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Review title

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

Abstract

Objective: To identify lung transplant recipients' experiences of and attitudes towards self-management.

Introduction: Lung transplantation 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. The current focus of care for lung transplant recipients is on their long-term management. Patients need to adapt and adhere to complex self-management tasks to prevent complications and to enable them to keep the transplanted graft as long as possible. However, to date no qualitative systematic reviews exist which identify lung transplant recipients' experiences of and attitudes towards self-management, which is the purpose of this review.

Inclusion criteria: The review included persons over 18 years who had received a lung transplant and were able to perform their self-management tasks independently. All studies that investigated the experiences and attitudes of lung transplant recipients towards self-management in any setting where the topic was addressed were included in this review. All types of studies that focused on qualitative data including, but not limited to phenomenology, grounded theory, ethnography, action research and feminist research were considered. Mixed-methods studies were included only when qualitative data could be extracted separately and if they reported results relating to the phenomena of interest. Studies published in English or German were considered for inclusion in this review.

Methods: The search strategy aimed to find published studies from six databases from database inception to March 2022. Methodological quality of studies was independently assessed by two independent reviewers using the JBI checklist for qualitative research. For data collection, the standardized data extraction tool from JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; JBI, Adelaide, Australia) was used by two reviewers. As data synthesis, a meta-aggregation was undertaken and the final synthesis of the findings was reached through discussion. Results are presented as four aggregated qualitative syntheses which were graded according to the ConQual approach.

Results: Ten studies with a sample size from eight to 73 participants from North America and Central/Northern Europe were included in the review. The critical appraisal scores of the included studies varied from three to nine out of 10. A total of 137 findings were extracted and aggregated to form 19 categories and the following four aggregated syntheses: (1) Patients play a pivotal role in their adaptation and self-management. (2) Life after transplantation is characterized by ambiguity. (3) Psychosocial support is an essential aspect of life after transplantation. (4) After transplantation, engaging with others plays a crucial role. Based on the ConQual scores, two synthesized findings were graded as moderate and two as low.

38 **Conclusions:** Nuanced emotional, social, relational and psychological adjustment is required of lung
39 transplant recipients in self-management. Loved ones and health professionals contribute significantly
40 to this process, but psychosocial or peer support may further facilitate this transition.

41 **Systematic review registration number:** <https://doi.org/10.11124/jbisrir-2017-003524>

42 **Abstract word count:** 438 words

43 **Keywords:** *lung transplantation; self-management; qualitative research; systematic review*

44

45 **Summary of Findings**

Lung transplant recipients' experiences of and attitudes towards self-management: a qualitative systematic review					
Synthesized Finding	Type of research	Dependability	Credibility	ConQual score	Comments
Changes in routines, beliefs, and sense of responsibility are essential for better adaptation and self-management after lung transplantation.	Qualitative	Downgrade one level	Downgrade one level	Low	Dependability: Downgraded one level due to common dependability issue across included primary studies (the majority of studies had no statement locating the researcher and no acknowledgment of their influence on the research). Credibility: Downgraded one level due to a mix of unequivocal (U) and credible (C) findings. U = 42, C = 8
Life after transplantation is characterized by both positive and negative feelings and experiences.	Qualitative	No change	Downgrade one level	Moderate	Credibility: Downgraded one level due to a mix of unequivocal (U) and credible (C) findings. U = 39, C = 8
Better adjustment and self-management after a lung transplant require dealing with one's own feelings and beliefs.	Qualitative	Downgrade one level	Downgrade one level	Low	Dependability: Downgraded one level due to common dependability issue across included primary studies (the majority of studies had no statement locating the researcher and no acknowledgment of their influence on the research). Credibility: Downgraded one level due to a mix of unequivocal (U) and credible (C) findings. U = 19, C = 6
After transplantation, engaging with relatives, friends, medical team and donors is essential to improve experiences and adapt to being a transplant recipient.	Qualitative	No change	Downgrade one level	Moderate	Credibility: Downgraded one level due to a mix of unequivocal (U) and credible (C) findings. U = 14, C = 1

46

Introduction

There have been nearly 70,000 lung transplant procedures registered on the International Thoracic Organ Transplant Registry since its inception in 1992.¹ Lung transplantation is now an established treatment for patients with end-stage lung diseases, such as chronic obstructive pulmonary disease, cystic fibrosis, pulmonary fibrosis and other lung pathologies.² Patients eligible for transplant have end-stage lung disease and meet transplantation criteria but there are a variety of absolute and relative contraindications including but not limited to untreatable dysfunction of another major organ system or non-adherence to medical therapy.³ Singer and colleagues⁴ indicated that lung transplantation substantially improves quality of life, especially in the domains of physical health and functioning. 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 and a median survival time of 5.8 years.⁵

Despite the undoubted benefits of lung transplantation, it is not a 'cure' for end-stage lung diseases.^{6,7} 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 patients⁶ who need to adapt to and follow complex self-management tasks⁸ to prevent complications, such as graft rejection or infections, and to enable the patient to maintain a healthy 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 (p. 178)

To understand self-management in the context of lung transplant, a conceptual model 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 various behaviors, which may include abstinence from harmful substances, attending medical appointments, refraining from smoking, eating healthily, exercising, and avoiding exposure to the sun.^{10,12,14} Hence 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.^{9,10,18-20} In relation to self-management, medication adherence has been studied most extensively with up to 72% of lung transplant recipients displaying some extent of medication non-adherence.^{10,19} Suboptimal transplant-related self-management is also

reported in other self-management tasks including self-monitoring of lung function.^{17-19,21} Likewise, smoking cessation proves difficult for some lung transplant recipients.^{22,23} Consequently, there is a gap between patients' awareness of the need and importance of self-management and individual health-related behavior.²³

Research has shown that for recipients of solid organ transplants, adherence to self-management tasks depends on personal experiences and attitudes rather than on non-modifiable factors such as gender, age, or ethnicity.²⁴⁻²⁶ Qualitative research has identified that a major driver for medication adherence for patients who have received a renal transplant is their experience of dialysis treatment.²⁷⁻²⁹ Likewise, lung transplant recipients with cystic fibrosis and prior experience of home spirometry displayed better adherence to home monitoring when compared to those with other underlying pathologies.¹⁷ In renal transplant recipients, skepticism or medication-related concerns were shown to be associated with inadequate medication adherence.^{30,31} 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.^{32,33}

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.³⁴⁻³⁶ 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,²⁹ social adaptation,¹⁶ alcohol abstinence,³⁷ smoking cessation,³⁸ or physical activity.³⁹ Thus, the multidimensionality of self-management after solid organ transplantation has been neglected.⁴⁰

Synthesizing qualitative evidence by conducting systematic reviews is essential in deepening 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 published.²⁴ However, no qualitative systematic review on lung transplant recipients' experiences of and attitudes towards self-management has been conducted.

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. The findings of this review will also contribute to recommendations for further research and possibly the development of clinical guidelines. The objectives, inclusion criteria and methods of analysis for this review were specified in advance and documented in a protocol.⁴¹

Review question

The objective of this review was to identify lung transplant recipients' experiences of and attitudes towards self-management.

Inclusion criteria

Participants

This review considered studies that included men and women over 18 years of all ethnicities who had received a lung transplant, regardless of type of underlying disease and length of time since transplant, employment status and type of hospital in which they received their pre- and post-transplant care.

Excluded were studies that focused on self-management related to other conditions and studies that focused on participants who were unable to perform their self-management tasks independently. Studies that focused on participants with mental health issues were also excluded as were studies focusing on participants having received more than one transplant or single lung or lung lobe transplants.

Phenomena of interest

The review considered studies that investigated the experiences of lung transplant recipients towards self-management or the attitudes of lung transplant recipients towards self-management.

Context

This review considered all available evidence on lung transplant recipients worldwide. All settings where this topic has been addressed, with participants meeting the inclusion criteria, were considered.

Types of studies

This review considered studies that focused on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, and feminist research. Mixed-methods studies were included only when qualitative data could be extracted separately. Studies published in English or German were considered for inclusion in this review. No date restrictions were imposed for inclusion.

Methods

This systematic review was conducted in accordance with JBI methodology for systematic reviews of qualitative evidence.⁴² This review was conducted in accordance with an *a priori* protocol.⁴¹

Search strategy

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was utilized in this review. An initial limited search of MEDLINE and CINAHL was undertaken followed. The initial keywords used were: "lung transplantation", AND "self-management", AND ("attitude" OR "experience").

A second comprehensive search using all identified keywords and index terms (see Appendix I) was

undertaken across all the following databases: Web of Science; PsycINFO, MEDLINE, EMBASE and Emcare (via OVID platform); CINAHL (via the EBSCO platform). This approach was a deviation from the protocol in which we stated that we would search British Nursing Index, but as our institution no longer subscribed to this database, we substituted it with Emcare (OVID). The search for unpublished studies included ProQuest Dissertation & Theses Database, EThOS and Open Grey. The search strategies for all of the databases are included in Appendix I.

Thirdly, the reference list of all included reports and articles was searched for additional studies. Studies published in English and German (based on languages spoken by authors) from inception of databases to March 2022 were considered for inclusion in this review. The most recent copies of the journals that the included studies were published in were hand searched to ensure that any current relevant papers that may not be indexed in the major databases were located, however this did not yield any additional publications.

Study selection

Following the search, all identified citations were collated and uploaded into Endnote 20 (Clarivate Analytics, PA, USA) and duplicates removed. Following a pilot test, titles and abstracts were screened by two independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant studies were retrieved in full and their citation details imported into the JBI System for the Unified Management, Assessment, and Review of Information (JBI SUMARI; JBI, Adelaide, Australia).⁴³ Full-text studies that did not meet the inclusion criteria were excluded and reasons for their exclusion are provided in Appendix II. Any disagreements that arose between the reviewers were resolved through discussion or with a third reviewer.

Assessment of methodological quality

Qualitative papers selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using JBI Checklist for Qualitative Research.⁴² Any disagreements that arose between the reviewers were resolved through discussion. All studies, regardless of the results of their methodological quality, underwent data extraction and synthesis.

Data extraction

Qualitative data (illustrations and findings) were extracted verbatim from papers included in the review using the standardized data extraction tool from JBI-SUMARI (JBI, Adelaide, Australia)⁴³ by two independent reviewers. The data extracted included specific details about the lung transplant recipients (and not caregivers, clinicians or other solid organ transplant recipients), geographical location of the research study, study methods and the phenomena of interest relevant to the review question and specific objectives.

Data synthesis

Qualitative research findings were pooled using the JBI method of meta-aggregation.⁴² This involved the aggregation or synthesis of finding using JBI levels of credibility (i.e. credible and unequivocal findings) to generate a set of statements that represented that aggregation, through assembling the findings rated

according to their quality, and categorizing these findings based on similarity in meaning. These categories were then subjected to a meta-synthesis to produce a single comprehensive set of synthesized findings that could be used as a basis for evidence-based practice. The synthesized findings were drafted by the primary reviewer then discussed with the second author for validation. All analytic data within the paper that met the objectives of the review were considered as findings. These were identified through repeated reading of the results sections within the included papers. Categories were developed based on similarity in wording and concepts, descriptions were drafted by the primary reviewer then discussed with the second author for validation. The same process was then repeated to create the synthesized findings.

Assessing confidence in the findings

The final synthesized findings were graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings table.⁴⁴ The Summary of Findings contains the title, target population, phenomena of interest, and context for this review. Additionally, each synthesized finding from the review is presented, along with the type of research that produced the finding, the dependability and credibility scores for the finding, and the finding's overall ConQual score.

Results

Study inclusion

There were 1,493 citations identified as being potentially relevant to the review. After the duplicates had been removed the titles and abstracts of 1298 records were reviewed. Based on the study eligibility criteria, 1256 citations deemed not relevant. Forty-four full text publications were retrieved and reviewed against the eligibility. Ten publications that were assessed as suitable for inclusion in the review (Figure 1). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist was followed for the reporting of this review.⁴⁵

Insert Figure 1 around here

Methodological quality

The JBI checklist for qualitative research was used to assess the methodological quality of all publications.⁴² When a study met a criterion for inclusion (for example, 10 items for qualitative studies) a score of one was given. Where a particular point for inclusion was regarded as “unclear” or no it was given a score of zero. All included studies were assessed using this method and their overall critical appraisal scores presented. All studies, regardless of the results of their methodological quality were included in the review and are presented in Table 1.

Insert Table 1 around here.

Three studies^{33,46,47} scored nine out of 10; four scored eight out of 10⁴⁸⁻⁵² and one scored seven out of 10, Sabati and colleagues⁵³ scored six out of 10 and one study⁵⁴ scored three out of 10 in total. All studies demonstrated congruence between the research methodology and the research question /

objectives (question two), the research methodology and the methods used to collect data (question three) and the research methodology and the representation and analysis of data (question four). None of the studies located the researcher culturally or theoretically (question six). One study⁵⁴ failed to demonstrate alignment between the research methodology and the interpretation of results (question five) and did not clearly demonstrate the relationship between the conclusions drawn and the analysis or interpretation of the data (question 10). Two studies^{53,54} did not clearly demonstrate alignment between the stated philosophical perspective and the research methodology (question one) and there was also a lack of clarity regarding whether the research was ethical according to current criteria (question nine). One study⁵⁴ was unclear regarding whether the participants' voices were adequately represented (question eight) and another study⁵² did not provide sufficient evidence of this. Seven studies⁴⁸⁻⁵⁴ did not consider the influence of the researcher on the research, and vice-versa (question seven).

Characteristics of included studies

A table detailing the characteristics of the included studies is shown in Table 2.

Insert Table 2 around here

Of the 10 qualitative studies, four were conducted as part of a wider mixed methods study.^{48,51,53,54} The methodologies were described as qualitative descriptive (n=5),^{33,49,50,53,54} grounded theory (n=2),^{47,52} a hermeneutic phenomenological approach (n=1)⁴⁶ and contextual inquiry (n=1).⁵¹ One further study did not describe the type of qualitative methodology used.⁴⁸

The 10 studies were conducted across USA (n=4),^{47,48,53,54} Denmark (n=2),^{33,46} Sweden (n=1),⁵² Canada (n=1),⁴⁹ Switzerland (n=1)⁵⁰ and Belgium (n=1).⁵¹

The participants were recruited from a single transplant center (n=7)^{46-48,50,51,53} from two transplant centers (n=1),⁵² or nationwide^{33,49} either selected from a national list of lung transplant patients³³ or recruited via social media accounts of Canadian Donation and Transplantation Research Program.⁴⁹

The overall number of participants across the included studies was 255 (however Vanhoof et al.⁵¹ do not state how many of their 18 included participants with various solid organ transplants had received a lung transplant) The numbers of lung transplant participants ranged from eight⁴⁸ to 73.⁵³ The lowest age incorporated into the age range was 20 years old⁵⁰ and the highest was 78 years old.⁴⁹ Age was not reported in one study.⁴⁶ The percentage of females within the samples ranged from 33%⁵² to 57%.⁵⁴

Four studies did not state an underlying condition which had necessitated the transplant (n=4).^{49,51,53,55} The underlying conditions cited across the remaining six studies included cystic fibrosis (n=3),^{47,48,50} COPD (n=5),^{33,47,50,52,54} pulmonary fibrosis (n=4).^{47,48,50,52} Other conditions that were mentioned included alpha 1 anti-trypsin deficiency, emphysema,⁴⁸ pulmonary hypertension, rheumatoid arthritis and Langerhans cell histiocytosis,⁵² scleroderma and hypersensitivity pneumonitis.⁴⁷

261 All of the studies conducted interviews to gather this data.^{33,46-50,52,53} The time between transplant and
262 the interview varied from 42 days⁴⁸ to 24 years.⁵¹ One study conducted interviews at three different
263 timepoints post-transplant: 2 weeks, 3 months and 6 months.⁵⁰

264 **Review findings**

265 To identify lung transplant recipients' experiences of and attitudes towards self-management: a total of
266 137 findings from ten qualitative studies were extracted and aggregated to form 19 categories. An
267 additional 61 findings were extracted and classified as not supported (NS) but these were not included
268 in the final synthesis. Full details of study findings and illustrations are reported in Appendix III.

269 Table 3 shows the meta-aggregation process and the level of credibility of study findings.

270 *Insert table 3 around here*

271 The illustrations for each of these findings can be found in Table 3. Findings were categorized as follows:

272 Unequivocal (U): evidence beyond reasonable doubt, which may include findings that are matter of fact,
273 directly reported / observed and not open to challenge (113 findings).

274 Credible (C): related to those findings that are, albeit interpretation, plausible considering the data and
275 theoretical framework. They can be inferred logically from the data although because the findings are
276 essentially interpretative, they can be challenged (24 findings).

277 The 19 categories were further synthesized in a meta-synthesis which yielded four synthesized findings.

278 The final synthesized findings were graded according to the ConQual⁴⁴ approach (see Summary of
279 Findings). The level of confidence for each synthesized finding all start with a ranking of 'high' on a scale
280 of high, moderate, low to very low and are then downgraded based on their dependability and credibility.
281 Dependability was established by rating each included study using questions Q2, Q3, Q4, Q6 and Q7
282 from the JBI Checklist for Qualitative Research.⁴² If 4-5 responses to the questions are yes then this
283 suggests a high level of dependability and for this review three studies received a high dependability
284 rating^{33,46,47}. Seven of studies⁴⁸⁻⁵⁴ included in this review scored three and received a moderate
285 dependability rating which was because there was no statement locating the researcher theoretically,
286 and the influence of the researcher on the research was not addressed. Next, by evaluating the
287 congruency between the author's interpretation and the supporting data, credibility was established. For
288 a high level of credibility then a synthesized finding can only have unequivocal findings. For this review,
289 the findings within each synthesized finding were a combination of unequivocal and credible findings
290 and as a result the credibility was downgraded from a high level to a moderate level. Finally, a ConQual
291 score was assigned to each of the synthesized findings and is presented in the Summary of Findings
292 along with the scores for dependability and credibility for each synthesis.

293 **Synthesized finding 1: Changes in routines, beliefs, and sense of responsibility are essential for**
294 **better adaptation and self-management after lung transplantation.**

A total of 50 findings from nine studies^{33,46-53} formed the six categories which informed the first synthesized finding. This synthesis revealed that lung transplant recipients play a pivotal role when it comes to adapting to the situation as a transplant recipient. This may involve fundamental changes in routines in daily life in order to follow all the guidance required to maintain the best possible health status. Following this guidance, however may prove challenging and may also challenge one's sense of independence.

Category 8: Establishing routines

A total of nine findings from two studies^{51,53} formed category eight. It was identified that establishing routines may be helpful in accomplishing self-management tasks:

"At first it was 8AM and 8PM, but I gradually changed it to 12 o'clock. I'm a student and I found out those are better hours. If I want to go out, I don't want to wake up the next morning at 8AM to take my medication".^{51(p.11)}

On the other hand, deviation from routines such as oversleeping or having visitors may cause non-adherence:

"We had a Christmas party and my family came over. It [cell phone] was lying next to me, it went off and I thought 'I'll do it later' because we were talking. So I told my partner to bring them [medication] to me, but he was busy in the kitchen. I saw them standing when we were cleaning up, I felt so bad!"^{51(p.13)}

Routines may involve the conscious use of reminders, such as other people, electronic reminders, links to other routines or keeping track of stock:

"I always watch the news at 7PM, and then I know I have to take them".^{51(p.11)}

Category 13: Challenging one's sense of independence

A total of four findings from three studies^{48,51,56} formed category 13. Some lung transplant recipients feel that following medical guidance may violate their independence which they try to maintain:

"I cannot spontaneously go out for dinner with my husband because I have to be home in time to take my medications; and, when I want to go on holiday, I have to plan carefully what I need to bring. I have to think not only of my pills, but also my inhalers, the blood pressure meter, the home spirometer, the cold box for the medication... this is just tedious".^{50(p.553)}

Also, consulting healthcare practitioners before making decisions may represent a change in behavior and may not even be perceived as helpful.

"When we're in the waiting room at the outpatient clinic, we very often see other patients quickly filling in their medication intakes and temperatures in their diary, unbelievable! [...] I do always mark most of my medication intakes for the upcoming weeks, because I don't like filling it in.... If something does change along the way, I just delete it." ^{51(p.14)}

Category 5: Contributing to one's own health

A total of 15 findings from seven studies^{33,48-53} formed category five. Many lung transplant recipients are highly motivated to engage in self care and health-promoting activities:

"I will do what I have to; getting better and getting home is my job".^{48(p.387)}

This often involves an active interest in learning new ways of doing things such as home monitoring and interpreting vital signs:

"I want to know everything there is to know about my tests, medications, everything".^{48(p.387)}

Contributing to one's health is also often characterized by a strong commitment to taking over responsibility for the transplant and associated tasks:

"A few patients [...] reported perceiving the new lungs as "a gift" or as "something of particular value"^{53(p.552)}

Category 12: Following all rules can be challenging

A total of ten findings from four studies^{46,49,51,53} formed category 12. This category emphasizes that translating clinical guidelines into lung transplant recipients' everyday lives and being able to follow them was reported as time consuming and sometimes challenging:

"Actually, I know very well what I'm expected to do. Doing it, that's something else"^{51(p.9)}

It also shows that many lung transplant recipients have difficulties in adhering to all requirements post-transplant:

"It is a challenge for me to adhere to all the rules of my new life and to take the medication"^{46(p.3548)}

A lack of adherence may be due to different reasons such as motivational problems or problems in understanding the necessity or benefit of rules:

"...I shouldn't look for excuses, if it [fitness equipment] would stand here, I still wouldn't use it, I don't really like being active."^{51(p.9)}

Category 16: Having to make adjustments in life

A total of eight findings from six studies^{33,47,48,50-52} formed category 16. Many transplant recipients feel that they need to adjust their life or alter plans according to the requirements of their transplant:

"On another the day-to-day living is the hardest waking up every morning and think, "Oh, here we go again." It's constant. It's constant. It's relentless, it doesn't stop."^{47(p.1530)}

Category 7: Developing individual coping strategies

A total of four findings from two studies^{51,52} formed category seven. After transplantation, lung transplant recipients develop individual coping strategies to manage their medical requirements:

"I keep a lot of things in an Excel-file on my computer...I always ask a printout of my blood results in the hospital and when I'm home, I enter them here and it shows in this graph. Here you see my personal creatinine level and the ideal and permitted level... It's still too high, but I'm making progress."^{51(p.10)}

Synthesized finding 2: Life after transplantation is characterized by both positive and negative feelings and experiences.

A total of 47 findings from nine studies^{46 33,47,49-54} formed the six categories which led to the development of synthesized finding two. This synthesis revealed that many lung transplant recipients only realize post-operatively that transplantation often brings a significant improvement in quality of life, but is not a cure for their chronic disease. Rather, transplant recipients experience both positive experiences such as a renewed joy of life when compared to their health status prior to transplantation. However, negative feelings such as an awareness of never being free from disease or facing a limited life expectancy may also be experienced.

Category 15: Having received a transplant does not meet expectations

A total of five findings from four studies^{46,47,53,54} formed category 15. Some lung transplant recipients expect life with a transplant to be different to the reality:

376 *"It's got to get better. Of all the people in the world, I should be living life to the fullest. Two of the*
377 *reasons are this depression and this pain, and there has to be something we haven't figured out*
378 *yet because I'm taking medications for everything else and I still feel this way, It's very depressing*
379 *to tell about my day because every day is the same". 54(p.5)*

380 **Category 18: Never being disease free**

381 A total of eight findings from three studies^{49,51,53} formed category 18. Lung transplant recipients realize
382 that in the majority of cases transplantation does not cure a chronic underlying condition but may even
383 add new signs and symptoms of illness that need to be interpreted:

384 *"So it is kind of hard for me to gauge if I am really sick or not. I don't want to be sitting at home*
385 *for two weeks thinking nothing is going on and it is. But at the same time I don't want to be calling*
386 *off the hook ... driving everybody nuts, driving myself nuts when there's nothing going on ... there's*
387 *no "normal" for me to follow". 47(p.1524)*

388 **Category 9: Experiencing a multitude of bodily symptoms**

389 A total of 13 findings from five studies^{33,46,47,50,51} formed category nine. Many lung transplant recipients
390 describe multiple physical and/ or emotional symptoms and side effects that are usually caused by the
391 transplant procedure or by their medication:

392 *"I used to be very good with numbers, you know, I could remember people's telephone numbers,*
393 *addresses, and everything else, and I just kind of lost a little bit of that. I used to be able to do*
394 *mathematics in my head very easily... it seems like I slowed down a little bit on that". 47(p.1526)*

395 **Category 6: Coping with a limited life expectancy**

396 A total of six findings from three studies^{33,47,50} formed category six. Many lung transplant recipients are
397 aware that they face a limited life expectancy despite their transplantation:

398 *"I ... try not to go there too often mentally, but there's always a chance this might not work... that*
399 *little gray area where there might be rejection and suddenly everything would be different. So*
400 *there always is that kind of fear, but I try not to go there too often. I just kind of stay... in the*
401 *present, and know that I am feeling good ... I can't look too far forward". 47(p.1525)*

402 **Category 10: Experiencing renewed joy in life**

403 A total of eight findings from six studies^{33,46,47,49,50,52} formed category ten. Lung transplantation often
404 leads to significant health improvements and transplant recipients are again able to do things they enjoy:

405 *"I have no shortness of breath and I feel like a 20-year-old again". 46(p.3546)*

406 **Category 4: Comparing one's current health status with that before transplantation**

407 A total of seven findings from three studies^{46,47,52} formed category seven. Many lung transplant recipients
408 compare their health status to that before transplantation:

409 *"Yes, but they are not so big these problems (complications), compared to what you had before,*
410 *they become trivial after a while when you live with it". 52(p.2289)*

411 Some even refer to their status before the onset or aggravation of their lung disease:

412 *"We will travel, rediscover and relive being a family". 46(p.3548)*

413 **Synthesized finding 3: Better adjustment and self-management after a lung transplant require** 414 **dealing with one's own feelings and beliefs.**

415 A total of 25 findings from eight studies^{33,46-48,50-53} formed the three categories that were synthesized to
416 develop this third finding. This synthesis revealed that adjustment to having experienced a life

417 threatening condition and transplantation may require new approaches to deal with one's emotions and
418 focus in life. In this regard, holding certain beliefs may also play a role in the adaptation process.

419 **Category 14: Handling emotions**

420 A total of nine findings from four studies^{33,46,47,50} formed category 14. Having received a transplant may
421 offer positive, negative or also mixed emotional feelings that need to be dealt with:

422 *"Physically, I am in good condition. However, when I was allowed to leave the hospital, suddenly*
423 *I found myself suffering from a number of fears. I had great difficulties structuring and organizing*
424 *my daily life. I quickly felt distressed and overwhelmed doing things that used to be easy for me.*
425 *My wife worked full-time and could not be with me all day. I was not able to cope with the situation*
426 *at home and felt like I was going crazy. So I let myself be hospitalized again".* ^{50(p.551)}

427 Lung transplant recipients report a variety of emotional coping strategies:

428 *"The new lungs are my Empress, so I call them Sissi".* ^{50(p.552)}

429 **Category 17: Holding beliefs**

430 A total of eleven findings from three studies^{51,53,56} formed category 17. Many lung transplant recipients
431 have come to certain beliefs regarding different aspects of life after transplantation, such as healthy
432 eating or home monitoring:

433 *"One subject stated, "At the time I felt so good that I thought it wasn't necessary, never had any*
434 *lung complications".* ^{53(p.183)}

435 Another topic associated with different beliefs is how immunosuppressive medication works in the body
436 and how strict intake prescriptions need to be followed:

437 *"Patients referred to drugs as "little bombs", "an enormous load of chemistry", "a necessary evil",*
438 *and "an unresolved dilemma".* ^{50(p.552)}

439 The perceived integration of the donor organ is also associated with certain beliefs:

440 *"The advantage is that you cannot see the transplant. If I had the hand of a Chinese woman, I*
441 *would be constantly reminded that I carry something foreign. But I cannot see the lungs, so I can*
442 *live with the idea that my old lungs simply got cleaned".* ^{50(p.552)}

443 **Category 11: Focusing on hope and optimism**

444 A total of five findings from four studies^{46-48,52} formed category eleven. Despite complications and/or
445 symptoms many lung transplant recipients decide to focus on hope and optimism for the future:

446 *"I just don't worry about things, I have very strong faith, and I really live my life and I have fun and*
447 *I help people...And even if I did die tomorrow, I would be totally cool with that...I pretty much*
448 *eradicated my whole, entire fear of dying through that aspect".* ^{47(p.1527, table 2)}

449 **Synthesized finding 4: After transplantation, engaging with relatives, friends, medical team and** 450 **donors is essential to improve experiences and adapt to being a transplant recipient.**

451 A total of 15 findings from six studies^{33,46,47,49,53,56} formed the four categories that informed the
452 development of synthesized finding four. This synthesis revealed that other people play a very important
453 role in life after a lung transplant. This concerns not only relatives, friends and the medical team, but
454 also the donors, to whom many lung transplant recipients feel deeply indebted.

455 **Category 1: Appreciating the role of others**

A total of five findings from three studies^{33,46,47} formed category one. Family, friends and caregivers play a pivotal role in people's lives after transplant:

"But she (a daughter) has been extremely supportive without even being aware of it that I needed her and there was a reason to fight".^{33(p.3474)}

Category 2: Being able to engage with others

A total of three findings from three studies^{46,47,50} formed category two. Lung transplant recipients are again able to participate in social activities and play active roles in their families:

"I have the energy to be part of my family and to love life again, and I can accommodate husband and kids again".^{46(p.3546)}

Category 3: Being committed to the donor and the medical team

A total of four findings from three studies^{49,50,53} formed category three. Many lung transplant recipients feel extremely committed to the donor and/ or the medical team:

"I feel obliged to take care of the matter, mainly out of respect for the donor, but also for the transplant team".^{50(p.553)}

Category 19: Re-establishing relationship with spouses

A total of three findings from one study⁴⁷ formed category 19. This category illustrates that relationships with spouses that have been characterized by lung disease sometimes need to be re-established and sometimes the transplant itself may alter the relationship with spouses:

"[My wife] was afraid ... There was less touching and feeling and such things just because she ... didn't want to hurt anything".^{47(p.1529)}

Discussion

Although approximately 70,000 lung transplant procedures have been registered to date,¹ to the best of our knowledge, this is the first review to synthesize lung transplant recipients' experiences of and attitudes towards self-management. Just ten qualitative studies, published between 2001 and 2021, were eligible for inclusion. Thus, the need for further high quality research is clear.

However, despite the paucity of research in the field, this systematic review has clearly demonstrated that lung transplantation not only has a serious impact on transplant recipients themselves, it also affects transplant recipients' social networks, making self-management a task with shared responsibility.

Synthesized finding one of this review has shown that lung transplant recipients perceive themselves to be at the core of self-management which, in many cases, requires fundamental changes in lifestyle, beliefs and assumptions around responsibility. These changes may be perceived positively and be embraced as a part of lung transplants' post-transplant persona, but they may also be perceived on a continuum ranging from being challenging to an invasion of one's individual life. Similar findings are described in a review on kidney transplant recipients' motivations, challenges and attitudes to self-management by Jamieson et al.,⁵⁷ which concluded that kidney transplant recipients also aimed to achieve mastery related to self-management. This finding is in line with other research emphasizing the importance self-efficacy plays in self-management after heart and kidney transplantation.^{58,59}

Synthesized finding two demonstrated that life after transplantation is characterized by a high degree of ambiguity, since life after lung transplantation may not deliver total health and well-being as anticipated by many transplant recipients. This ambiguity means that although lung transplant recipients often experience a significant rise in quality of life, at the same time they are confronted with new bodily as well as emotional challenges, including the realization that there is no prospect of ever being free of disease. Similarly, a recent review of qualitative studies identified that solid organ transplant recipients were in “both states of illness and health”.⁶⁰ Our finding is also confirmed by other reviews in the field that highlight both severity of symptom experience^{61,62} and simultaneous significant increase in quality of life across all solid organ transplantations.⁶³⁻⁶⁵

Relatedly, synthesized finding three revealed that psychosocial support is an essential aspect of life after lung transplantation and that many lung transplant recipients may benefit from support in dealing with emerging emotions. Emotional challenges may not only relate to fear regarding graft failure and with it presumably finiteness of life, but also to processing and making the most of a regained joy of life. As with synthesized finding two, these emotional challenges may have both positive and negative connotations, or even both, adding to the state of ambiguity described above. This sense of ambiguity has also been described elsewhere in the context of solid organ transplantation.^{57,60,66}

Synthesized finding three also demonstrated a surprising depth and breadth of beliefs regarding different aspects of self-management after lung transplantation, particularly medication-taking. From a clinical perspective, this finding emphasizes that neither frequency nor quality of follow-up should be diminished as time after transplantation passes. In addition, it has demonstrated that even experienced lung transplant recipients may not fully understand the importance of self-management tasks.

Likewise, synthesized finding four emphasized how crucial engagement with others is perceived to be by lung transplant participants. This does not only refer to the recipients' social network but may also extend to the medical team as well as a sense of indebtedness and commitment to the deceased lung donor. Similar conclusions were drawn by other reviews in the field^{57,60} who also emphasize the importance of social engagement after solid organ transplantation.

Self-management post lung transplantation is, therefore, a complex process, demanding adjustment that extends beyond the individual recipient. Hence, traditional models of compliance are likely to have limited impact since they ignore the importance of social networks and psychosocial adaptation. These findings also raise issues regarding the organization of services for this population. Traditionally, lung transplant teams have mainly consisted of medics, specialist nurses and a variety of other healthcare professions such as physiotherapists, nutritionists or psychologists. However, the findings of this review suggest that a more holistic approach is required, involving more people from the transplant recipients' social environment, such as relatives or peers, from a very early stage. Similarly, recent qualitative research has demonstrated that peer support would be highly appreciated by adolescent solid organ transplant recipients.⁶⁷

Limitations

The findings of this review are limited by the small number of research studies that have been published in the field. The studies included in this review were conducted in six countries in North America and Central/Northern Europe. There is, therefore, a very limited representation of lung transplant recipients' experiences of and attitudes towards self-management. This may have been compounded by studies included in the review being limited to English and German language studies, which means that specific cultural experiences and cultural issues and the needs of populations beyond North America and Central/Northern Europe may not have been captured. The findings of this review may also be limited by the fact that all studies, regardless of their methodological quality, were included.

Conclusions

This review has illuminated the nuanced emotional, social, relational and psychological adjustment that is required of lung transplant recipients in self-management and, the significant role others contribute to this process. Healthcare professionals need to be sensitive to the complex needs of patients and their loved ones in adapting to life post-transplantation and fulfilling all the requirements that their new status demands of them. In addition, the findings of this review suggest that health care professionals should be cognizant of the potential challenges patients face in fulfilling the various demands of self-management and aim to ameliorate these challenges by making psychological support available. However, this review has also clearly demonstrated that lung transplant recipients are ready to take their share of responsibility in performing self-management.

Recommendations for practice and/or policy

We recommend that the following interventions should be implemented in clinical practice:

- Patients should be provided with support in establishing new routines, modifying their health beliefs and sense of responsibility in order to enhance their self-management following lung transplantation. (JBI Grade of Recommendation: A)
- Potential lung transplant recipients should be prepared for both the positive and negative aspects of receiving a lung transplant. (JBI Grade of Recommendation: A)
- Lung transplant recipients require psychological and social support (JBI Grade of Recommendation: A)

Recommendations for research

We recommend that further high quality, contemporary, qualitative research should be conducted to examine lung transplant recipients' experiences of and attitudes towards self-management globally. In particular, international qualitative studies which examine aspects of self-management following lung transplantation that go beyond medical management to also focus on psychosocial and emotional aspects are required. (JBI Grade of Recommendation: A)

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744

745 Appendix I: Search strategies

746 Ovid MEDLINE(R) ALL (Search conducted from database inception to 10th March 2022)

Search	Query	Records retrieved
1	"lung transpl*".ti,ab.	18834
2	"lung re-transpl*".ti,ab.	19
3	exp *Lung Transplantation/	14758
4	"self manage*".ti,ab	23464
5	"self car*".ti,ab.	21184
6	self-manage*.ti,ab.	23464
7	self-car*.ti,ab.	21184
8	exp *Self Care/ or exp *Self-Management/	30638
9	exp *Chronic Disease/	99560
10	"chronic illness".ti,ab.	12697
11	"chronic disease".ti,ab.	37935
12	manage*.ti,ab.	1484992
13	9 and 12	4760
14	10 and 12	3123
15	11 and 12	9427
16	exp *Disease Management/	44359
17	"decision making".ti,ab.	160527
18	exp *Decision Making/	102832
19	illness behavior?.ti,ab	1205
20	exp *Illness Behavior/	678
21	"health behavior?".ti,ab.	12578
22	exp *Health Behavior/	12578
23	"health knowledge".ti,ab.	12578
24	exp *Health Knowledge, Attitudes, Practice/	67851
25	adherence.ti,ab.	138166
26	"medication adherence".ti,ab.	12182
27	exp *TREATMENT ADHERENCE AND COMPLIANCE"/	131827
28	compliance.ti,ab.	128014
29	exp *Self Concept/	55227
30	"self concept".ti,ab.	5199
31	"social support".ti,ab.	45259
32	exp *Social Support/	29128
33	attitude*.ti,ab.	169822
34	exp *Attitude to Health/	242530
35	exp *ATTITUDE/	334050
36	percept*.ti,ab.	339734
37	exp *Perception/	268695
38	perspective*.ti,ab.	384381
39	experience*.ti,ab.	1222102
40	view*.ti,ab.	515819
41	qualitative.ti,ab	272728
42	exp *QUALITATIVE RESEARCH/	3515
43	interview.ti,ab.	154364
44	1 or 2 or 3	21472
45	4 or 5 or 6 or 7 or 8 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32	881156
46	33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43	2885956
47	44 and 45 and 46	204

747

Search	Query	Records retrieved
S1	TI(lung n1 transpl*) OR AB(lung n1 transpl*)	3,475
S2	TI(lung n1 retranspl*) OR AB(lung n1 retranspl*)	9
S3	(MM "Lung Transplantation+")	2,308
S4	TI(Self n1 manage*) OR AB(self n1 manage*)	18,488
S5	TI(Self-manage*) OR AB(self-manage*)	17,170
S6	TI(Self n1 care*) OR AB(self n1 care*)	20,933
S7	TI(Self-care) OR AB(self-care)	18,357
S8	(MM "Self Care+")	29,946
S9	(MM "Chronic Disease")	24,300
S10	TI(Chronic n1 disease) OR AB(Chronic n1 disease)	63,506
S11	TI(Chronic n1 illness) OR AB(Chronic n1 illness)	12,694
S12	TI(manage*) OR AB(manage*)	545,550
S13	S10 AND S12	12,627
S14	TI(decision n1 making) OR AB(decision n1 making)	75,296
S15	(MM "Decision Making+")	64,938
S16	TI(illness n1 behavio?r) OR AB((illness n1 behavio?r)	204
S17	TI(health n1 behavio?r) OR AB(health n1 behavio?r)	4,059
S18	MM "Health Behavior+")	61,342
S19	TI(health n1 knowledge) OR AB(health n1 knowledge)	5,125
S20	(MM "Health Knowledge")	16,426
S21	MM "Medication Compliance") OR (MM "Patient Compliance+")	27,432
S22	TI(adherence) OR AB(adherence)	55,909
S23	TI(medication n1 adherence) OR AB(medication n1 adherence)	8,264
S24	TI(compliance) OR AB(compliance)	43,135
S25	MM "Self Concept+")	29,623
S26	(TI(self n1 concept) OR AB(self n1 concept)) OR (TI(self-concept) OR AB(self-concept)	3,698
S27	TI(social n1 support) OR AB(social n1 support)	32,465
S28	TI(attitude*) OR AB(attitude*)	90,600
S29	(MM "Attitude+") OR (MM "Attitude to Illness+")	277,396
S30	TI(percept*) OR AB(percept*)	149,641

S31	(MM "Perception+")	51,470
S32	TI(perspective*) OR AB(perspective*)	155,367
S33	TI(experience*) OR AB(experience*)	479,275
S34	TI(view*) OR AB(view*)	146,175
S35	TI(qualitative) OR AB(qualitative)	150,310
S36	MM "Qualitative Studies+")	7,591
S37	TI(interview*) OR AB(interview*)	244,895
S38	(MM "Semi-Structured Interview") OR (MM "Interviews+") OR (MM "Unstructured Interview") OR (MM "Structured Interview")	2,710
S39	S1 OR S2 OR S3	3,868
S40	S9 and S12	4,650
S41	S11 and S12	3,186
S42	S4 OR S5 OR S6 OR S7 OR S8 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S40 OR S41	381,906
S43	S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38	1,175,272
S44	S39 AND S42 AND S43	65

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750 **EMBASE:** (Search conducted from database inception to 10th March 2022)

Search	Query	Records retrieved
1	(lung adj1 transpl*).ti,ab.	33664
2	lung adj1 re-transpl*.ti,ab.	61
3	lung adj1 retranspl*.ti,ab.	123
4	exp *Organ Transplantation/ and lung.ti,ab.	24555
5	"self manage*".ti,ab.	33615
6	"self car*".ti,ab.	29986
7	self-manage*.ti,ab.	33615
8	self-car*.ti,ab.	29986
9	exp *Self Care/ or exp *Self-Management/	31252
10	exp *Chronic Illness/	32090
11	"chronic illness".ti,ab.	17367
12	"chronic disease".ti,ab.	53535
13	manage*.ti,ab.	2050392
14	10 and 13	5696
15	11 and 13	4294
16	12 and 13	13438
17	exp *Disease Management/	483488
18	"decision making".ti,ab.	218646
19	exp *Decision Making/	88435
20	illness behavio?r.ti,ab.	1452
21	exp *Illness Behavior/	1506
22	"health behavio?r".ti,ab.	14603
23	exp *Health Behavior/	150561
24	"health knowledge".ti,ab.	4142
25	exp *Health Knowledge/	61497
26	adherence.ti,ab.	209751
27	"medication adherence".ti,ab.	19990
28	exp *Treatment Compliance/	35769
29	compliance.ti,ab.	204398
30	exp *Self Concept/	69942
31	"self concept".ti,ab.	5742

32	"social support".ti,ab.	55906
33	exp *Social Support/	24930
34	exp *attitude to illness/ or exp *attitude/ or exp *patient attitude/ or exp *attitude to health/	305405
35	attitude*.ti,ab.	210677
36	percept*.ti,ab.	409061
37	exp *Perception/	159287
38	perspective*.ti,ab.	460860
39	experience*.ti,ab.	1699389
40	view*.ti,ab.	643413
41	qualitative.ti,ab.	337324
42	exp *QUALITATIVE RESEARCH/	14824
43	interview.ti,ab.	201935
44	1 or 2 or 3 or 4	38461
45	5 or 6 or 7 or 8 or 9 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33	1450199
46	34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43	3625183
47	44 and 45 and 46	550

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Search	Query	Records retrieved
1	"lung transpl*".ti,ab.	212
2	"lung re-transpl*".ti,ab.	0
3	exp *Organ Transplantation/ and lung.ti,ab.	217
4	"self manage*".ti,ab.	10837
5	self car*".ti,ab.	10837
6	self-manage*.ti,ab.	10837
7	self-car*.ti,ab.	10837
8	exp *Self Care/ or exp *Self-Management/	7807
9	exp *Chronic Illness/	26101
10	"chronic illness".ti,ab.	7906
11	"chronic disease".ti,ab.	7143
12	manage*.ti,ab.	302660
13	9 and 12	5323
14	10 and 12	1738
15	11 and 12	2079
16	exp *Disease Management/	5839
17	"decision making".ti,ab.	93667
18	exp *Decision Making/	102186
19	illness behavior?.ti,ab	1172
20	exp *Illness Behavior/	4605
21	"health behavior?".ti,ab.	8360
22	exp *Health Behavior/	29005
23	"health knowledge".ti,ab.	1436
24	exp *Health Knowledge/	6713
25	adherence.ti,ab.	32017
26	"medication adherence".ti,ab.	4422
27	exp *Treatment Compliance/	13538
28	compliance.ti,ab.	25283
29	exp *Self Concept/	60964
30	"self concept".ti,ab.	20753
31	"social support".ti,ab.	50805

32	exp *Social Support/	29427
33	exp *"PHYSICAL ILLNESS ATTITUDES TOWARD"/ or exp *ATTITUDES/ or exp *HEALTH ATTITUDES/	341669
34	attitude*.ti,ab.	217422
35	percept*.ti,ab.	373381
36	exp *Perception/	383905
37	perspective*.ti,ab.	296562
38	experience*.ti,ab.	695530
39	view*.ti,ab.	317769
40	qualitative.ti,ab.	188146
41	exp *QUALITATIVE RESEARCH/	10802
42	interview.ti,ab.	119792
43	1 or 2 or 3	266
44	4 or 5 or 6 or 7 or 8 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32	394133
45	33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42	1982534
46	43 and 44 and 45	32

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Search	Query	Records retrieved
#1	((((TI=(lung AND retransplant*)) OR (TS=(lung AND retransplant*))))))	604
#2	((((TI=(lung AND re-transplant*)) OR (TS=(lung AND re-transplant*))))))	145
#3	((((TI=(lung AND transplant*)) OR (TS=(lung AND transplant*))))))	46,418
#4	#1 OR #2 OR #3	46,452
#5	((((TI=(self AND manage*)) OR (TS=(self AND manage*))))))	169,572
#6	((((TI=(self AND care*)) OR (TS=(self AND care*))))))	195,536
#7	((((TI=(chronic AND disease AND manage*)) OR (TS=(chronic AND disease AND manage*))))))	91,495
#8	((((TI=(decision AND making)) OR (TS=(decision AND making))))))	642,434
#9	((((TI=(illness AND behaviour)) OR (TS=(illness AND behaviour))))))	31,969
#10	((((TI=(health AND behavior)) OR (TS=(health AND behavior))))))	291,575
#11	((((TI=(health AND knowledge)) OR (TS=(health AND knowledge))))))	218,604
#12	((((TI=adherence)) OR (TS=(adherence))))	193,044
#13	((((TI=compliance)) OR (TS=(compliance))))	193,567
#14	((((TI=(self AND concept)) OR (TS=(self AND concept))))))	90,860
#15	((((TI=(self-concept)) OR (TS=(self-concept))))))	16,376
#16	((((TI=(social AND support)) OR (TS=(social AND support))))))	309,588
#17	#5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16	2,053,106
#18	((((TI=attitude)) OR (TS=(attitude))))	460,331
#19	((((TI=percept*)) OR (TS=(percept*))))	840,769
#20	((((TI=perspective*)) OR (TS=(perspective*))))	1,100,563
#21	((((TI=experience*)) OR (TS=(experience*))))	2,091,436
#22	((((TI=view*)) OR (TS=(view*))))	1,302,853
#23	((((TI=qualitative)) OR (TS=(qualitative))))	594,419
#24	((((TI=interview)) OR (TS=(interview))))	649,903
#25	#18 or #19 OR #20 OR #21 OR #22 or #23 or #24	5,693,582
#26	#4 or #17 or #25	541

Search	Query	Records retrieved
1	"lung transpl*".ti,ab.	4205
3	"lung re-transpl*".ti,ab.	3
3	exp *Lung Transplantation/	2402
4	"self manage*".ti,ab.	16356
5	"self car*".ti,ab.	15441
6	self-manage*.ti,ab.	16356
7	self-car*.ti,ab	15441
8	exp *Self Care/ or exp *Self-Management/	14882
9	exp *Chronic Disease/	17210
10	"chronic illness".ti,ab.	8134
11	"chronic disease".ti,ab.	18860
12	manage*.ti,ab.	603229
13	9 and 12	4334
14	10 and 12	2242
15	11 and 12	5850
16	exp *Disease Management/	161073
17	"decision making".ti,ab.	84404
18	exp *Decision Making/	36534
19	illness behavior?.ti,ab.	394
20	exp *Illness Behavior/	237
21	"health behavior?".ti,ab	9198
22	exp *Health Behavior/	45238
23	"health knowledge".ti,ab.	2368
24	exp *Health Knowledge, Attitudes, Practice/	5692
25	adherence.ti,ab.	63707
26	"medication adherence".ti,ab.	7360
27	exp *"TREATMENT ADHERENCE AND COMPLIANCE"/	10186
28	compliance.ti,ab.	51490
29	exp *Self Concept/	42974
30	"self concept".ti,ab.	3681
31	"social support".ti,ab.	35114

32	exp *Social Support/	13626
33	attitude*.ti,ab.	108147
34	exp *Attitude to Health/	5692
35	exp *ATTITUDE/	71530
36	percept*.ti,ab.	188537
37	exp *Perception/	49267
38	perspective*.ti,ab.	177288
39	experience*.ti,ab.	553628
40	view*.ti,ab.	180227
41	qualitative.ti,ab.	171287
42	exp *QUALITATIVE RESEARCH/	28393
43	interview.ti,ab.	88700
44	1 or 2 or 3	4397
45	4 or 5 or 6 or 7 or 8 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32	505767
46	33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43	1130347
47	44 and 45 and 46	98

757 **Open Grey** (Search conducted from data inception to 12th March 2022)

Search	Query	Records retrieved
1	Lung transplant*(title)	3
2	Lung re-transplant* (title)	0
3	Lung retransplant (title)	4
4	Organ transplant (title)	4
No qualitative studies		

758 **Ethos** (Search conducted from data inception to 12th March 2022)

Search	Query	Records retrieved
1	Lung transplant**or "lung re-transplant**" or "lung retransplant" or "organ transplant	51
One qualitative study		

759 **ProQuest Dissertations and thesis** (Search conducted from data inception 12th March 2022)

Search	Query	Records retrieved
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1	ti(("lung transplant" OR "lung transplantation" OR "lung transplants")) or ti("lung re-transplant*") or ti ("lung retransplant") or ti(("organ transplant" OR "organ transplantation" OR "organ transplants"))	0
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Appendix II: Studies excluded on screening after reading full papers

1. Behr J, Neurohr C. Lung transplantation: indication and long-term outcomes. Atemwegs- und Lungenkrankheiten. 2007; 33(5):86-94.	Wrong study design - textbook style article on lung transplantation in general (indication and outcomes)
2. Chen J, Stewart A, Katz P, Blanc P, Singer J. Identifying and validating novel health-related quality of life domains in lung transplant. J Invest Med. 2014; 62(1):184	Wrong study design - quantitative
3. David V, Feldman D, Danner-Boucher I, Le Rhun A, Guyomarch B, Ravilly S, et al. Identifying the educational needs of lung transplant recipients with cystic fibrosis. Prog Transplant. 2015; 25(1):18-25.	Wrong study design – quantitative
4. Davis LA, Ryszkiewicz E, Schenk E, Peipert J, LaSee C, Miller C, et al. Lung transplant or bust: patients' recommendations for ideal lung transplant education. Prog Transplant. 2014; 24(2):132-41.	Wrong outcomes for qualitative component of this mixed methods study focusing on educational needs
5. de Souza Pena, S. B. Goersch Silva, A. C. de Oliveira Ramos, I. Soares Barbosa, A. Borges Studart, R. M. Atividades da vida diária de pacientes após transplante pulmonar. Enfermagem em Foco. 2019; 10(7):70-5.	Portuguese
6. Evald L, Graarup J, Hojskov I. E. Diary for self-observation: a self-management tool for recipients of lung transplantation: a pilot study. Nursing Open. 2020;7(6):1766-73	Wrong participants – nurses views for qualitative component of mixed methods study
7. Goetzmann L, Lieberherr M, Krombholz L, Ambuhl P, Boehler A, Noll G, et al. Subjective experiences following organ transplantation - a qualitative study of 120 heart, lung, liver, and kidney recipients. Zeitschrift Fuer Psychosomatische Medizin und Psychotherapie. 2010; 56(3):268-82.	Wrong participants – heart, lung, liver and kidney recipients and results not separated out
8. Goetzmann L, Moser K. S, Grieder E, Klaghofer R, Naef R, Russi E.W, et al. The interplay of "big five" personality factors and metaphorical schemas: a pilot study with twenty lung transplant recipients. Qual Rep. 2007; 12(3):397-413.	Wrong outcomes - the interplay between personality factors and metaphorical schemas
9. Goetzmann L, Moser KS, Vetsch E, Klaghofer R, Naef R, Russi EW, et al. What do patients think after a lung transplantation about their self, lung and social network? A quantitative analysis of categorical interview data. Psychosoc Med. 2006; 3:Doc03.	Wrong study design – quantitative exploration of interview data using content analysis
10. Goetzmann L. The 'feeling of being unsafe' after a lung transplant: aetiological considerations and psychotherapeutic intervention tools. Psychodyn Pract 2006; 12(2):165-76.	Wrong outcomes – psychosocial issues are lung transplantation
11. Goetzmann L, Moser K. S, Vetsch E, Grieder E, Naef R, Russi EW, et al. "Drugs are bombs" - the use of metaphors in lung recipients with high or low	Wrong study design – quantitative

compliance. Zeitschrift Fuer Psychosomatische Medizin und Psychotherapie. 2009; 18(3):72-80.	
12. Goetzmann L, Wagner-Huber R, Andenmatten-Barenfaller M, Gunthard A, Alfare C, Buddeberg C, et al. Group therapy following lung transplantation - first experiences with a theme-centered "life management group." Psychotherapie Psychosomatik Medizinische Psychologie 2006; 56(7):272-75.	Wrong study design – experiences of running a self-management group
13. Goetzmann L, Moser K. S, Vetsch E, Klaghofer R, Naef R, Russi E. W, Buddeberg C, Boehler A. How does psychological processing relate to compliance behaviour. after lung transplantation? A content analytical study. Psychol Health Med. 2007; 12(1):94-106.	Wrong outcomes – psychological processing
14. Gries C. J. Dew M. A. DeVito Dabbs A. J. Pilewski J. M. Patterson S. J. White D. B. Preliminary results: Both high and low literacy lung transplant patients have difficulty adhering to and interpreting home spirometry. J Heart Lung Transplant. 2013; 1:S124.	Conference abstract and no full text of research available
15. Hobler M, Bartlett L, Kapnadak S, Reid N, Hartzler A, Ramos K. A qualitative analysis of CF lung transplant recipients' experiences: CF stories as a form of education in the pre-transplant period. Journal of Cystic Fibrosis. 2021; 20(Supplement 2):S90	Wrong outcomes - pre transplant education
16. Ivarsson B, Ekmehag B, Sjoberg T. Patients' experiences of information and support during the first six months after heart or lung transplantation. Eur J Cardiovasc Nurs. 2013; 12(4): 400-406.	Wrong participants – heart or lung transplant recipients and results not separated out
17. Ivarsson B, Ekmehag B, Sjoberg T. Patient's retrospective views on information and support while waiting for heart or lung transplantation. Scand Cardiovasc J. 2012; 60:8.	Conference abstract full text of publication retrieved
18. Ivarsson B, Ekmehag B, Sjoberg T. Heart or lung transplanted patients' retrospective views on information and support while waiting for transplantation. J Clin Nurs. 2013; 22(11-12): 1620-1628.	Wrong outcomes – focus on pre transplant information
19. Ivarsson B, Ingemansson R, Sjoberg T. Experiences of supportive care when waiting for a lung re-transplantation. SAGE Open Med. 2017; 5:2050312117697151.	Wrong outcomes – focus is on pre transplant period
20. Lange L. Identity and uncertainty: life after a lung transplant. Teksty Drugie. 2021;1:155-171.	Polish
21. Lewin T, Neukom M, Boothe B, Boehler A, Goetzmann L. The other in me. Organ transplantation as a relational experience. Psyche-Zeitschrift Fur Psychoanalyse Und Ihre Anwendungen. 2013; 67(2):120-144.	Wrong study design - not qualitative research. Psychodynamic considerations

22. McCarthy, J. M. 2001. Fighting time: A qualitative analysis on the impact of lung transplantation in adults with Cystic Fibrosis. PhD thesis. University of Leeds	Wrong outcomes – not about self-management of experiences post-transplant
23. Nilsson M, Persson L. O, Forsberg A. Perceptions of experiences of graft rejection among organ transplant recipients striving to control the uncontrollable. J Clin Nurs. 2008; 17(18):2408-417.	Wrong participants – kidney, liver, heart or lung transplant recipients and results not separated out
24. O'Brien R. A, Aslani P, Ciccio M. A, Brien J. A. Medication adherence among heart and/or lung transplant recipients: An exploratory study. Patient Prefer Adherence 2008; 2:115-120.	Wrong study design – quantitative
25. Pangarakis S. J, Harrington K, Lindquist R, Peden-McAlpine C, Finkelstein S. Electronic feedback messages for home spirometry lung transplant recipients. Heart Lung 2008; 37(4):299-307.	Wrong participants – focus groups included lung transplant candidates, recipients, support personnel, and significant others and results not separated out
26. Piot-Ziegler C. The definition of quality of life in heart, lung, liver and kidney transplantation: a model based on the interviews of patients. Transplant. 2010;1:209	Conference abstract and no full text of research available
27. Seiler A, Klaghofer R, Ture M, Komossa K, Martin-Soelch C, Jenewein J. A systematic review of health-related quality of life and psychological outcomes after lung transplantation. J Heart Lung Transplant. 2016; 35(2):195-202.	Systematic review all relevant publications retrieved
28. Singer L. G, Chowdhury N, Chaparro C, Hutcheon M. Post-lung transplant health-related quality of life: perception and reality. J Heart Lung Transplant. 2009; 1:S127	Conference abstract full text of publication retrieved
29. Stubber C, Kirkman M. The experiences of adult heart, lung, and heart-lung transplantation recipients: A systematic review of qualitative research evidence. 2020; PLoS ONE. 2020;15(11):	Systematic review all relevant publications retrieved
30. Tang J, Kerklaan J, Wong G, Howell M, Scholes-Robertson N.; Guha C, et al. Perspectives of solid organ transplant recipients on medicine-taking: Systematic review of qualitative studies. Am J Transplant. 2021; 21(10):3369-387	Systematic review all relevant publications retrieved
31. Textor L. H, Hedrick J. The lived experience of peripheral neuropathy after solid organ transplant. Prog Transplant. 2012; 22(3):271-9.	Wrong participants – no lung transplant recipients
32. Ullrich G, Schmidt S, Scharf E, Penkert J, Niedermeyer J, Schulz W. Lung transplant recipients' views on the integration of their new organs. Disability Rehab. 2010; 32(9):713-722.	Wrong outcomes – views on integration with new lung

33. Lundmark M, Lennerling A, Almgren M, Forsberg A. Recovery after lung transplantation from a patient perspective – proposing a new framework. J Ad Nurs. 2016; 72(12):3133-24	Wrong outcomes - A re-analysis of data already included in the review ⁵² to develop a new framework
34. Lundmark M, Lennerling A, Forsberg A. Developing a grounded theory on adaptation after lung transplantation from intermediate-term patient experiences. Prog Transplant. 2019; 29(2):135-143	Wrong outcomes – not about self-management of experiences post-transplant

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Study: Dabbs 2006	
Theme: Positive attitude	
Finding 1	Takes news about complications in stride, remains optimistic about recovery. (C)
Illustration 1	I know that I will do well. . . I can tell things will go my way. p.387.
Theme: Inquisitive	
Finding 2	Asks for further clarification and explanations on rounds. (U)
Illustration 2	I want to know everything there is to know about my tests, medications, everything. p.387.
Theme: Independent	
Finding 3	Works around hospital routines and schedules to maintain her independence. (U)
Illustration 3	I'm an independent type. . . I'll get myself better and get home soon. p.387.
Theme: Involved	
Finding 4	Determines personal readiness to advance activity, diet, self-medication. (U)
Illustration 4	I've been involved in all aspects of my care up until now, and I'll continue to be after I leave the hospital. p.387.
Theme: Commitment	
Finding 5	Pushes self to perform physical activities (e.g., exercises, getting out of bed, walking the halls). (U)
Illustration 5	I will do what I have to; getting better and getting home is my job. p.387.
Theme: Resourceful	
Finding 6	Watches staff closely to learn ways of doing things. (C)
Illustration 6	I'll find a way to do almost anything I need to do; I'm used to solving problems. p.387.
Theme: Too self-reliant	
Finding 7	Too self-reliant - Recipient's spouse is used to making decisions without consulting clinicians. (U)
Illustration 7	I have to be in the driver's seat. p.387.

Study: Graarup 2017	
<i>Theme: Receiving a lung transplant is an overwhelming experience</i>	
This theme highlights the comprehensive life changes after lung transplantation. The transplantation 'event' is experienced as an existential turning point which changes the ways interviewees sensed their own body.	
Finding 8	The interviewees experienced gaining physical capacity and described their joy in physical activity. (U)
Illustration 8	'I have no shortness of breath and I feel like a 20-year-old again'. p. 3546.
Finding 9	Although many of the interviewees in this study mentioned doing everyday tasks that are a feature of healthy people's daily lives, they stated that the joy in doing these activities is related to their having suffered physical limitations in previous years. (U)
Illustration 9	'I found I could do a lot of things which were impossible before'. p.3546.
Finding 10	Another aspect of the lung transplant as an overwhelming experience is a sense of regained energy to be part of family. (U)
Illustration 10	'I have the energy to be part of my family and to love life again, and I can accommodate husband and kids again'. p.3546.
Finding 11	Male interviewees in the present study stated that taking up their roles combined with the possibility of returning to work was very important and significant. (C)
Illustration 11	They (male interviewees) described work as an important part of their identity; it allows them to have a life of their own, to have co-workers, to be able to contribute to the family and recreate a 'normal' daily life which gave them a focus on life where illness faded to the background of their consciousness. p.3547.
Finding 12	Although half of the interviewees described themselves as being highly motivated for post-surgery recovery, all of them said that motivation from family and close friends had been extremely important after transplantation. (U)
Illustration 12	'My family has been by my side from day one and has encouraged me'. p. 3547.
Finding 13	The interviewees also described how important relations of love are when it comes to a desire to fight for your life. (U)
Illustration 13	'My son said, "Mom you must promise not to give up"'. p.3547.
<i>Theme: Being troubled by physical and psychological challenges which reveals how the patients' body and mind are influenced by the transplantation 'event'.</i>	
Finding 14	The interviewees felt that these difficulties sometimes overshadowed the pleasures of the life they had expected, after receiving a lung transplant. Some of them suffered from nausea,

	vomiting and stomach problems for weeks, and that chain of symptoms invariably led to fatigue and exhaustion. (U)
Illustration 14	'I had no appetite, thirst or strength, and I had constant nausea the first eight weeks. But I forced myself to eat. The pain made me tired and sad'. p. 3547.
Finding 15	Whereas insomnia could be a prolonged problem, especially if the interviewee had an acute rejection treated with Solu-Medrolin heavy doses. (U)
Illustration 15	'All the medication does you – you are not yourself. And you feel really 'crazy' from not sleeping'. p. 3548.
Finding 16	Some of the interviewees said that they had difficulties in adhering to the requirements of life post-transplant. (U)
Illustration 16	'it is a challenge for me to adhere to all the rules of my new life and to take the medication'. p. 3548
<i>Theme: A balance between joys and challenges expresses how the participants experience hopes and dreams of a future and do believe in life despite strict requirements in relation to health, concerns and uncertainty.</i>	
Finding 17	For the patient who is newly transplanted life was described with a sense of hope and freedom. (C)
Illustration 17	Interviewees experienced the feeling of having gotten another chance – having received life again and they were grateful to donors and the donors' relatives. p.3548.
Finding 18	Second many of the interviewees talked about travelling – like they had been travelling earlier in life. (U)
Illustration 18	'We will travel, rediscover and relive being a family'. p.3548.
Finding 19	A mixture of both positive and negative feelings was described in the present study related to the burden of these activities. (U)
Illustration 19	'I have come to the realization that if I want to live, I must take care of what I've got. I try with food and exercise to give my new lungs the best conditions, so I can hope for the best result'. p.3548.

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Study: Lundmark 2016a	
Theme: Regaining	
<i>This phase involved regaining vital functions after the transplantation which was done mainly at the hospital but also at home</i>	
Finding 20	All the informants were strongly focused on exercising. They went from fatalistic to focusing on restoring their everyday life and they all understood the importance of exercising. (U)
Illustration 20	'The exercise, I think that is very important. That I have been motivated to keep going. And it (exercise) is really important in the future as well'. p.2289.
Finding 21	A key strategy was a constant comparing with their pretransplant condition and noticing the progress post-transplant. In doing so they heightened the awareness of their progress and comparisons helped them to master setbacks and complications. (U)
Illustration 21	'Yes, but they are not so big these problems (complications), compared to what you had before, they become trivial after a while when you live with it'. p.2289.
Finding 22	Initially after the transplantation they managed recuperation by learning new skills. (C)
Illustration 22	This involved many physical aspects like learning how to breathe again and to walk but also mental aspects like comprehending that they actually could do things after transplantation that they hadn't done for a very long time. p.2289.
Finding 23	The informants used different types of coping. (C)
Illustration 23	For example, confronting the demands for exercise, noticing progress or accepting restriction p.2289.
Finding 24	Many used the strategy goal setting and worked hard to achieve their goals. (C)
Illustration 24	The goal setting could involve anything from riding a bike, taking long walks or being able to enjoy a hockey game with friends. p.2289.
Finding 25	All the informants were strongly focusing on their recuperation but in different ways. (C)
Illustration 25	They turned to positive role-models, that is, were inspired by other organ transplant recipients who had recovered successfully and regained health. p.2289.
Theme: Reorganising	
When still admitted to the hospital, the healthcare professionals were in charge of the informants' recuperation but at hospital discharge they were responsible themselves. This meant an insight of the need for reorganising their everyday life, that is, daily occupations.	

Finding 26	All of the informants had to relate to several adjustments in their new life as lung recipients and they were willing to do so by adapting to new conditions. This adaptation involved adjusting their daily occupations depending on complications and symptoms and doing things in new ways. (U)
Illustration 26	'Well of course it strengthens you when you notice the results getting better, so that has been positive.' Regarding complications "but that are things that, well I can still live a normal life so to speak.' p.2290.
Theme: Enriching The reorganization of daily occupations preceded the enriching phase where the informants started to direct themselves towards enjoying their restored everyday life and even more, appreciating breathing which enabled health	
Finding 27	With their ability to breathe came the possibility to manage and enjoy everyday life. (U)
Illustration 27	"I imagine that we who suffer from a lung disease and can't breathe properly, we can never imagine how it is to breathe properly. It is somehow such a utopian feeling, you can't describe it in words. Now you understand how easy it's supposed to be to breathe. You had no idea about that before. It's supposed to be this way and you kind of get used to it. You adjust after your own capability. And this I can't do and this I can, but now, there are no limits at all. I can do whatever I want'. p.2290.
Finding 28	After the informants had regained their physical strength, they valued their newfound capability of choosing activities in life. (U)
Illustration 28	"Now I do things I dreamt about before.' p.2290.
Finding 29	They embraced their new personality and the feeling of gratitude of being alive. In this phase most of the informants started to make plans ahead and hoping and believing became new strategies for the future. (C)
Illustration 29	"Now I feel as if life, now it has started.' p.2290.
Finding 30	By putting the past aside, they now wanted to move forward beyond their identity as transplanted and realising dreams. (C)
Illustration 30	'I focus on health and don't think that much about my illness." p. 2290.

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Study: Mathur et al 2021	
Theme: Honouring donors and second chances	
Finding 31	Motivations to be physically active were shaped by a moral imperative to honour their donors, as well as the apparent 'second chance' afforded to the respondents by their donors, and in some cases their donor's loved ones. (C).
Illustration 31	My lungs came from a young girl, and I communicate with her father through letters. I've been given this by them, and I have this responsibility to do the best with it. And if I sit at home and eat crap food all the time and do nothing, is that doing the best and honouring her and her family for their choice? It's just being lazy if I choose not to do it (lung & kidney) p.5.
Theme: Mental health: self-care and trauma	
Finding 32	Physical activity was identified as being a promoter of well-being, and thus a motivating factor. (U)
Illustration 32	"Exercises is like a break from the world. I'm just doing something for me (lung and kidney)" p.5.
Theme: Access to appropriate fitness training	
Finding 33	Some respondents pointed out that standard gyms might not be suitable resources for solid organ transplant recipients. (U)
Illustration 33	I had 20 to 30 percent lung function and [my trainer] had no idea how treat somebody who had 20% oxygen. So, I would be completely saturated, and he'd be like "come on more and more" and push me. And he just didn't understand that he's throwing me into a heart attack range (lung) p.5.
Theme: Rewards accounting for non-linear trajectories	
Finding 34	Participants sometimes experienced comorbidities or multiple health ailments, which prevented physical activity. (C)
Illustration 34	I've realized that I have to motivate myself to do stuff. Sometimes it's hard. I'm tired. Um, and I've had a number of medical issues along the way (lung) p.6.
Finding 35	For some, frequent illness was a sizeable barrier to PA, and respondents often experienced frustrations working towards fitness goals. (U)
Illustration 35	We're sick and unable to move, and then they're going to get penalized again on top of that, it would be, so I think that that's not necessarily very good (lung). p.6.

Theme: Transplant specific features	
Finding 36	Respondents showed interest in a tool that would aid in monitoring vital signs - lung transplant recipients had an interest in monitoring their oxygen levels (saturation). (U)
Illustration 36	To be able to track my oxygen saturation while I'm exercising so I can adjust my oxygen as needed- (lung) p.7.
Study: Sabati et al 2001	
Theme: health	
Sub theme: infection/rejection	
Finding 37	They adhered to home monitoring because it helped to detect early signs of infection or rejection. (U)
Illustration 37	'Keep an eye on things, especially after my first rejection'. p.181.
Theme: health	
Sub theme: Overall health	
Finding 38	They adhered to home monitoring to promote overall health. (U)
Illustration 38	'Make sure everything is going okay'. p.182.
Theme: Self care	
Finding 39	Many respondents noted that home monitoring makes them feel more self-reliant. (U)
Illustration 39	'Good way to keep abreast of how I'm doing'. p.182.
Finding 40	Responses reflected subjects' assuming responsibility for their health and progress. (U)
Illustration 40	'Interest and pride in knowing my progress' p.182.
Theme: Commitment to research	
Finding 41	Responses in the commitment to research category reflected the subjects' gratefulness for receiving a lung transplant and their commitment to assisting others. (U)
Illustration 41	'It's the least I can do to help out in research'. p.182.
Theme: Following advice	
Theme: Routine	
Finding 42	It appears that once subjects began, the process (use of electronic spirometry) became part of their daily routine and it was easy for them to continue using home monitoring. (C)
Illustration 42	"Keeps me on a routine and makes me more conscious for the rest of my self-care." p.182.
Theme: Commitment	
Finding 43	Subjects who had stopped using the electronic spirometry unit and then resumed use after receiving a telephone call from the research team indicated that they resumed using the home spirometry unit because they had made a commitment or their conscience bothered them when they did not use it. (U)
Illustration 43	'I signed up for it—I should be more committed'. p.182.
Theme; Time conflict	
Finding 44	11 subjects stated that they did not use the home monitoring unit because of time conflicts. (U)
Illustration 44	'I have a lot of other things to do' p.182.
Theme: Sick/upset with health status	
Finding 45	For many subjects in the non-adherers group, failure to use the spirometry unit was related to their poor health status. For some, this was a legitimate reason as they were frequently hospitalized. (U)
Illustration 45	'One subject noted, "Don't feel good; in hospital a lot." Another noted that he was "doing so poorly" and did not want to use the spirometry unit'. p.183.
Finding 46	For some subjects—particularly those experiencing possible rejection or infection—use of the spirometry unit was a reminder of their deteriorating status. (U)
Illustration 46	'Psychologically it was doing harm to me to watch the numbers go down—it was a sense of denial. I didn't want to see the numbers as I was thinking I was going through rejection.' p.183.
Theme: Felt healthy	
Finding 47	In contrast to subjects who did not transmit because of poor health, three subjects noted that they felt so good that they saw no need to use the spirometry unit. (U)
Illustration 47	'One subject stated, "At the time I felt so good that I thought it wasn't necessary, never had any lung complications. p.183.
Theme: See no benefits	
Finding 48	Four subjects indicated that they could see no benefit from using the home spirometry unit and thus had stopped using it. (U)

Illustration 48	'One stated, "It was worthless as I still got sick."' p.183.
Theme: See no benefits	
Finding 49	Patients didn't use the home electronic spirometry Unit as they saw it as futile. (U)
Illustration 49	Four respondents indicated that they "didn't know" of anything that could be done. One subject stated, "Nothing can help, it didn't work out for me." p.183.

Study: Seiler 2016	
Finding 50	Physical benefits encompassed significant improvements in physical function, vitality and health perceptions, such as being able to breathe again, being able to walk without supplementary oxygen, generally having more energy for conducting day to-day activities and being able to participate in sporting activities such as hiking, riding a bicycle and playing tennis, or being able to play music. (U)
Illustration 50	'It is crazy how quickly one forgets how bad it was before transplantation... I was no longer mobile; I could not feed myself; drinking was difficult; and going to the toilet required an enormous effort... I had to refuse to do many enjoyable things. My life was restricted by my poor physical condition. Today, I can breathe without being exhausted, I can walk without getting short of breath, and can speak or laugh simultaneous with walking'. p.550/551.
Finding 51	Despite significant physical benefits, patients also reported numerous physical complaints. (U)
Illustration 51	'It bothers me that I am still not physically fit. Even though I train regularly, I lack muscle strength and quickly get exhausted. I am very tired and need a lot of rest. After a busy day, I am so tired that I can hardly do anything'. p.551 .
Finding 52	Emotional distress also occurred because of the prolonged rehabilitation process, major adverse effects of medication, social isolation for fear of infections, insecurity in physical symptom recognition and in dealing with medication, and repeated hospital admissions. (U)
Illustration 52	'Physically, I am in good condition. However, when I was allowed to leave the hospital, suddenly I found myself suffering from a number of fears. I had great difficulties structuring and organizing my daily life. I quickly felt distressed and overwhelmed doing things that used to be easy for me. My wife worked full-time and could not be with me all day. I was not able to cope with the situation at home and felt like I was going crazy. So I let myself be hospitalized again'. p.551.
Finding 53	Patients were happy to again be able to take care of their family and to engage in social and cultural activities and pursue hobbies. (U)
Illustration 53	'Thanks to the transplant, I can again provide care for my family. At the time I was sick, I always felt I was a bad mother. This feeling bothered me deeply... Before transplantation, I had no energy at all and had to tell my children that they had to look after themselves or that they had to go somewhere alone. Today, I thoroughly enjoy that I can be there for my family. But I also enjoy that I can be independent again and I feel more like going out'. p.551.
Finding 54	The majority of patients anticipated that, sooner or later, their transplant would be rejected. (U)
Illustration 54	'The latent fear of rejection is always present. Every time I need to go to the clinic to check my numbers (e.g., oxygen levels, spirometry testing, pulmonary function tests, and blood tests), I worry about my health, even though I am feeling well. It is confusing, because you cannot rely on how your body feels; you can never be certain...'. p.551.
Finding 55	Approximately one-third of the patients reported that they perceived the new lungs to be part of themselves. (U)
Illustration 55	'Used statements such as "the lungs belong to me", "the lungs became part of me", or "I have fully adopted the lungs"'. p.552.
Finding 56	One patient gave the new lungs a name. (U)
Illustration 56	'the new lungs are my Empress, so I call them Sissi'. p.552.
Finding 57	A few patients expressed feelings of responsibility for their new lungs and that they have to take care of and look after (U)
Illustration 57	reported perceiving the new lungs as "a gift" or as "something of particular value" p.552.
Finding 58	Two patients had the feeling that their lungs had been repaired instead of replaced. (U)
Illustration 58	'The advantage is that you cannot see the transplant. If I had the hand of a Chinese woman, I would be constantly reminded that I carry something foreign. But I cannot see the lungs, so I can live with the idea that my old lungs simply got cleaned'. p.552.
Finding 59	Only a minority of patients mentioned perceiving their new lung(s) as a foreign object though this feeling tended to decrease over time. (C)

Illustration 59	They made statements such as “the lungs are something new”, “as of yet, the lungs have not arrived”, “the lungs need to get used to my body”, and “this represents a dynamic process that takes a while”. p.552.
Finding 60	In the early post-operative phase, patients were most concerned about dealing with the nausea and vomiting caused by their new medication. (U)
Illustration 60	‘In the beginning, I had to take the medications two or even three times because I vomited them all up .Even thinking about the medication, I had to throw up. I had troubles accepting that I have to take so many drugs’. p.552.
Finding 61	Concerns also related to long-term adverse effects and damage to other organs, as well as at the mercy of physicians. (C)
Illustration 61	‘The feeling of being at the mercy of the transplant team, without being involved in decisions, makes me feel helpless. Sometimes I feel like a passenger in a plane, but worse’. p.552.
Finding 62	Metaphorical concepts of treatment included the idea that drugs attack and destroy one’s body. (U)
Illustration 62	Patients referred to drugs as “little bombs”, “an enormous load of chemistry”, “a necessary evil”, and “an unresolved dilemma”. p.552.
Finding 63	Most patients were aware of the importance and necessity of their drugs (U)
Illustration 63	‘Mentioned advantages of the medical treatment included the following: “the medical treatment ensures that the lung is not rejected”; “thanks to the medication, I am doing fine”; “the drugs give me a chance to survive, a chance to live”; “without the drugs, the transplant won’t work”; and “they are protection against infections and rejection”’. p.552.
Finding 64	Restrictions referred to the large number of medications required and the strict dosing schedule. (U)
Illustration 64	‘My everyday life must comply with that strict drug schedule. I don’t feel free anymore; my life is determined by my medication regimen’. p.552.
Finding 65	Some felt that their required adherence to strict diets was somehow an invasion into their everyday life. (U)
Illustration 65	‘I cannot spontaneously go out for dinner with my husband because I have to be home in time to take my medications; and, when I want to go on holiday, I have to plan carefully what I need to bring. I have to think not only of my pills, but also my inhalers, the blood pressure meter, the home spirometer, the cold box for the medication... this is just tedious’. p.553.
Finding 66	Sustained motivation for regular medication intake stemmed from the belief that the medications were imperative for their survival. (U)
Illustration 66	‘The medications are indispensable to life’. p.553.
Finding 67	But also from a sense of commitment and responsibility towards the donor and the transplant team. (U)
Illustration 67	‘I feel obliged to take care of the matter, mainly out of respect for the donor, but also for the transplant team’. p.553.

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Study: Singer 2015	
Overall comment before themes	
Finding 68	Patients identified being alive to participate in life activities as critically important to their HRQL. (U)
Illustration 68	‘I am so grateful and I am healthy...I plan to find the donor’s family and show my appreciation to them too because I wouldn’t be here. I wouldn’t have the quality of life I have now or the quality of life I’ve been gifted down the road...I am lodging these [complaints], but they are so miniscule to the whole picture...they don’t even hit the radar screen as far as the whole thing’. p.1523.
Theme: Symptoms	
<i>Problems impacted by transplant surgery or the side effects of medications</i>	
Finding 69	Patients uniformly emphasized the importance of the palliation of respiratory symptoms and liberation from supplemental oxygen achieved by lung transplantation. (U)
Illustration 69	‘There’s not a backpack, there’s not cannula, you’re not hypoxic, you’re not dizzy anymore... I’m getting the oxygen that I need and that oversees everything’. p.1524.
Finding 70	Symptoms were commonly attributed to medication side effects and included neurological effects such as tremors or neuropathy; leg muscle weakness; gastrointestinal symptoms including difficulty swallowing, reflux, nausea, and diarrhoea; skin changes, including easy bruising and photosensitivity; insomnia; and chest and incisional pain. (U)

Illustration 70	'Before, I was always in the sun, always had my shirt off, and I never wore sunscreen, I hate sunscreen. That's the one thing that bugs me. Basically my solution so far has just been to stay out of the sun, I just don't go to the river, I don't hang out at the river. And I love sitting in the sun because it makes me happy'. p.1525.
<i>Theme: Transplant-related health outlook: Uncertain future health hinders life planning</i>	
Finding 71	Patients were keenly aware that approximately 50 % of lung transplant recipients die within 5–6 years after surgery. (U)
Illustration 71	'When I was in evaluation, they give you the sheet of paper that says 'rates of survival' and you see the one year, 95%, that's very hopeful. But then you see the number, I think it was five years drops to like 60-something, it was like...oh, that's only five years. I focused on that and I always feel that as technology's moving forward, these statistics are based on what's come before. And in the next five years there may be huge advances that may project these numbers way out. So I just always pull back and I'm trying to stay more in the present'. p.1525.
Finding 72	Younger patients struggled with whether to return to school, marry, or start a family. Others nearer retirement age decided that returning to work was no longer a priority (C)
Illustration 72	'Life's good at the present, right? But - if you look to the future... grasping or hoping or whatever...it's a futile attempt because there's not much you can do about the future'. p.1525.
Finding 73	Limited life expectancy and possible chronic rejection hinders ability to plan for the future. (U)
Illustration 73	'Well, it's just the unknown. You know, I don't think there's a day goes by where I don't think, how much longer do I have to live? I mean, I just turned 50 two months ago and so that's a concern.' p.1525.
<i>Theme: Transplant-related health distress Emotional distress caused by health concerns/issues</i>	
Finding 74	The constancy of allograft care and new symptoms after transplant caused considerable emotional distress. Patients were reminded daily that they are never free from disease or the need to take numerous medications. Many struggled with interpreting the importance of new subtle signs or symptoms. (U)
Illustration 74	'So it is kind of hard for me to gauge if I am really sick or not. I don't want to be sitting at home for two weeks thinking nothing is going on and it is. But at the same time I don't want to be calling off the hook ... driving everybody nuts, driving myself nuts when there's nothing going on ... there's no "normal" for me to follow'. p.1524.
Finding 75	The intense allograft monitoring requirements also contributed to fear and anxiety. Fear and worry that transplant will not 'work', including fear of eventual death and other complications/ health issues. (U)
Illustration 75	'I ... try not to go there too often mentally, but there's always a chance this might not work... that little gray area where there might be rejection and suddenly everything would be different. So there always is that kind of fear, but I try not to go there too often. I just kind of stay... in the present, and know that I am feeling good ... I can't look too far forward'. p.1525.
Finding 76	Worry about misinterpreting symptoms or signs. (C)
Illustration 76	'I feel guilty because people ... say, 'You're alive.' I say, 'I know I'm alive... I'm not saying I'm not grateful to be alive, I am so grateful to be alive.' But at the same time it is hard, just hard, you know, every day... And if it can be better...I'm human, I would like it to be better'. p.1525.
Finding 77	Never free from disease or its treatment. (C)
Illustration 77	'I was scared off my ass on that [infection]...you think about it when you wake up. You go to bed and you think about it. Then you need a Valium or something to knock you out because you'll just keep - your mind will just keep going'. p.1525.
<i>Theme: Risk of transplant-related illness Risk of infection and allograft rejection due to immunosuppression</i>	
Finding 78	Patients understood they were always vulnerable to infection and acute rejection. (U)
Illustration 78	'I try not to go to places that are too crowded... I am protecting myself from other people'. p.1525.
Finding 79	A patient recalled his struggle to balance his susceptibility to infection and his relationship with his wife. (U)

Illustration 79	[My wife] being a teacher ... we were going to hose her off before she came in the house every day from work ... she routinely sanitizes her hands before she gets in the car to come home ... we just kind of keep separated'. p.1528.
Theme: Cognitive limitations Reduced ability to perform mental processes	
Finding 80	Patients encountered problems with forgetfulness, reasoning, confusion, and maintaining focus. (U)
Illustration 80	'I used to be very good with numbers, you know, I could remember people's telephone numbers, addresses, and everything else, and I just kind of lost a little bit of that. I used to be able to do mathematics in my head very easily... it seems like I slowed down a little bit on that'. p.1526.
Theme: Depression symptoms	
Finding 81	Depressive symptoms were particularly common and were affected by many factors including medications and limitations on intimacy, socializing, working, and physical functioning. (C)
Illustration 81	'So psychologically it has been hard trying to find a baseline for me where I feel that I'm ok up here [points to his head] without worrying about stuff going on because there's no black and white for me'. p.1526.
Theme: Intimacy <i>Challenges to physical and emotional closeness</i>	
Finding 82	Challenges to physical and emotional closeness. (U)
Illustration 82	'I haven't had any sex since the surgery. [Patient was 8 months post-transplant]' p.1525
Finding 83	'Early after transplant, patients expressed concerns that physical intimacy could harm their surgical site or lung allograft itself'. (U)
Illustration 83	'[My wife] was afraid ... There was less touching and feeling and such things just because she ... didn't want to hurt anything'. p.1529.
Theme: Social relationships <i>Change in self-identity and transplant-related experiences alters relationships with others</i>	
Finding 84	Patients' perception of their identities became partly defined by their status as lung transplant recipients. This perception impacted friendships and the ability to relate to others around shared experiences or outlooks on life. (U)
Illustration 84	'If you're not careful you can make everything about "me," and I think there was a little time where that happened...what I want is to be actually functioning with other human beings...I didn't want my entire life to become this bloody surgery'. p.1529 .
Finding 85	For others, overcoming adversity engendered a new capacity to support and relate to others. (U)
Illustration 85	'I tell people, "Oh, I had a transplant," and they're, "Oh my God, are you OK? I am so sorry for you." I was like, "Dude, don't be sorry, be happy for me, it's awesome, you know, it's really cool." ...when anyone else with CF or someone else [is] getting a transplant and they figure that out and can talk to me, it's a really powerful and uplifting thing to be able to be there'. p.1529.
Finding 86	All patients acknowledged the burden experienced by their caregivers. Expressions of gratitude were common. (U)
Illustration 86	'On the relationship front, [my wife] was there for me. She took care of me [for] two years...when I was sick... slept in the hospital beds and weird stuff for me... so I asked her to marry me'. p.1529.
Theme: Body image <i>The effects of surgery and medications on perceived physical appearance</i>	
Finding 87	Immunosuppressants, particularly corticosteroids, caused distressing changes in physical appearance including hair loss/gain, weight gain, and skin fragility. (U)
Illustration 87	'I am gaining a little bit more weight, for some reason I'm constantly hungry lately, and they increased my Prednisone, my God, just can't eat enough it seems like...I don't like gaining weight'. p.1527.
Finding 88	Chest scarring, swelling or numbness causes insecurity. (U)
Illustration 88	'I'm still not healed...the scars are not going to be where anybody can see them...I'm never going to wear a two-piece suit'. p.1527.
Theme: Treatment burden <i>The impact of medications, testing, monitoring of the allograft on daily life and finances</i>	

Finding 89	Even after the first several months when the intensity of testing and follow-up care and number of medications prescribed decreased substantially, some patients continued to struggle with the daily requirements of allograft maintenance. (U)
Illustration 89	On another the day-to-day living is the hardest waking up every morning and think, "Oh, here we go again." It's constant. It's constant. It's relentless, it doesn't stop.'p.1530.
Finding 90	The impact of medications, testing, monitoring of the allograft on daily life (U)
Illustration 90	'The way I feel now...is a good quality of life. Although I gotta take medications and attend meetings and appointments and all this, but that's nothing, you know?
Theme: Spirituality and transcendence <i>Transplantation is a transformative experience</i>	
Finding 91	Nearly all patients found the lung transplant process to be a positive transformative experience and time of substantial spiritual growth. (U)
Illustration 91	'I just reflected on what has happened quickly and I thought, I am going to be a better person for this, the profound change that's happened in my life. It's really stuck with me, and I think that I do try to be kinder to people... I think I do have a more Zen kind of way of looking at the world since transplant'. p.1527.
Finding 92	Patients were acutely aware that they perceived the world and prioritized areas in their life differently than before transplant. (U)
Illustration 92	One thing is that I never thought about... as much as when I was dead and then recovering and ...all of a sudden you realize, especially when you see your family who are just wide eyed and crying, you realize how important this whole system of life is. Without the transplant that happened... wouldn't have it's an awakening'. p.1530.
Finding 93	Overcoming death and achieving new potential for life redefines priorities and sense of self. (U)
Illustration 93	'I just don't worry about things, I have very strong faith, and I really live my life and I have fun and I help people...And even if I did die tomorrow, I would be totally cool with that...I pretty much eradicated my whole, entire fear of dying through that aspect'. p.1527.
Finding 94	Spirituality helps patients through transplant or is rediscovered after. (U)
Illustration 94	'Without [cystic fibrosis and lung transplant], I wouldn't have my understanding and awareness of my own mortality, and that to me has been a big catalyst in my spiritual growth. And that, in turn, affects my music, and the lyrics in that...people are really moved and touched by the positive messages in it'. p.1527.
Theme: Physical functioning <i>Limitations in physical activities due to health</i>	
Finding 95	Limitations in physical activities due to health. (U)
Illustration 95	"The biggest problem is the lack of physical ability. So that's what gets me the most. It's constantly, it's day in, day out, 24 hours a day. It's, you know, from getting up to use the bathroom, in the night, or just stuff, that you wouldn't think twice about. Going out, I notice every little hill that most people wouldn't notice. Even a slight one will make a difference on whether I'm exhausted at the other end of it'. p. S1.
Theme: Role physical <i>Problems with work or other daily activities as a result of physical health</i>	
Finding 96	Problems with work or other daily activities as a result of physical health. (U)
Illustration 96	'Because going clothes shopping, it's like I can't walk around the stores, I can go from the car to a store. Going in and trying clothes, I just can't do it. It's hard'. p. S1.
Theme: Body pain <i>Pain severity and its interference with normal work</i>	
Finding 97	Pain severity and its interference with normal work. (U)
Illustration 97	'I still have like an incisional pain at the plate. And I've had this for two years. The sternum is just – I mean it's very sensitive'. p. S2.
Theme: General health <i>Self evaluation of current health, resistance to illness and future health</i>	
Finding 98	Self evaluation of current health, resistance to illness and future health. (U)
Illustration 98	'Well, there's no question, since the lung transplant, I feel a lot better. Although I might have some of these new problems but I think that is to be expected'. p. S2.
Theme: Vitality <i>Amount of time felt tired and energetic</i>	
Finding 99	Amount of time felt tired and energetic. (U)

Illustration 99	'My main issue is kind of fatigue... Maybe I am more aware of it because of the transplant too, and there's certainly issues with medications and things that make you feel different'. p. S2.
Theme: Social functioning <i>Physical health or emotional problems interfere with normal social activities</i>	
Finding 100	Physical health or emotional problems interfere with normal social activities. (U)
Illustration 100	'They [friends] call all the time. A friend of my called on Saturday to go over to a barbeque. It was going to be a Saturday night and I just can't do it. I mean, I do go out occasionally in the evenings, but usually it is afternoon... So, it really is a problem and I think it really affects my social life, especially in the evenings... So, it's like my world has got significantly smaller'. p. S3.
Theme: Role emotional <i>Problems with work or other daily activities as a result of emotional problems</i>	
Finding 101	Problems with work or other daily activities as a result of emotional problems. (C)
Illustration 101	'[Discussing an altercation with his employer] You know, you can call me mistaken, but you don't sit there and call me a liar. So I asked for a boss and I pretty much stopped the whole floor with my [yelling]. Well, I got home and thought about what I said, because I probably used some language I shouldn't have. I knew I was wrong for my language, but I did flip out, and that's the only bad part I've had out of all the drugs and everything'. p. S3.
Theme: Mental health <i>Amount of time felt emotional distress (nervous, down in the dumps) and wellbeing (peaceful, happy, calm)</i>	
Finding 102	Amount of time felt emotional distress (nervous, down in the dumps) and wellbeing (peaceful, happy, calm). (U)
Illustration 102	'Before I had a transplant, probably I was more fretful about things than I am now. Because I was almost dead. Now I'm fully alive again, so I try not to worry'. p. S4.

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Thomsen and Jensen 2009	
Theme: A second chance unequivocal	
Finding 103	A second chance could be expressed in the following way: (U)
Illustration 103	I am deeply thankful to the person who donated organs; I am grateful to have regained life, to have been given a second chance to live. p.3475.
Theme: An ordinary life without chronic rejection	
Finding 104	Participants claimed that they had regained the freedom to do whatever they pleased, to have a satisfactory life. (U)
Illustration 104	'I also have a boat that I sail – and live in – in my Summer holiday, you know, time passes as in the old days before the operation' p. 3474.
Finding 105	Although the participants considered all their problems as 'minor' compared with getting their lives back, side effects of the medication, such as warts, skin cancer, back pain and infections, were the most inconvenient problems. (U)
Illustration 105	'I have had a thingy on my nose, I had it removed and then I had a small one here as well, it was also removed. I became anxious as I thought it could be something bad'. p. 3475.
Finding 106	Participants also focused on their own life length compared to that of other lung transplanted patients and they worried if their 'lung brother/sister' got critically ill. (U)
Illustration 106	'It is true that I live on borrowed time and I know that; It does not overshadow my everyday life, but of course I am aware that I am in no position to make plans for the next 10 years'. P. 3475.
Theme: Even minor daily activities take time with chronic rejection	
Finding 107	All participants wished to take care of themselves as far as possible in terms of personal hygiene, cleaning and washing. (U)
Illustration 107	'Just to take a bath and tidy myself up and stuff like that take time, even on a good day'. p. 3475.
Finding 108	Struggling with daily activities could be expressed as follows. (U)
Illustration 108	'A bad day is when I hardly get dressed; a bad day is when I am in bed for most of the day, or lying on the couch ...' p. 3476.
Theme: Need for support and knowledge	
Finding 109	Personal support by family, relatives or fellow patients was highly rated. (U)
Illustration 109	'But she (a daughter) has been extremely supportive without even being aware of it that I needed her and there was a reason to fight' p. 3474.

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Main finding: Physical activity	
Finding 110	Most participants deemed physical activity important to remain healthy and prevent physical deterioration (n=10), such as muscle stiffness, dialysis, and especially weight gain. (U)
Illustration 110	'I need to remain active, otherwise my weight will increase' p.7.
Finding 111	Most physical activity was obtained from executing activities of daily living, such as cleaning, shopping and working, and participants considered these activity levels as being sufficient. (U)
Illustration 111	'Why would I exercise? Where would I go? I'm not going anywhere without a goal, I do everything on foot' p. 8.
Finding 112	Participants experience a range of factors that limit them in their physical activity. (C).
Illustration 112	Bad weather is the most prominent (n=12), with nearly all stating to be more active during summer. p.8
Finding 113	Eight participants acknowledged being too tired or lacking sufficient energy regularly. (U)
Illustration 113	'I did my groceries and then visited a friend in the hospital, I was so tired'. p. 8.
Finding 114	In between was 'physical discomforts' (n=11), with mainly pain, muscle cramps and shortness of breath. (U)
Illustration 114	'When I was ready assembling that IKEA-closet, it felt like I ran a marathon, I completely collapsed and took the next day off'. p. 8.
Finding 115	Others tried certain strategies to increase their activity - more specifically, being active with others. (C)
Illustration 115	(e.g., participating in a walk that was organized by the patient association), was an enjoyable strategy for six participants. p.8.
Finding 116	In addition, eight participants stated that they owned a stationary bicycle or cross step. (U)
Illustration 116	'That will be here!' [Participant 15 points at the living room where seats are put aside and a stationary bicycle is facing the television] 'I have balancing problems, so this is ideal. I ride it every day while watching the news, sometimes even with my pyjamas on.' p. 9.
Finding 117	Finding solutions to overcome these difficulties would presumably not help, as insufficient motivation was often the underlying reason. (U)
Illustration 117	'...I shouldn't look for excuses, if it would stand here, I still wouldn't use it, I don't really like being active.' p. 9.
Main finding: eating habits	
Finding 118	However, not all participants understood why following a diet was good for their health. (U)
Illustration 118	'Because if you're transplanted, are your blood vessels more sensitive to fat? They tell us to take care of our foods, but sometimes you wonder why' p. 9.
Finding 119	In addition, knowing how to translate all 'hospital dietary and eating instructions' into daily life was by far the most frequent difficulty participants encountered. (U)
Illustration 119	'Actually, I know very well what I'm expected to do. Doing it, that's something else' p. 9.
Finding 120	Likewise, six participants admitted to violate the guidelines occasionally. (U)
Illustration 120	'(Partner of participant 3) I like eating my steak medium rare. It should be well done for him, but we don't like that. (Participant) I just take a very small piece then.' p. 10.
Finding 121	Being tired of eating the same foods was also perceived as difficult. (U)
Illustration 121	'Actually, I should eat more vegetables, but sometimes I'm just fed up with it. [sighs] Always lettuce and carrots, I'm not a rabbit you know!' p. 10.
Finding 122	Finally, the majority of participants (n=11) indicated that healthy eating was time consuming, as witnessed by the commonly heard phrase. (U)
Illustration 122	'I didn't have time to cook, so I drove to the take-away' p. 10.
Finding 123	Some participants were very creative in finding ways to overcome hindrances. (U)
Illustration 123	'(Participant 6) I keep a lot of things in an Excel-file on my computer...I always ask a printout of my blood results in the hospital and when I'm home, I enter them here and it shows in this graph. Here you see my personal creatinine level and the ideal and permitted level... It's still too high, but I'm making progress. p. 10.
Finding 124	Some choices were mistakenly held for healthier. (U)
Illustration 124	'I have to avoid salt. I do use sea salt sometimes and that's not a problem ...' p. 11.
Finding 125	Additionally, deviations from personal routines, like having visitors (n=4) or holidays (n=3), or unexpected events, tended to make 'guideline adherence' more difficult. (U)
Illustration 125	'On Sunday morning, my children and grandchildren came over. Then we have a full breakfast: I go to the bakery, bake eggs and bacon, and everything that goes with it'. p. 11.
Main finding: immunosuppressive medication taking	
Finding 126	The vast majority of participants understood the importance of taking their immunosuppressive medication, as well as taking them every day at the same time (i.e.

	importance of regularity of medication intake), and many found ways to make medication taking a routine. (U)
Illustration 126	'At first it was 8AM and 8PM, but I gradually changed it to 12 o'clock. I'm a student and I found out those are better hours. If I want to go out, I don't want to wake up the next morning at 8AM to take my medication'. p. 11.
Finding 127	Participants found it unclear how strictly the medication regimen needs to be followed and what an 'acceptable deviation of the usual hour of intake' is. (U)
Illustration 127	'They say it's okay to take your medication up to 4 hours after your scheduled time of intake' (Participant 1) to '8 o'clock is 8 o'clock. It's never 7h30 or 7h45, always 8, every day!' p. 12.
Finding 128	These broad interpretations often were consequences of believing that immunosuppressive medication do not always need to be taken at the same time that strictly, and the transplant team often played a role in this misconception (n=6). (U)
Illustration 128	'I can't take my pills when going to the outpatient clinic. I have to take them when I leave and it's sometimes noon, so it's probably not that important'. p. 12.
Finding 129	Many patients also did not know what to do when being late with their medication, and do what seems to be most logic to them. (U)
Illustration 129	'If I'm 3 hours late, I still take them, if I find out in the middle of the night, I wait for the next dose.' p. 12.
Finding 130	Participants told us how others remind them to take the medication (n=8), like family or even pupils, by placing them in sight (n=7), setting alarms (n=10) and linking medication intakes to other routines (n=13). (U)
Illustration 130	'I always watch the news at 7PM, and then I know I have to take them' p. 11.
Finding 131	All except two participants took their medication with them when going away. (U)
Illustration 131	'That's a method I developed! All the medication I need is in that 'purse' [laughs]. It used to be in a drawer, but that's easy to forget if you're going out. Or I put that one in my pocket if I go to the hospital for example'. p. 12.
Finding 132	Most participants also have a routine in preparing medication, by keeping a small medication stock in a closet, drawer or box, or by having a fixed time (n=11) or place (n=7) to prepare them in smaller cups for the upcoming days or the next scheduled intake. (U)
Illustration 132	'Every day! It's a routine. I take the pills out of this big box I bought 7 years ago, and take them out of the package, because I recognize them without it. Next, I put them in these plastic cups with the hours written on, can't miss! My wife always does a double check. Then I place them on the box with my thermometer, the thing to blow on [spirometer] and my diary and put them by the sink. p. 13.
Finding 133	Furthermore, some keep track of their stock and intakes in a diary or Excel-file. (U)
Illustration 133	Yes [opens diary], here I write my daily temperature, the number I've blown and the weekly weight. And here, I fill in my medication: red for the morning, blue for the evening'. p.13.
Finding 134	Many still experienced adherence issues, because of falling asleep or oversleeping (n=3), forgetfulness (n=5), being busy (n=11) or interruptions in their routines (n=14). (U)
Illustration 134	'We had a Christmas party and my family came over. It [cell phone] was lying next to me, it went off and I thought 'I'll do it later' because we were talking. So I told my partner to bring them [medication] to me, but he was busy in the kitchen. I saw them standing when we were cleaning up, I felt so bad!' p.13.
Finding 135	Some were aware of available solutions, but considered these not suitable for them for various reasons. (U)
Illustration 135	'I know many people who set the alarms of their cell phone, but that wouldn't work for me. It already contains so many alarms from my agenda, it wouldn't work'. p.13.
Finding 136	In contrast, some participants did use strategies, often presented by transplant professionals, which they found unhelpful, cumbersome or even hated. (C)
Illustration 136	'When we're in the waiting room at the outpatient clinic, we very often see other patients quickly filling in their medication intakes and temperatures in their diary, unbelievable! [...] I do always mark most of my medication intakes for the upcoming weeks, because I don't like filling it in.... If something does change along the way, I just delete it. p. 14.

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Finding 137	He was following the posttransplant medical regimen, doing everything he was supposed to, but still felt depressed, had pain, and was expressing extreme frustration about not being able to live life to the fullest. (U)
Illustration 137	'It's got to get better. Of all the people in the world, I should be living life to the fullest. Two of the reasons are this depression and this pain, and there has to be something we haven't

	figured out yet because I'm taking medications for everything else and I still feel this way, It's very depressing to tell about my day because every day is the same'. p.5.
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