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

3

4 **Background**

5 Lung transplantation (LuT) is an established treatment to improve the survival of patients with  
6 end-stage lung diseases and has been performed in over 40,000 patients worldwide.<sup>1,2</sup> Lung  
7 transplantation is performed in patients suffering from a variety of lung diseases such as  
8 chronic obstructive pulmonary disease, bronchiectasis, cancer, connective tissue disease,  
9 idiopathic interstitial pneumonia, interstitial lung disease, pulmonary arterial hypertension,  
10 lymphangiomyomatosis, obliterative bronchiolitis, sarcoidosis, other lung diseases or  
11 retransplant.<sup>3</sup> Eligible for transplant are patients with one of the above end-stage lung  
12 diseases who meet all of the following criteria: (1) High (>50%) risk of death from lung  
13 disease within 2 years if LuT is not performed, (2) high (>80%) likelihood of surviving at least  
14 90 days after LuT and (3) high (>80%) likelihood of 5-year post-transplant survival from a  
15 general medical perspective provided that there is adequate graft function.<sup>4</sup> There are  
16 various absolute and relative contraindications including but not limited to untreatable  
17 dysfunction of another major organ system or non-adherence to medical therapy. A recent  
18 review indicates that LuT substantially improves quality of life, especially in the domains of  
19 physical health and functioning.<sup>5</sup> Over recent years, survival time after receiving a lung  
20 transplant has improved significantly, with 79% of all lung transplant recipients surviving the  
21 first year after transplantation. The median survival of patients is now about eight years  
22 following LuT.<sup>3</sup>

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

29 This paradigmatic shift from short to long-term care of lung transplant recipients has resulted  
30 in the application of chronic illness management strategies that aim to foster lung transplant  
31 recipients' self-management.<sup>10</sup> Self-management, in this regard, can be defined as an:

32 "individual's ability to manage the symptoms, treatment, physical and  
33 psychological consequences and life style changes inherent in living with a  
34 chronic condition".<sup>11(p178)</sup>

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

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

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

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

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

## 92 **Keywords**

93 lung transplantation; self-management; attitude; experience

## 94 **Review Question**

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

## 96 **Methods**

### 97 **Inclusion Criteria**

#### 98 **Participants**

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

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

### 106 ***Phenomena of Interest***

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

### 109 ***Context***

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

### 113 ***Study Types***

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

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

### 121 ***Search Strategy***

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

130 The databases to be searched from their inception will include:

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

132 The search for unpublished studies will include:

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

### 134 ***Study Selection***

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



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

### 145 **Critical Appraisal**

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

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

### 154 **Data Extraction**

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

### 161 **Data Synthesis**

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

### 169 **Assessing Confidence**

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

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

177 ***Conflicts of Interest***

178 No conflict of interest.

179 ***Acknowledgements***

180 None

181

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312

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

314

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] OR "chronic disease"[Mesh] OR chronic illness management[title, abstract] OR chronic illness[title, abstract] OR Decision making[title, abstract] OR "decision making"[Mesh] OR Illness behavior?[title, abstract] OR "illness behavior"[Mesh] OR Health behavior?[title, abstract] OR "health behavior"[Mesh] OR Health knowledge[title, abstract] OR "health knowledge, attitudes, practice"[Mesh] OR Adherence[title, abstract] OR "medication adherence"[Mesh] OR compliance[title, abstract]
	AND	
	Attitude Experience	attitude[title, abstract] OR "Attitude"[Mesh] OR "attitude to health"[Mesh] OR percept*[title, abstract] OR "Perception"[Mesh] OR experience[title, abstract] OR "social support"[Mesh] OR "self concept"[Mesh])
Context	Internationally	n/a

315