# Lung transplant recipients' experiences of and attitudes towards self-management: a qualitative systematic review protocol.

## Background

Lung transplantation (LuT) is an established treatment to improve the survival of patients with end-stage lung diseases and has been performed in over 40,000 patients worldwide.[1,2] Lung transplantation is performed in patients suffering from a variety of lung diseases such as chronic obstructive pulmonary disease, bronchiectasis, cancer, connective tissue disease, idiopathic interstitial pneumonia, interstitial lung disease, pulmonary arterial hypertension, lymphangioleiomyomatosis, obliterative bronchiolitis, sarcoidosis, other lung diseases or retransplant.[3] Eligible for transplant are patients with one of the above end-stage lung diseases who meet all of the following criteria: (1) High (>50%) risk of death from lung disease within 2 years if LuT is not performed, (2) high (>80%) likelihood of surviving at least 90 days after LuT and (3) high (>80%) likelihood of 5-year post-transplant survival from a general medical perspective provided that there is adequate graft function.[4] There are various absolute and relative contraindications including but not limited to untreatable dysfunction of another major organ system or non-adherence to medical therapy. A recent review indicates that LuT substantially improves quality of life, especially in the domains of physical health and functioning.[5] Over recent years, survival time after receiving a lung transplant has improved significantly, with 79% of all lung transplant recipients surviving the first year after transplantation. The median survival of patients is now about eight years following LuT.[3]

Despite the undoubted benefits of LuT, it is not a ‘cure’ for end-stage lung diseases.[6] Similar to other solid organ transplant recipients, the focus of care for lung transplant recipients has shifted from the direct postoperative phase to one of long-term follow-up.[7] Lung transplant recipients are increasingly regarded as chronically ill patients[6] who need to adapt to and follow complex self-management tasks[8] to prevent complications, such as graft rejection or infections, and to enable the patient to keep the transplanted graft as long as possible.[9]

This paradigmatic shift from short to long-term care of lung transplant recipients has resulted in the application of chronic illness management strategies that aim to foster lung transplant recipients’ self-management.[10] Self-management, in this regard, can be defined as an:

> “individual’s ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic condition”.[11(p178)]

To understand self-management after LuT, a conceptual model originally developed in the context of renal transplantation may be useful.[12] This model reports that self-management after transplantation comprises of adherence to a life-long medical regimen including medication-taking,[8,10] self-monitoring of lung function and signs and symptoms of complications,[10,13] and maintaining a healthy lifestyle.[10] The latter requires lung transplant recipients to adapt to various behaviors, which may include fundamental lifestyle changes for individual patients, such as abstaining from harmful substances, keeping medical appointments, refraining from smoking, eating healthily, exercising, and protecting from the sun.[10,12,14] In order to follow these behaviors, lung transplant recipients need to possess and execute a set of skills including action-taking, decision making, problem solving, resource finding and utilization as well as the establishment of partnerships with healthcare providers.[15]

Research has indicated that lung transplant recipients realize the importance of following multi-dimensional self-management behaviors.[16,17] However, research has also shown that self-management is insufficient in many aspects.[9,10,18-21] Of these self-management aspects, medication adherence has been studied most extensively with up to 72% of lung transplant recipients displaying some extent of medication non-adherence at some time.[10,22] Suboptimal implementation of transplant-related self-management is also reported in other self-management tasks including infrequent use of self-monitoring of lung function.[16,19,20,23] Likewise, smoking cessation proves difficult in some lung transplant recipients.[24,25] Consequently, there is a gap between patients' awareness of the need and importance of self-management and individual health-related behavior.

Research in solid organ transplant recipients has shown that adherence to self-management tasks depends on patients' personal experiences and attitudes rather than on non-modifiable factors such as gender, age or ethnicity.[26-28] Qualitative research in renal transplant recipients, for example, has demonstrated that a major driver for medication adherence is experience of dialysis treatment.[29-31] Likewise, lung transplant recipients with cystic fibrosis with prior experience of home spirometry displayed better adherence to home spirometry than other lung transplant patients.[16] Attitudes also play an important role in the self-management of many conditions. In 2003, the World Health Organization[32] identified patients' attitudes as one of several patient-related factors which affected adherence to self-management in patients with HIV[33], epilepsy,[34] and diabetes.[35] In renal transplant recipients, skepticism or medication-related concerns were shown to be associated with inadequate medication adherence.[36,37] A positive, optimistic attitude to life and illness in general was also shown to be an important part of managing ones' everyday life after lung and heart transplantation.[38,39]

Experiences and attitudes, defined as a "tendency that is expressed by evaluating a particular entity with some degree of favor or disfavor"[13(p666)], as well as values, beliefs or knowledge can best be explored using qualitative research methods.[40-42] In the case of solid organ transplant recipients, this has been performed to some extent, however, research has primarily focused on isolated self-management tasks such as medication-taking[28], social adaptation[17], alcohol abstinence[43], smoking cessation [44] or physical activity[45], neglecting the multidimensionality of self-management after solid organ transplantation.[46] Synthesizing qualitative evidence by conducting systematic reviews may deepen our comprehension of how patients perceive and execute self-management. A systematic review on renal transplant recipients' motivations, challenges and attitudes to self-management has been performed recently.[27] However, no qualitative systematic review on any aspect of LuT or on lung transplant recipients' experiences of and attitudes towards self-management could be found in the Joanna Briggs Institute (JBI) Database of Systematic Reviews and Implementation Reports, the Cochrane database of systematic reviews or the PROSPERO international prospective register of systematic reviews.

The reasons for the gap between lung transplant recipients' awareness of the need for self-management and their self-management behavior remain unclear. This review aims to identify lung transplant recipients' experiences of and attitudes towards self-management. The findings of this review will help healthcare practitioners to better understand the challenges their patients face, potentially resulting in more patient-centered education and an increase in lung transplant recipients' self-management abilities.

***Keywords***

lung transplantation; self-management; attitude; experience

## Review Question

What are lung transplant recipients' experiences of and attitudes towards self-management?

## Methods

### Inclusion Criteria

#### *Participants*

This review will consider studies that include persons over 18 years who have received a lung transplant. No restrictions on underlying diseases, gender, ethnicity or length of time since transplant will be imposed. Studies including participants with mixed types of solid organ transplantations will be included where it is possible to accurately identify data on aspects of lung transplant-related self-management separately. Data on self-management

related to other conditions will be excluded. Only studies on participants who are able to perform their self-management tasks independently will be included.

### *Phenomena of Interest*

This review will consider studies on the experiences and attitudes of lung transplant recipients towards self-management.

### *Context*

This review will consider all available evidence on lung transplant recipients worldwide. If this review reveals regional and/or cultural differences in lung transplant recipients' experiences and attitudes towards self-management, these will be explicated in the review.

### *Study Types*

This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, and feminist research. Mixed-methods studies will be included only when qualitative data can be extracted separately.

Studies published in English or German will be considered for inclusion in this review, however studies found in any other languages will be mentioned in the review. No date restrictions will be imposed for inclusion in this review.

### *Search Strategy*

The search strategy will aim to find both published and unpublished studies. An initial limited search of MEDLINE and CINAHL has been undertaken using the terms "lung transplantation", AND "self-management", AND ("attitude" OR "experience"). This was followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. This informed the development of a search strategy which will be tailored for each information source. A full search strategy for MEDLINE is detailed in Appendix 1. The reference list of all studies selected for critical appraisal will be screened for additional studies.

The databases to be searched from their inception will include:

MEDLINE, CINAHL, PsycINFO, EMBASE, Web of Science, British Nursing Index

The search for unpublished studies will include:

Proquest Dissertation & Theses Database, EThOS, Open Grey (Sigle)

## Study Selection

Following the search, all identified citations will be collated and uploaded into Endnote and duplicates removed. Titles and abstracts will then be screened by two independent reviewers

for assessment against the inclusion criteria for the review. Studies that may meet the inclusion criteria will be retrieved in full and their details imported into JBI SUMARI. The full text of selected studies will be retrieved and assessed in detail against the inclusion criteria. Full text studies that do not meet the inclusion criteria will be excluded and reasons for exclusion will be provided in an appendix in the final systematic review report. Included studies will undergo a process of critical appraisal. The results of the search will be reported in full in the final report and presented in a PRISMA flow diagram.[47] Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

## Critical Appraisal

Selected studies will be critically appraised by two independent reviewers for methodological quality in the review using the JBI Qualitative Assessment and Review Instrument.[48] Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. The results of critical appraisal will be reported in narrative form and in a table.

All studies, regardless of the results of their methodological quality, will undergo data extraction and synthesis. Studies rated as “unclear” or “no” in seven or more QARI items will be specified.

### *Data Extraction*

Qualitative data will be extracted from papers included in the review using the standardized data extraction tool[49] from JBI SUMARI by two reviewers. The data extracted will include specific details about the populations, context, culture, geographical location, study methods and the phenomena of interest relevant to the review question and specific objectives. Findings, and their illustrations, will be extracted and assigned a level of credibility. Authors of primary studies will be contacted for clarification or missing information when necessary.

### *Data Synthesis*

Qualitative research findings will, where possible be pooled using JBI SUMARI with the meta-aggregation approach.[48] This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings and categorizing these findings on the basis of similarity in meaning. These categories are then subjected to a synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.

## Assessing Confidence

The final synthesized findings will be graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a

Summary of Findings table.[50] The Summary of Findings table includes the major elements of the review and details how the ConQual score is developed. Included in the table is the title, population, phenomena of interest and context for the specific review. Each synthesized finding from the review is then presented along with the type of research informing it, a score for dependability, credibility, and the overall ConQual score.

### *Conflicts of Interest*

No conflict of interest.

### *Acknowledgements*

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313 **Appendix I: Initial Search Strategy (Medline via Ovid)**

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| Question part | Question term | Search terms |
|---|---|---|
| Population | Lung transplant recipients | lung transpl*[title, abstract] OR "Lung Transplantation"[Mesh] |
| AND | | |
| Phenomena of Interest | Self-management | self managemen*[title, abstract] OR self car*[title, abstract] OR "Self Care"[Mesh]<br>OR<br>“chronic disease”[Mesh] OR chronic illness management[title, abstract] OR chronic illness[title, abstract]<br>OR<br>Decision making[title, abstract] OR “decision making”[Mesh]<br>OR<br>Illness behavio?r[title, abstract] OR “illness behavior”[Mesh]<br>OR<br>Health behavio?r[title, abstract] OR “health behavior”[Mesh]<br>OR<br>Health knowledge[title, abstract] OR “health knowledge, attitudes, practice”[Mesh]<br>OR<br>Adherence[title, abstract] OR “medication adherence”[Mesh] OR compliance[title, abstract] |
| | AND | |
| | Attitude<br>Experience | attitude[title, abstract] OR "Attitude"[Mesh] OR “attitude to health”[Mesh]<br>OR<br>percept*[title, abstract] OR "Perception"[Mesh]<br>OR<br>experience[title, abstract]<br>OR<br>“social support”[Mesh]<br>OR<br>“self concept”[Mesh]) |
| Context | Internationally | n/a |

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