






BMJ Open Self-management in adults after solid-organ transplantation: a scoping review protocol

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ABSTRACT

Introduction After solid-organ transplantation (SOTx), recipients must adhere to a lifelong medical regimen, change their lifestyle and cope with physiological and psychosocial challenges. This requires active participation in their care and self-management abilities. The concept of self-management after SOTx has only been described regarding specific organs and focused on adherence to medical treatment. A comprehensive conceptualisation of self-management entailing all solid organs and beyond medical aspects does not exist. This might lead to unmet self-management support needs of SOTx recipients and hinder a more holistic and integrative approach in self-management support. Therefore, a better understanding of the concept of self-management after SOTx is needed to facilitate a comprehensive evidence base for healthcare providers and researchers. The purpose of this scoping review is to explore existing evidence on self-management in adults after SOTx.

Methods and analysis To identify relevant evidence, six electronic databases and three study registers will be searched, supplemented by handsearches, reference checking and expert recommendations. Screening and selection of available evidence will be carried out in a two-step process by two independent reviewers. International evidence published in English or German reporting on adults after heart, lung, liver, pancreas, kidney or small bowel transplantation will be considered. To meet inclusion criteria, articles have to focus on either: self-management, self-management support or recipients' or healthcare providers' perspectives of challenges and needs potentially addressable by self-management. Data extraction will be performed by two reviewers independently using a structured form. Data will be analysed descriptively and using content analysis procedures. Findings will be summarised narratively and presented in tabular format.

Ethics and dissemination The consultation and approval of an ethics committee is not required for this scoping review. Findings of the scoping review will be published in a peer-reviewed open-access journal and presented at conferences.

INTRODUCTION

Solid-organ transplantation (SOTx) is the optimal therapy for end-stage organ diseases. It is a well established, complex procedure that

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ To the best of our knowledge, our scoping review will be the first overarching evidence synthesis on self-management of solid-organ transplant recipients.
- ⇒ Planning and conducting of this scoping review is based on recommendations of the Joanna Briggs Institute and other recent methodological guidance.
- ⇒ Our comprehensive, sensitive search strategy was developed in cooperation with experienced librarians and will consider a wide range of bibliographic databases and study registers, and is not limited to specific study designs or time period.
- ⇒ The search strategy, the screening process and data extraction will be piloted, discussed with experts and adapted as necessary to increase their feasibility and reliability.
- ⇒ No quality assessment of the included evidence will take place—this is in line with accepted methodological recommendations on scoping reviews. The results of the review are to be interpreted accordingly.

comprises the transplantation of kidney, heart, lung, liver, pancreas and small bowel.¹ SOTx is life-saving, cost-effective and increases the quality of life and social functioning of recipients.^{2–5} After a steady increase since 2005, the global number of SOTx reached a peak of 163 141 transplantations in 2019 before the number decreased to 137 000 in 2020, presumably due to the COVID-19 pandemic.⁶ Encouragingly, given the advances in SOTx and the resulting decline in mortality rates, the number of recipients attributable to long-term care is accumulating.⁷

However, SOTx is a treatment and not the cure of a chronic disease. Contrarily, SOTx recipients need to implement fundamental lifestyle changes and be adherent to a complex medical regimen in order to prevent graft rejection, infections and secondary complications.^{8–10} Furthermore, recipients face various psychological, physiological and

social difficulties and challenges after SOTx such as fear and anxiety concerning graft loss, fatigue and distressing medication side effects, or social isolation due to infection prevention.¹¹ Lifelong medical follow-up in cooperation with healthcare providers and self-management of recipients is required to manage and cope with the situation post transplantation and to maintain health and quality of life.^{9 10 12}

Self-management is defined as the ‘individual’s ability, in conjunction with family, community and the appropriate healthcare professionals, to successfully manage the symptoms, treatment, physical, psychosocial, cultural and spiritual consequences and inherent lifestyle changes required for living with a long-term chronic disease’.¹³ Conceptually, self-management is closely linked to other terms or concepts, such as self-care or self-monitoring. Even though there is sometimes no clear conceptual distinction between these terms, self-management is mostly used in relation to illness.¹⁴ Self-management has been interpreted as a behaviour inherent to the human being, which is undertaken as a matter of course, but which can be expressed differently according to the will or motivation of the individual.¹⁵ Furthermore, self-management has to be based on problems and needs of individuals affected by a chronic condition¹⁵ and influenced by the individuals’ self-efficacy and health literacy.^{14 16}

Previous research suggests that some SOTx recipients struggle with the implementation of necessary self-management tasks and lifestyle changes^{11 17–22} and therefore need self-management support.^{11 17 23–25} Literature review findings suggest that the majority of self-management support interventions mainly focus on treatment and medication adherence after SOTx.^{26–32} Such a focus is justifiable given the serious consequences associated with non-adherence to post transplant recommendations.^{33 34} However, there is evidence to suggest self-management needs extend beyond adherence and medical therapy. Research revealed psychological (emotional and spiritual), relational and social support needs.^{11 24} A potential explanation for this is the fact that self-management after transplantation is only partially conceptualised and thus lacks a theoretical basis for further supportive interventions.

The most comprehensive conceptualisation for self-management after transplantation to date exists for kidney recipients and has been presented in a ‘conceptual model of the (renal) transplant recipients’ self-management’ by Schäfer-Keller *et al.*³⁵ This model is based on research on the self-management of chronically ill patients^{15 36} and has been translated into the specific needs of renal transplant recipients on the transplant trajectory. Self-management tasks following renal transplantation can be broadly divided into three categories: managing (1) the medical regimen, (2) emotions and (3) (new) life roles. These categories are embedded in, and influenced by, contextual factors and individuals affected by self-management. Factors may include but are not limited to the transplant recipients themselves, their families

and healthcare professionals, but also other stakeholders such as transplant communities and health systems.³⁵ Additionally, the Schäfer-Keller model incorporates core self-management skills according to Lorig and Holman that are necessary to perform self-management.¹⁵ The model initially specified tasks in the area of managing the medical regimen. Other self-management-related categories, that is, managing emotions and managing (new) life roles, have been explored and defined to a lesser extent. In this respect, the model was extended to include the perspective of renal transplant recipients. Nevertheless, conceptualisation still reveals gaps.³⁷ Concerning other types of transplanted organs we could solely identify a study by Beckmann *et al.*³⁸ that adapted the Schäfer-Keller model for liver transplant recipients and one narrative review, also including recipients of liver transplant, which aimed to synthesise evidence concerning self-management on a conceptual level.²² A comprehensive overview covering the concept of self-management across all SOTx population could not be identified. As outlined above, conceptualisations of self-management exist either on a superordinate or macro level in so far as tailoring to population groups, based on research on chronic diseases or sporadically on a microlevel specific for kidney and liver transplant patients. The conceptualisation on an intermediate or mesolevel, related to all solid-organ types, remains unclear. Although recipients of different organ types certainly have specific self-management needs, it stands to reason that on a meso level there are more similarities than differences. In this respect, we agree with van Zanten *et al* who postulated that ‘self-management support is important for all transplant recipients regardless of the organ’³⁹ and assume that there is a common ground regarding self-management for all SOTx recipients. In addition, transplant recipients differ from those affected by chronic conditions by the fact that they are supposed to experience an amelioration in health status by a procedure, that is, SOTx, rather than a steady decline in health status by which most other chronic conditions are characterised. Therefore, it seems difficult to transfer overarching self-management concepts to this population without negotiating aspects specific to transplantation.

The dearth of such meso level syntheses in the field of SOTx risks missing important unmet self-management support needs of SOTx recipients and, in turn, preventing a more holistic attempt to provide self-management support. Thus, a better understanding of the concept of self-management after SOTx is needed to facilitate a comprehensive evidence base for healthcare providers and researchers to support adult recipients in their self-management after SOTx. The Schäfer-Keller model can serve as a reference point for this endeavour.⁴⁰

Overarching review objective

As part of a large-scale research project, an intervention to support self-management of recipients after SOTx will be developed and tested (SMART-study).⁴¹ The evidence

synthesis outlined here represents the first step in the intervention development process by delineating the concept of self-management in adults after SOTx and gathering information on associated needs and existing support.

Two objectives are derived from this: (1) To explore existing evidence on self-management and self-management support in adults after SOTx and (2) to identify challenges and/or needs related to life after SOTx that are amenable to be addressed by self-management.

METHODS AND ANALYSIS

Design

A scoping review (ScR) will be conducted. An ScR is a specific systematic form of evidence synthesis that is suitable for exploring, mapping and summarising literature to identify or clarify concepts and their characteristics.^{42 43} Concept clarification can be seen as the overarching methodological background for this ScR.^{44 45}

The development and reporting of this ScR protocol is based on the framework of Arksey and O'Malley⁴⁶ and was guided by the recommendations of the Joanna Briggs Institute,⁴⁷ and further current methodological literature.^{43 48} Reporting of this protocol is informed by relevant items of the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocol (PRISMA),⁴⁹ with adaptations as recommended by Peters *et al.*⁵⁰

ScR questions

The main review questions are: (1) what is the current state of evidence on the concept of self-management in adults after SOTx and (2) which potential challenges or

needs related to life after SOTx that are amenable to be addressed by self-management from the perspectives of adult SOTx recipients or healthcare providers are indicated in the literature?

These questions were split into the following sub-questions that were structured according to the Population, Concept and Context framework⁴³:

1. How is self-management after SOTx defined, operationalised or conceptualised and which are core aspects associated with self-management after SOTx? (Concept, Population)
2. Which are needs, requirements, problems or challenges in relation to life after SOTx either from the perspective of adult SOTx recipients or healthcare providers? (Concept, Population)
3. How many self-management support interventions are reported? (Concept)
4. In which contexts (temporal, geographical) has the concept of self-management after SOTx been studied to date? (Context)
5. Which research methodologies are used in the eligible evidence and which publication types are provided? (Context)

Eligibility criteria

This ScR seeks to retrieve evidence on self-management of adult SOTx recipients. According to this purpose, eligibility criteria have been developed on the basis of the review questions and the elements of the Population, Concept and Context framework. [Table 1](#) presents all the criteria in detail.

Inclusion criteria	Exclusion criteria
Types of participants	
▶ At least 18 years old; and after human SOTx (heart, lung, liver, pancreas, kidney or small bowel transplantation, including combined forms)	▶ Younger than 18 years; or 'mixed' samples (eg, participants with 14–25 years of age); or individuals without transplantation, before transplantation (listed), or recipients of tissue/composite tissue, cell, alloplastic, uterus or xenotransplantation; or animal studies
Concept	
▶ Focused on self-management or associated concepts (eg, self-care, self-monitoring, self-efficacy); or aspects of maintaining one's own health or well-being or coping with illness (based on the definition of self-management by Wilkinson and Whitehead ¹³ and the classification of 'everyday problems' ⁵¹) that can be modified, controlled, influenced or performed by SOTx recipients without immediate assistance; or needs, requirements, problems, or challenges in relation to life after SOTx either from the perspective of recipients (eg, needs, problems) or healthcare providers (eg, tasks) that are amenable to be addressed by or associated with self-management	▶ Self-management or associated concepts are not the key concepts and related concepts/terms are mentioned but without any relevant reference to any of the questions of the ScR; or interventions in which SOTx recipients are involved or are the target group, but which are not aiming at supporting them to act themselves (eg, testing the effectiveness of a specific medication for SOTx recipients); or problems/requirements from the point of view of healthcare providers that can only be addressed by them ('treatment')
Context	
▶ Healthcare settings from all regions and countries worldwide regardless of cultural background or level of industrial development of the country of origin	▶ Self-management or self-care in the context of a discipline other than healthcare (eg, business, education)
Types of evidence sources	
▶ Published evidence (primary studies, evidence syntheses, ongoing studies/study protocols, letters to the editor(s), conference papers) of all designs and research methods; and language of evidence: English or German*	▶ Books/Book chapters/Book reviews, websites, commentaries, posters, editorials, abstracts or unpublished evidence/grey literature
*Linguistic eligibility criteria are only applied in full-text screening. SOTx, solid-organ transplantation.	

Inclusion criteria in the Concept domain are based on definitions of self-management by Wilkinson and Whitehead¹³ and the classification of ‘everyday problems’⁵¹ and self-management support by Orrego *et al.*⁵²

Search strategy and information sources

In collaboration with a team of experienced librarians (PZ, JW, SB), we developed a comprehensive and sensitive literature search strategy. Initially, a search on Medline (PubMed) and Google Scholar using central terms (“self-manage*” and “solid organ transplant*”) identified evidence that was analysed by the research team in order to extract relevant keywords. In parallel, a review and analysis of frameworks pertinent to, and definitions of, the concept of self-management^{14 15 53–68} identified further keywords. This iterative process resulted in a search strategy based on three conceptual building blocks of terminology related to “SOTx”, “self-management” and the “perspective of recipients/HCP” and was operationalised for an initial search on Medline (Ovid) (online supplemental file 1). All identified keywords and MeSH (medical subject headings) terms were collected, merged and discussed in group sessions. The search strategy was reviewed and validated by an information retrieval specialist (KG) using the Peer Review of Electronic Search Strategies guideline.⁶⁹ The final Ovid search strategy will be adapted to search the following electronic databases: Medline (OVID), CINAHL (EBSCO), PsycINFO (EBSCO), Emcare (OVID), Web of Science (Clarivate) and the Cochrane Library (Wiley). Searches will be conducted from inception to September 2021. The time period to be searched on the respective databases will not be limited due to the explorative nature of this ScR and its purpose to discover the breadth of the literature of the evidence concerning self-management after SOTx.^{43 70} In addition, searches for ongoing or completed and not published studies will be conducted on ClinicalTrials.gov (www.clinicaltrials.gov), WHO International Clinical Trials Registry Platform (www.who.int/ictpr/search) and the DRKS (the German study register; www.drks.de). Reference lists of included studies will be screened in order to identify additional relevant studies. The search will be complemented by recommendations of experts in the field and forward citation tracking on the basis of included study protocols and study registry entries.

Selection of evidence

All records identified will be deduplicated via EndNote reference manager⁷¹ and the Systematic Review Accelerator.⁷² Study selection will be executed by a team of five reviewers (SJ, JS, LW, AR and JT) based on the eligibility criteria. Relevant evidence will be selected in a two-step approach using Covidence.⁷³ First, titles and abstracts of the identified records will be screened and irrelevant references excluded. Second, full texts of all potentially eligible records will be retrieved and reviewed for final inclusion. Both steps will be performed by two reviewers independently. Any disagreements between reviewers will

be resolved through discussion. If no consensus can be reached, a third reviewer (AR) will be consulted. Reasons for excluding studies in the full-text screening stage will be reported.

Prior to each step of the screening process (title/abstract and full text), all reviewers will screen a random set of 25 records in stages of the initial search strategy and title/abstract screening. Results of this pilot screening will be discussed by the whole research team, discrepancies will be addressed, and necessary changes concerning the eligibility criteria or supporting guidance documents implemented. During the screening phase, reviewers meet biweekly to resolve conflicts or questions.

Data extraction

Data extraction will be performed via Covidence by the research team.⁷³ Each included full text will be extracted by two reviewers independently. Consensus of extracted data will be formed by a reviewer with expertise in self-management and SOTx (AR or SJ). Reviewers will use a structured data extraction form including the following elements, which are based on the recommendations by Peters *et al.*⁴⁷ and Pollock *et al.*⁷⁴:

- ▶ First author (last name).
- ▶ Year of publication.
- ▶ Origin/country of origin.
- ▶ Type of article.
- ▶ Methodologic approach (research design).
- ▶ Aim/purpose.
- ▶ Type of transplant.
- ▶ Country of origin of study population.
- ▶ Sample size (in case of evidence syntheses number of included studies).
- ▶ Definition or conceptualisation of self-management after SOTx.
- ▶ Aspects associated with self-management after SOTx.
- ▶ Reporting on a self-management (support) intervention.
- ▶ Problems, challenges or needs, amenable to be addressed by self-management (from the perspective of healthcare professionals or recipients).
- ▶ Comments.

In a pilot phase, every reviewer will extract four methodologically different full texts to ensure adequacy of the data extraction form. Results will be discussed and the form will be adapted if necessary.

Analysis of the evidence

Extracted data will be analysed descriptively using frequency counts and mapped by means of basic coding to specific categories. Qualitative data, that is, textual data in the form of sentences, half-sentences or combinations of words describing aspects or problems concerning self-management will be categorised by means of basic content-analytical procedures.^{75 76} Content analysis will follow an deductive-inductive approach. First, data will be categorised according to a pre-developed coding frame that will be grounded in existing evidence self-management after

organ transplantation and developed by the research team. Its basic structure will correspond to the 'tasks' and 'skills' according to the description of Lorig and Holman and Corbin and Strauss, as it is also depicted in the Schäfer-Keller model, in order to enable a later comparison with it.^{15 35 36} Data that cannot be assigned to any of these pre-existing categories will be analysed inductively. Finally, emerged categories and subcategories will be compared with the content of the Schäfer-Keller model³⁵ in the sense of the 'best fit' framework synthesis.^{77 78}

Data concerning different organ types will not be distinguished in the analysis at this point and will be abstracted to a common level (mesolevel). While this somewhat limits the explanatory power regarding specific self-management aspects of different organ types, it is nevertheless consistent with one of the goals of ScR to provide an overview in order to explore or clarify concepts and definitions.^{43 79} However, indications of specific aspects are likely to become possible through descriptive subgroup analyses (related to different organ types).

In line with current methodological recommendations, assessment of the quality of included evidence will not take place because the purpose of this ScR is to 'map the available evidence rather than provide a synthesised and clinically meaningful answer to a question' or to the effectiveness of interventions.⁴³

Presentation of the results

The process of search and selection of evidence will be depicted in a flow diagram as recommended by the PRISMA Extension for ScR (PRISMA-ScR).⁸⁰ The results will be presented in tables and narrative summaries. In addition, data will be presented in tabular, and graphical forms as appropriate (eg, diagrammatic models and maps, word clouds).

DISCUSSION

This protocol describes the process of a planned ScR to conceptualise self-management after SOTx. The basis of this conceptualisation will be international literature identified through a sensitive and comprehensive literature search. Based on this and the quantitative and qualitative data contained therein, the concept of self-management after SOTx will be described at this meso population level. This descriptive overview will attempt to summarise the core elements of the concept across all solid organ types. However, this will limit the meaningfulness of specific aspects of different organ types. Nevertheless, the planned approach will provide an evidence base that can then be used as a starting point for further research and further theoretical refinement and testing in this field. Findings will also inform healthcare practice to ultimately improve the support for organ transplant recipients. This ScR focuses on an adult population which will not allow conclusions to be drawn about paediatric or adolescent recipients. This focus is reasoned by the distinctness of children from adults in terms of organ

transplantation and self-management and specific corresponding needs and challenges.^{81–85} Another limitation is that only German-language and English-language evidence will be included; relevant findings from evidence written in other languages may thus be neglected. Under certain circumstances, this can lead to relevant findings being overlooked. Nevertheless, our broad approach promises that a large part of the relevant sources will be taken into account. Finally, there will be no assessment of the quality of the included evidence. Even if this is not recommended for ScR, the results are to be interpreted accordingly later.^{43 76} Any changes or deviations from this protocol will be reported in detail in an anticipated publication of the results of the ScR.⁵⁰

Patient and public involvement

Patients or the public are not involved in this ScR.

Ethics and dissemination

The consultation and approval of an ethics committee is not required in the case of this research project, which only uses secondary data available from public sources. We plan to publish the results of the evidence syntheses described here in a peer-reviewed open-access journal and present our results at conferences. Reporting of results will follow the recommendations of the PRISMA-ScR extension.⁸⁰

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