

BMJ Open Challenges and support needs among family caregivers involved in solid organ transplant care process: a scoping review protocol

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ABSTRACT

Introduction Family caregivers play an indispensable role in the care of solid organ transplant patients, undertaking a wide range of tasks from basic daily care to complex medical management. However, these responsibilities come with substantial challenges, placing additional strain on caregivers who bear significant physical, emotional, financial and social burdens, along with numerous unmet support needs. Currently, the exploration of challenges and support needs among family caregivers in the caregiving process is limited to primary research, lacking a synthesised and comprehensive understanding of the issues. Therefore, the aim of this scoping review is to summarise the available evidence to accentuate the diverse challenges encountered by family caregivers and to identify their specific supportive needs, while also pinpointing the areas of research that have yet to be explored.

Methods and analysis Following the Joanna Briggs Institute methodology and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews, this review will be conducted. The initial search of PubMed to identify keywords was conducted on 16 November 2024. Additionally, Web of Science Core Collection, ProQuest, Scopus, CINAHL (EBSCOhost), China National Knowledge Infrastructure (CNKI) and China Wan Fang database will be systematically searched for relevant literature. No language or date restrictions will be applied. Two reviewers will independently screen the articles based on title, abstract and full text. Data extraction and analysis of results will be presented in tables or graphs.

Ethics and dissemination Ethical approval is not necessary for this scoping review. The study findings will be published in open-access journals after peer review. These findings will provide information for healthcare providers to alleviate the plight of family caregivers and to pave the way forward towards more resilient caregiver support systems.

INTRODUCTION

Solid organ transplantation is a life-saving intervention for patients with end-stage organ failure. The process involves the surgical replacement of the diseased organ, such as the heart, lung, liver and kidney, with

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ To our knowledge, this is the inaugural comprehensive review focusing on the experience of family caregivers involved in solid organ transplantation.
- ⇒ To expand the source material of this study, we will also conduct searches in Chinese databases and consolidate research surveys encompassing family caregivers from China, with the aim of minimising the impact of geographical restrictions.
- ⇒ This scoping review will be conducted following the Joanna Briggs Institute methodology and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews.
- ⇒ There will be no assessment of the quality of the studies included.

a healthy organ from a living or deceased donor.¹ It is a complex medical procedure that demands a rigorous pretransplant evaluation, a delicate surgical operation and an intensive postoperative recovery phase. The success of transplant procedures relies significantly on comprehensive caregiving, with family caregivers playing a vital role.² Caregiving for solid organ transplant patients encompasses a wide range of complex tasks and responsibilities.³ Initially, family caregivers deal with the stress of waiting for a donor organ and the preparation for surgery.⁴ Post-transplant, the focus shifts to managing immunosuppressive medication, monitoring for signs of organ rejection and infection and addressing lifestyle changes and psychosocial adjustments.⁵

Throughout the caregiving journey, family caregivers will confront a myriad of challenges that profoundly affect their quality of life. Particularly, with solid organ transplants, these challenges are amplified owing to the intricate medical and psychological requirements of the patients. These challenges may manifest as substantial physical and financial strains resulting from the intensity of



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caregiving, changes in employment status, disruption of personal plans and the costs associated with care.^{6–8} Additionally, the uncertainty surrounding transplant outcomes, along with the potential for organ rejection and complications, can compound the emotional burden on caregivers, leading to heightened levels of anxiety and depression compared with the patients.⁹ Furthermore, when caregivers' needs for knowledge, respite or emotional support are unmet, their ability to effectively care for patients may be compromised, thereby intensifying their own stress and potentially impacting patient outcomes.^{6 10}

The need for social support in the context of solid organ transplantation varies significantly among individuals and is influenced by a multitude of factors, which include the family caregivers' personal background, cultural beliefs, family dynamics, and the specific challenges they face during the pretransplant and post-transplant periods.^{7 11 12} Previous studies have highlighted the multifaceted support needs of organ transplant caregivers, spanning educational, psychological, emotional, and practical domains.^{7 11 13} Family caregivers of lung transplant candidates, for instance, have highlighted the necessity for increased support in healthcare communication, understanding what to anticipate going forward, and facing the array of financial and work-related challenges that arise during the caregiving process.⁷ Similarly, caring for patients after living donor liver transplantation revealed the emotional and physical demands on caregivers, as well as the need for comprehensive care plans.⁸ Organ transplant recipients reported fatigue, lack of energy, and tremor as the major symptoms, indicating a need for caregivers to understand patient experiences for better care management.^{14 15} It is evident from these studies that a diverse array of needs persists, highlighting gaps in current resource provision. These unmet needs can significantly impact the quality of life and overall well-being of caregivers.^{16 17} Therefore, to identify and address the social support needs of family caregivers is essential for sustaining their quality of life.¹⁸ Given the variability in social support needs of family caregivers, the significance of employing tailored approaches that address the unique needs of each patient and their family caregivers becomes evident.¹⁹ A personalised approach can enhance the effectiveness of support interventions and contribute to better overall outcomes.

It is a well-known fact that family caregivers play a vital role for solid organ transplant candidates or recipients. The 2019 Organ Transplant Caregiver Initiative brought attention to the significant impact of caregiving on caregivers, making it a focal point of current research.²⁰ A systematic review outlined the effects of non-pharmacological interventions on caregiver-reported outcomes, pointing to a shortage of focused interventions and unmet needs.²¹ To address this issue effectively, it is vital to delve into the root causes. This entails comprehending caregivers' experiences, the challenges they face and identifying their support needs, all of which are

crucial stages in prioritising outcomes that hold significance for them. However, to the best of our knowledge, despite the abundance of primary studies, there has not yet been synthesised into a comprehensive review, leading to fragmentation and repetitiveness. This gap poses a challenge for policymakers and practitioners in gaining a comprehensive understanding of caregiver needs, thereby impeding the development of suitable support and services.

The review will serve to collate and consolidate findings from a variety of sources, thereby providing a more holistic understanding of family caregivers' challenges and support needs. The knowledge gained can inform healthcare providers and policymakers in designing and implementing more effective support services that are attuned to caregivers' evolving needs. Additionally, recognising the gaps elucidated herein can steer future research towards filling these voids, thereby enhancing the well-being of both caregivers and transplant recipients.

Review questions

The research questions for the scoping review delve into exploring the experiences of family caregivers during their involvement in solid organ transplant care based on the existing literature. The subquestions are as follows:

1. What are the challenges and difficulties faced by family caregivers during their involvement in solid organ transplant care?
2. What does the existing literature show about the support needs of family caregivers during their involvement in solid organ transplant care?
3. To identify barriers to accessing support of family caregivers and assessing the impact of the care process on their well-being.
4. What are effective interventions and implementation strategies for family caregivers?

METHODS AND ANALYSIS

A preliminary search was carried out on PROSPERO, PubMed, China National Knowledge Infrastructure (CNKI), the Cochrane Database of Systematic Reviews and Joanna Briggs Institute (JBI) Evidence Synthesis. No existing or ongoing scoping reviews or systematic reviews on the topic were discovered.

The scoping review is planned to begin on 1 December 2024, and is expected to be completed by 30 December 2025. The planned scoping review will follow the JBI methodology²² and adhere to the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for Scoping Reviews.²³

Inclusion criteria

Participants

This review will consider studies involving family caregivers (aged 18 or older) who are engaged in the solid organ transplant process, providing care to individuals undergoing evaluation, on the waiting list or post-transplantation.

Concept

All articles exploring family caregivers' experiences during the transplant care process will be considered, focusing on the challenges encountered and support needed by these caregivers. Considering the substantial caregiving responsibilities they shoulder, family caregivers inevitably face a multitude of challenges and difficulties, encompassing physical, psychosocial, emotional, social and financial strains. Their support needs encompass a wide array of unmet requirements throughout the caregiving journey, including informational gaps, caregiving skills, social support, financial burdens, psychological distress and physical care demands.

Context

This review will consider studies conducted in various settings, such as hospitals, care institutions, homes, or other care facilities. Based on the variations in transplant practices and policies among national transplant ecosystems, assess the impact of these differences on patients and family caregivers.

The main variations among national transplant ecosystems may encompass multiple aspects, including allocation strategies for transplant medical resources, the professionalism of transplant technology and services, the diversity of sociocultural perspectives and variations in economic conditions.^{24–27} These variations potentially lead to an uneven distribution of public health resources and directly impact patients' treatment options and rehabilitation pathways. In light of this, it is particularly crucial to gain a comprehensive understanding of these differences among national transplant ecosystems. Each country should adapt its policies and measures based on its own unique circumstances to enhance the accessibility and quality of transplant services and ensure that more patients can benefit from them.

Types of sources

This scoping review will encompass quantitative, qualitative and mixed methods study designs. Moreover, primary studies, reviews, editorials and expert opinions will be taken into account for inclusion.

Search strategy

The search strategy will target published studies. An initial restricted search of PubMed was conducted on 16 November 2024, to identify relevant articles. The text words found in the titles and abstracts of relevant articles, as well as the index terms used to describe the articles, were used to create a comprehensive search strategy for PubMed. The search terms used included: ("organ transplant*" OR "solid organ transplant*" OR "lung transplant*" OR "heart transplant*" OR "liver transplant*" OR "kidney transplant*" OR "renal transplant*") AND ("caregivers" OR "family caregivers" OR "informal caregivers" OR "relatives" OR "spouse") AND ("needs" OR "experience" OR "challenges" OR "difficulties" OR "barriers"). This search strategy, comprising all identified keywords

and index terms, was customised for each information source included. Additionally, the reference lists of articles will be reviewed for supplementary articles, and the search strategy will not be limited by language and date.

The databases to be searched will encompass PubMed, Web of Science Core Collection, ProQuest, Scopus, CINAHL (EBSCOhost), CNKI, and China Wan Fang Database (refer to Supplementary file: online supplemental appendix A).

Study/source of evidence selection

After conducting the search, all identified records will be consolidated and uploaded into EndNote V.20 (Clarivate Analytics, Pennsylvania, USA), with duplicates being removed both automatically and manually. Subsequently, following a pilot test, two independent reviewers will screen titles and abstracts for compliance with the review's inclusion criteria. Potentially relevant papers will then be retrieved in full, and their citation details will be imported into Covidence software (Veritas Health Innovation, Melbourne, Australia). The full text of selected citations will undergo a detailed assessment against the inclusion criteria by two independent reviewers. Any reasons for excluding full-text papers that do not meet the inclusion criteria will be documented and reported in the scoping review. Any discrepancies that may arise between the reviewers at each stage of the selection process will be resolved through discussion or by involving a third reviewer. The findings of the search will be thoroughly reported in the final scoping review and illustrated in a PRISMA flow diagram.²⁸

Data extraction

Two independent reviewers (SH and NH) will use Microsoft Excel (Redmond, Washington, USA) to develop a preliminary data extraction form and extract data from relevant papers. The scoping review and data extraction process will adhere to the JBI template tool. An initial extraction form can be found in Supplementary file (online supplemental appendix B). This preliminary form will be adjusted and refined as needed while extracting data from each included paper, with any modifications being documented in detail in the comprehensive scoping review. Any discrepancies between the reviewers will be addressed through discussion or by consulting a third reviewer. In cases where necessary, authors of papers will be contacted to obtain missing or additional data.

Data analysis and presentation

The extracted data will be organised and presented using Microsoft Excel, while the article screening process will be visually depicted in a flowchart. Additionally, NVivo V.12 Plus software will be employed for data analysis and thematic integration. A concise three-line table will showcase the characteristics of each type of data in the scoping review results. The articles will undergo detailed scrutiny, focusing on extracting key findings related to the challenges and support needs of family caregivers in the transplant care process.

Patient and public involvement

This study does not involve patients or the general public.

Ethics and dissemination

Ethical approval is not necessary for this scoping review. Once the study findings undergo peer review, they will be published in open-access journals. These results will offer valuable information for health-care providers in addressing the challenges faced by family caregivers and in developing stronger support systems. The insights derived from this scoping review will also contribute to the enhancement of personalised care provided to family caregivers at our transplant centre.

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