pre-post assessment with retrospective analysis) | Caregivers to adult kidney transplant recipients across two conditions; conventional nursing (n = 36) or collaborative care model (n = 37)  | Implementation of the CCM conducted by an established collaborative nursing team (attending physician, primary nurse, the patient, and the patient's family members) over three months compared to conventional nursing care              | Caregiver in the CCM group displayed higher health literacy (measure created by the authors for the purpose of the study) at the time of discharge compared to caregivers in the conventional nursing group. However, no pre-intervention/baseline assessment of health literacy was performed to determine whether there were baseline differences. |

Note. HrQOL = health-related quality of life, MBSR = Mindfulness-Based Stress Reduction, NR = not reported, QI = quality improvement, REALM = Rapid Estimate of Adult Literacy in Medicine, SMART = Stress Management and Resilience Training, CCM = Collaborative Care Model, KDPI = kidney donor profile index, IRD = increased risk donor.

\*Whether caregiver was to a candidate or recipient reported in supplemental table. Did not report type of transplant by caregiver, recruitment rate, or why different sample sizes across caregivers and patients.

perceived stress, no studies included a specific measure of perceived caregiver burden (e.g., Zarit Burden Interview,<sup>53</sup> Caregiver Burden Inventory<sup>54</sup>). Of the 10 studies that included within (prepost assessment) or between (intervention/comparison) group comparisons (not including studies with single-arm post assessment only n = 2),<sup>48,50</sup> four studies did not find significant effects from the intervention.<sup>42,44,46,49</sup> However, two of these studies may have been underpowered (caregiver intervention samples  $n \leq 17$ ).<sup>42,46</sup> Kayler et al.<sup>49</sup> randomized kidney transplant candidates and their caregivers to either deceased kidney donor options educational animations with standard nurse discussion or standard nurse discussion alone. Results showed no significant differences between the intervention and control groups on caregiver knowledge or willingness toward different types of deceased donor kidney options (increased risk donor or IRD and kidney donor profile index or KDPI), as well as self-efficacy.<sup>49</sup> Bailey et al.<sup>44</sup> randomized liver transplant candidate-caregiver dyads to a telephone self-management condition versus education about liver disease. No significant differences were identified at 10 and 12-weeks post baseline on caregiver uncertainty, management of feelings of uncertainty,

or self-efficacy.<sup>44</sup> Alternatively, brief mindfulness-based interventions displayed small but significant reductions in perceived stress, but not depressed mood, sleep quality or HrQOL (albeit relatively small samples, caregiver  $n \leq 30$ ).<sup>47,51</sup> In another study, caregivers who participated in a 4-month multicomponent internet-based intervention that included online stress management workshops, discussion groups, electronic access to transplant providers (asynchronous), and general transplant-related educational information were compared to a retrospective cohort. Caregivers in the intervention group had reduced pre to postintervention anxiety and anger-hostility symptoms but no significant change in depressive symptoms.<sup>45</sup> Another study engaging both kidney transplant recipients and their caregivers in a nurse-led collaborative care model (CCM) showed significantly higher levels of kidney-specific health literacy among the observational group that received CCM compared to the control group.<sup>52</sup> Of note, despite eleven of the included twelve studies engaging both patients and caregivers (with dyads frequently reporting on the same or similar outcomes), no analyses were performed examining dyadic outcomes (e.g., actor-partner interdependence).

**TABLE 2** Risk of bias according to Cochrane ROB 2

|                     | Bias arising from the randomization process                                       | Bias due to deviations from intended interventions (effect of assignment to intervention) | Bias due to deviations from intended interventions (effect of adhering to intervention) | Bias due to missing outcome data  | Bias in measurement of the outcome  | Bias in selection of reported results   | Overall Risk of Bias  |
|---------------------|---|---|---|---|---|---|---|
| Bailey et al., 2017 |  |          |        |  |  |  |  |
| Kayler et al., 2020 |  |          |        |  |  |  |  |
| Yan et al., 2021    |  |          |        |  |  |  |  |

Key:  , High risk of bias;  , Some concerns;  , Low risk of bias.

**TABLE 3** Risk of bias according to the ROBINS-I

|                     | Confounding | Participant Selection | Classification of Intervention | Intervention deviations | Missing data | Outcomes measurement | Selection of reported results | Overall Bias |
|---------------------|-------------|-----------------------|--------------------------------|-------------------------|--------------|----------------------|-------------------------------|--------------|
| Dew et al., 2004    | M           | L                     | L                              | M                       | M            | S                    | L                             | S            |
| Gerity et al., 2018 | S           | L                     | L                              | L                       | M            | S                    | C                             | C            |

Key: **L = Low Risk**; **M = Moderate Risk**; **S = Serious Risk**; **C = Critical Risk**.

## 4 | DISCUSSION

The objective of this systematic review was to summarize the studies implementing nonpharmacological interventions involving caregivers for pediatric and adult organ transplant patient populations. We identified 12 studies that met inclusion criteria: nine focused on caregivers to adults and three on caregivers to pediatric organ transplant patients. While this review identified important work on the development of interventions, few interventions have moved beyond the single-arm pilot stage. The overall findings reflect the need for further research on identifying caregiver-prioritized outcomes and interventions to address the needs of organ transplant caregiver groups.

We were surprised to find only three pediatric caregiver interventions (with a total of 43 caregivers and 41 pediatric patients) in the published literature. Parents of pediatric organ transplant recipients report similar stressors as caregivers of adult recipients including worry about medical-related complications, balancing child's medical care with family routine, and role strain.<sup>6,55</sup> However, challenges parents encounter caring for a child in need of a transplant are likely contextually different from caring for adult populations. Family self-management interventions supporting the parent after transplant is an opportunity to improve caregiver quality of life<sup>56</sup> and may provide insight for the adult caregiver population. Additionally, no studies were identified on caregivers to living donors. While care-related needs of

living donors may be more time-limited, there are still educational and other needs associated with caregiving in the context of living donation that may require further consideration.<sup>57</sup> There was also only one study performed outside of the United States.<sup>52</sup> Caregiving related demands in organ transplantation may vary across countries, as cultural expectations and available resources (e.g., financial support such as paid leave) can also vary. Although the findings of this study are largely limited to the US, adapting interventions to be culturally appropriate and testing in relevant populations is a suitable future step.

Provision of education is a requirement for informed consent, a standard element of discharge education after transplant, and desired by both patients and caregivers.<sup>58,59</sup> Most studies implemented either an educational intervention alone or education in addition to another intervention. However, given methodological limitations and the variability across educational content, duration (ranging from one 45-minute session to seven two-hour sessions over two years), timing of provision (e.g., pretransplant, post-transplant), and format (e.g., in person, in groups), further research is needed to understand the most impactful approach to education on outcomes of interest. It is worth noting that meta-analytic data from caregivers to other chronic disease populations suggests education, when provided as the only interventional component, is associated with significant effects of moderate size on caregiver burden but no significant effects on depression or anxiety.<sup>27-30</sup> Meta-analytic data also suggests the provision of

education may have a synergistic effect within multicomponent interventions on depression and anxiety.<sup>29,30</sup> However, the most efficacious combination of treatments is not yet known and warrants further examination. Rigorous and systematic research applying contemporary learning theories is a needed next step to determine if education is impactful on targeted outcomes of interest. As no published studies at the time of this review specifically explored caregiver perceived burden as an outcome, this is an opportunity for future research to explore.

While no studies examined interventional effects on perceived benefits of caregiving, one study included resilience as a strength-based factor.<sup>51</sup> While there is little consensus on the specific definition of resilience, it has been described as both an adaptive coping strategy and a trait characteristic.<sup>60,61</sup> A pilot study examining brief mindfulness did not result in significant pre to postintervention caregiver reported resilience.<sup>51</sup> However, the study was possibly underpowered ( $n = 15$ ). Therefore, future interventions focused on facilitating resilience may be worthwhile as there is evidence from other lay-caregiver populations that resilience is associated with positive outcomes including better caregiver quality of life, general health, and lower depressive symptoms.<sup>62,63</sup>

Due to the small number of studies, variability across interventions, and methodological limitations (e.g., lack of randomization, no comparison cohorts, small sample sizes), clear clinical recommendations are limited at this time. However, much can be gleaned from these studies. First, importantly, caregivers provided positive feedback when asked about usefulness, appropriateness, and satisfaction across interventions. These are important factors when designing interventions to ensure future uptake, engagement, and sustainability. Second, although further research is warranted, mindfulness-based stress reduction and multicomponent interventions may have the potential to be effective in reducing transplant caregiver reported stress.

There were limitations to our systematic literature review. First, several of our inclusion criteria were intentionally broad (i.e., no date restrictions, all solid organs and stages of transplantation, adult and pediatric transplant populations, inclusion of non-RCT methodologies) in order to include all studies that focused on nonpharmacological interventions for caregivers of solid organ transplant patients. Even after applying our broad inclusion criteria, only 12 studies were included for final review. Also, only one study identified was performed outside of the USA.<sup>52</sup> Since our prereview protocols did not exclude studies performed outside of the USA, as we expected to find several, we decided to retain this study in the final report. However, caution should be made in making comparisons of interventions and potential intervention effects across countries and cultures. Alternatively, excluding studies published in languages other than English may have excluded internationally published interventions beyond the one that was included in our review. Another limitation to our systematic review was the clear heterogeneity across the 12 studies. As discussed earlier, there were major differences among the reviewed studies in regard to the designs and methodology of the studies, the interventions of interest, the selected outcomes measured, and the populations (e.g., the organ of interest, adult vs pediatric transplantation, the stage of transplantation). Lastly, given that the majority of included studies were

single-arm studies, many with small sample sizes, future interventional research should consider controlled trial methods.

## 5 | CONCLUSION

There are several important conclusions from this systematic review. First, this review shows that interventions targeting caregivers of organ transplant populations have been far less examined than other chronic disease populations (e.g., cancer, Alzheimer's<sup>27-33</sup>), despite evidence of being significantly impacted by caregiving. As such, considerably more interventional research is needed for lay-caregivers of organ transplant patient populations. As we have emphasized throughout this review, caregivers play a huge role in the transplantation process but are also impacted by their role.<sup>7-23</sup> As such, it is crucial for future interventional studies to address targeted psychosocial outcomes in transplant caregivers. However, research is needed identifying caregiver-reported priorities in outcomes, which will significantly aid in the design and focus of future interventions. An additional question is whether interventions that engage caregivers also have an impact on patient outcomes. Interventional research with controlled-trial methods is a necessary future step.

## CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

## AUTHOR CONTRIBUTION

MTJ and KG conceived of the study, participated in the research design, article selection and review, and writing of the manuscript.

GH and BL developed and performed the systematic review search and critically reviewed the manuscript.

HG and SL participated in the research design, article selection, and critical review of the manuscript.

MAD participated in the research design, article review, and critical review of the manuscript.

Data sharing is not applicable to this article, as no new data were created or analyzed in this study. However, relevant syntax to replicate search methods are included in supplemental materials.

## DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study. However, relevant syntax to replicate search methods are included in supplemental materials.

## ORCID

Michelle T. Jesse  <https://orcid.org/0000-0003-0847-0368>

Heather Bruschwein  <https://orcid.org/0000-0003-1180-5149>

## REFERENCES

1. Joshi SA, Almeida N, Almeida A. Assessment of the perceived quality of life of successful kidney transplant recipients and their donors pre- and post-transplantation. *Transplant Proc.* 2013;45:1435-1437.

2. Neovius M, Jacobson SH, Eriksson JK, Elinder CG, Hylander B. Mortality in chronic kidney disease and renal replacement therapy: a population-based cohort study. *BMJ Open*. 2014;4:e004251.
3. Tonelli M, Wiebe N, Knoll G, et al. Systematic review: kidney transplantation compared with dialysis in clinically relevant outcomes. *Am J Transplant*. 2011;11:2093-2109.
4. Beckmann S, Künzler-Heule P, Biotti B, Spirig R. Mastering Together the Highs and Lows: patients' and Caregivers' Perceptions of Self-Management in the Course of Liver Transplantation. *Prog Transplant*. 2016;26:215-223.
5. Green A, Meaux J, Huett A, Ainley K. Constantly responsible, constantly worried, constantly blessed: parenting after pediatric heart transplant. *Prog Transplant*. 2009;19:122-127.
6. Lerret SM, Johnson NL, Haglund KA. Parents' perspectives on caring for children after solid organ transplant. *J Spec Pediatr Nurs*. 2017;22. PMID: 28371009. <https://doi.org/10.1111/jspn.12178>
7. Boulware LE, Hill-Briggs F, Kraus ES, et al. Identifying and addressing barriers to African American and non-African American families' discussions about preemptive living related kidney transplantation. *Prog Transplant*. 2011;21:97-104. quiz 105.
8. Rodrigue JR, Dimitri N, Reed A, et al. Spouse caregivers of kidney transplant patients: quality of life and psychosocial outcomes. *Prog Transplant*. 2010;20:335-342. quiz 343.
9. Miyazaki ET, Dos Santos R Jr, Miyazaki MC, et al. Patients on the waiting list for liver transplantation: caregiver burden and stress. *Liver Transpl*. 2010;16:1164-1168.
10. Xu J, Adeboyejo O, Wagley E, et al. Daily burdens of recipients and family caregivers after lung transplant. *Prog Transplant*. 2012;22:41-47. quiz 48.
11. Kaan A, Young QR, Cockell S, Mackay M. Emotional experiences of caregivers of patients with a ventricular assist device. *Prog Transplant*. 2010;20:142-147.
12. Kirkpatrick JN, Kellom K, Hull SC, et al. Caregivers and Left Ventricular Assist Devices as a Destination, Not a Journey. *J Card Fail*. 2015;21:806-815.
13. Baker K, Flattery M, Salyer J, Haugh KH, Maltby M. Caregiving for patients requiring left ventricular assistance device support. *Heart Lung*. 2010;39:196-200.
14. Rodrigue JR, Dimitri N, Reed A, Antonellis T, Hanto DW, Curry M. Quality of life and psychosocial functioning of spouse/partner caregivers before and after liver transplantation. *Clin Transplant*. 2011;25:239-247.
15. Meltzer LJ, Rodrigue JR. Psychological distress in caregivers of liver and lung transplant candidates. *J Clin Psychol Med Settings*. 2001;8:173-180.
16. Kurz JM. Vulnerability of well spouses involved in lung transplantation. *Journal of Family Nursing*. 2002;8:353-370.
17. Pol SJ, Snyder J, Anthony SJ. "Tremendous financial burden": crowdfunding for organ transplantation costs in Canada. *PLoS One*. 2019;14:e0226686.
18. Bolckhir A, Loiselle MM, Evon DM, Hayashi PH. Depression in primary caregivers of patients listed for liver or kidney transplantation. *Prog Transplant*. 2007;17:193-198.
19. Ingerski LM, Shaw K, Gray WN, Janicke DM. A pilot study comparing traumatic stress symptoms by child and parent report across pediatric chronic illness groups. *J Dev Behav Pediatr*. 2010;31:713-719.
20. Goetzinger AM, Blumenthal JA, O'Hayer CV, et al. Stress and coping in caregivers of patients awaiting solid organ transplantation. *Clin Transplant*. 2012;26:97-104.
21. Holtzman S, Abbey SE, Singer LG, Ross HJ, Stewart DE. Both patient and caregiver gender impact depressive symptoms among organ transplant caregivers: who is at risk and why?. *J Health Psychol*. 2011;16:843-856.
22. Mantulak A, Nicholas DB. "We're not going to say it's suffering; we're going to say it's an experience": the lived experience of maternal caregivers in pediatric kidney transplantation. *Soc Work Health Care*. 2016;55:580-594.
23. Rodrigue JR, Baz MA. Waiting for lung transplantation: quality of life, mood, caregiving strain and benefit, and social intimacy of spouses. *Clin Transplant*. 2007;21:722-727.
24. Schubert CF, Schmidt U, Rosner R. Posttraumatic Growth in populations with posttraumatic stress Disorder-A systematic review on growth-related psychological constructs and biological variables. *Clin Psychol Psychother*. 2016;23:469-486.
25. Calhoun LG, Tedeschi RG. *Handbook of posttraumatic growth: Research and practice*. Routledge; 2014.
26. Abrahams R, Liu KPY, Bissett M, et al. Effectiveness of interventions for co-residing family caregivers of people with dementia: systematic review and meta-analysis. *Aust Occup Ther J*. 2018;65:208-224.
27. Cheng ST, Li KK, Losada A, et al. The effectiveness of nonpharmacological interventions for informal dementia caregivers: an updated systematic review and meta-analysis. *Psychol Aging*. 2020;35:55-77.
28. Jensen M, Agbata IN, Canavan M, McCarthy G. Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: systematic review and meta-analysis of randomised controlled trials. *Int J Geriatr Psychiatry*. 2015;30:130-143.
29. Williams F, Moghaddam N, Ramsden S, De Boos D. Interventions for reducing levels of burden amongst informal carers of persons with dementia in the community. A systematic review and meta-analysis of randomised controlled trials. *Aging Ment Health*. 2019;23:1629-1642.
30. Teahan Á, Lafferty A, McAuliffe E, et al. Psychosocial Interventions for Family Carers of People With Dementia: a Systematic Review and Meta-Analysis. *J Aging Health*. 2020;32:1198-1213.
31. Hu Y, Liu T, Li F. Association between dyadic interventions and outcomes in cancer patients: a meta-analysis. *Support Care Cancer*. 2019;27:745-761.
32. Dalton J, Thomas S, Harden M, Eastwood A, Parker G. Updated meta-review of evidence on support for carers. *J Health Serv Res Policy*. 2018;23:196-207.
33. Bom J, Bakx P, Schut F, van Doorslaer E. The Impact of Informal caregiving for older adults on the health of various types of caregivers: a systematic review. *Gerontologist*. 2019;59:e629.
34. Liberati A, Altman DG, Tetzlaff J, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *PLoS Med*. 2009;6:e1000100.
35. Rodrigue JR, Widows MR, Baz MA. Caregivers of lung transplant candidates: do they benefit when the patient is receiving psychological services?. *Prog Transplant*. 2006;16:336-342.
36. Sörensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist*. 2002;42:356-372.
37. Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan-a web and mobile app for systematic reviews. *Syst Rev*. 2016;5:210.
38. Higgins JP, Thomas J, Chandler J, et al. *Cochrane handbook for systematic reviews of interventions*. John Wiley & Sons; 2019.
39. Sterne JAC, Savović J, Page MJ, et al. RoB 2: a revised tool for assessing risk of bias in randomised trials. *Bmj*. 2019;366:l4898.
40. Sterne JA, Hernán MA, Reeves BC, et al. ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. *Bmj*. 2016;355:i4919.
41. Annunziato RA, Emre S, Shneider BL, et al. Transitioning health care responsibility from caregivers to patient: a pilot study aiming to facilitate medication adherence during this process. *Pediatr Transplant*. 2008;12:309-315.
42. Anton CM, Anton K, Butts RJ. Preparing for transition: the effects of a structured transition program on adolescent heart transplant patients' adherence and transplant knowledge. *Pediatr Transplant*. 2019;23:e13544.

43. Bababekov YJ, Ven Fong Z, Chang DC, Simpson MA, Yeh H, Pomposelli JJ. Is liver transplant education patient-centered?. *Liver Transpl.* 2017;23:1070-1072.
44. Bailey DE Jr, Hendrix CC, Steinhauser KE, et al. Randomized trial of an uncertainty self-management telephone intervention for patients awaiting liver transplant. *Patient Educ Couns.* 2017;100:509-517.
45. Dew MA, Goycoolea JM, Harris RC, et al. An internet-based intervention to improve psychosocial outcomes in heart transplant recipients and family caregivers: development and evaluation. *J Heart Lung Transplant.* 2004;23:745-758.
46. Gerity SL, Silva SG, Reynolds JM, Hoffman B, Oermann MH. Multimedia education reduces anxiety in lung transplant patients. *Prog Transplant.* 2018;28:83-86.
47. Haines J, Spadaro KC, Choi J, Hoffman LA, Blazeck AM. Reducing stress and anxiety in caregivers of lung transplant patients: benefits of mindfulness meditation. *Int J Organ Transplant Med.* 2014;5:50-56.
48. Jesse MT, Rubinstein E, Eshelman A, et al. Lifestyle and self-management by those who live it: patients engaging patients in a chronic disease model. *Perm J.* 2016;20:15-207.
49. Kayler LK, Dolph BA, Cleveland CN, Keller MM, Feeley TH. Educational animations to inform transplant candidates about deceased donor kidney options: an efficacy randomized trial. *Transplant Direct.* 2020;6:e575.
50. Shellmer DA, Dew MA, Mazariegos G, DeVito Dabbs A. Development and field testing of Teen Pocket PATH(®), a mobile health application to improve medication adherence in adolescent solid organ recipients. *Pediatr Transplant.* 2016;20:130-140.
51. Stonnington CM, Darby B, Santucci A, et al. A resilience intervention involving mindfulness training for transplant patients and their caregivers. *Clin Transplant.* 2016;30:1466-1472.
52. Yan L, Lin J, Zhao C, Xiong C. The effects of collaborative care model (CCM) guided nursing practice on the self-management and self-efficacy of kidney transplant recipients. *Int J Clin Exp Med.* 2021;14:356-364.
53. Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist.* 1986;26:260-266.
54. Novak M, Guest C. Application of a multidimensional caregiver burden inventory. *Gerontologist.* 1989;29:798-803.
55. Lerret SM, Weiss ME, Stendahl G, et al. Transition from hospital to home following pediatric solid organ transplant: qualitative findings of parent experience. *Pediatr Transplant.* 2014;18:527-537.
56. Lerret SM, White-Traut R, Medoff-Cooper B, et al. Pilot study protocol of a mHealth self-management intervention for family members of pediatric transplant recipients. *Res Nurs Health.* 2020;43:145-154.
57. Taylor LA, Bahreman N, Hayat MJ, Hoey F, Rajasekaran G, Segev DL. Living kidney donors and their family caregivers: developing an evidence-based educational and social support website. *Prog Transplant.* 2012;22:119-128.
58. Haspeslagh A, De Bondt K, Kuypers D, Naesens M, Breunig C, Dobbels F. Completeness and satisfaction with the education and information received by patients immediately after kidney transplant: a mixed-models study. *Prog Transplant.* 2013;23:12-22.
59. Moloney S, Cicutto L, Hutcheon M, Singer L. Deciding about lung transplantation: informational needs of patients and support persons. *Prog Transplant.* 2007;17:183-192.
60. Kunzler AM, Helmreich I, Chmitorz A, et al. Psychological interventions to foster resilience in healthcare professionals. *Cochrane Database Syst Rev.* 2020;7:Cd012527.
61. Lepore SJ, Revenson TA. Resilience and posttraumatic growth: recovery, resistance, and reconfiguration. In: Calhoun LG, Tedeschi RG, eds. *Handbook of posttraumatic growth: Research & practice.* Lawrence Erlbaum Associates Publishers; 2006:24-46.
62. Palacio GC, Krikorian A, Gómez-Romero MJ, Limonero JT. Resilience in Caregivers: a Systematic Review. *Am J Hosp Palliat Care.* 2020;37:648-658.
63. Dias R, Santos RL, Sousa MF, et al. Resilience of caregivers of people with dementia: a systematic review of biological and psychosocial determinants. *Trends Psychiatry Psychother.* 2015;37:12-19.

#### SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

**How to cite this article:** Jesse MT, Gartrelle K, Bruschein H, et al. Non-pharmacological interventions engaging organ transplant caregivers: A systematic review. *Clin Transplant.* 2022;e14611. <https://doi.org/10.1111/ctr.14611>