







# Expectations of patients awaiting lung transplantation: A qualitative study

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## Abstract

**Aim:** The main aim of the present study is to examine the expectations and feelings of people awaiting lung transplantation.

**Background:** The assessment of the benefits of lung transplant should consider, among other things, the subjective perceptions of patients about the procedure, especially in relation to the context and to their values, goals and expectations. This is an issue that has not been studied in depth, especially in Spain.

**Design:** Exploratory qualitative study.

**Methods:** Data were collected through semi-structured interviews during the period of being on the waiting list for transplantation. Thematic analysis of the data was supported by the Atlas.ti software.

**Results:** The study population comprised 16 patients awaiting lung transplant, a number sufficient to reach data saturation. Four categories were identified to describe patients' feelings and expectations: (1) reasons for undergoing the transplant, (2) expectations about life post-transplant, (3) emotional state, and (4) relationship with the healthcare team.

**Conclusions:** Patients have high expectations of lung transplantation. They see it as offering them a second chance at life, although the future creates uncertainty. The healthcare professionals are identified as key actors, providing essential support and information throughout the various stages of the process. Future research should explore recipients' experiences of lung transplant at later stages.

**Relevance to clinical practice:** It is important to adapt care through all the lung transplant process, which is accompanied by intense and complex emotions since the beginning. Thus, providing social and psychological support from the beginning may contribute to their health status, helping them deal with all the emotions and feelings experienced, and find balance between expectations and reality.

**Patient or public contribution:** Sixteen patients awaiting lung transplant were interviewed. Interview transcripts were returned to participants to check for accuracy with their experiences.

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**KEYWORDS**

expectations, healthcare professionals, lung transplant, patient experience, qualitative research

## 1 | INTRODUCTION

Today, lung transplantation (LT) is a widely accepted therapeutic option in patients with advanced and progressive chronic respiratory disease once all other treatments have been exhausted. LT prolongs survival and patients' quality of life (Román et al., 2011). According to the Spanish National Transplant Organization, 362 lung transplants were performed in Spain in 2021 (Organización Nacional Trasplantes, 2021), and the Hospital where the research was carried out was the centre with the highest transplant activity, having surpassed the figure of 1000 LTs in adults since 1990. Despite this significant growth, waiting lists for LT remain long; the mean waiting period at our hospital is 56 days. It is a well-established fact that there are a total of 260 centres worldwide that perform lung transplantation. As of June 2018, a total of 65,200 LTs have been carried out, with 81% of them being bilateral. It is worth noting that the number of these procedures has consistently increased over the years and is expected to continue increasing in the future (Chambers et al., 2019).

LT aims not just to increase survival, but also to improve health-related quality of life. In recent decades, health systems around the world have introduced person-centred care models (Al-Sahli et al., 2021) in which the incorporation of the patient's perspective is essential to guarantee that the outcomes measured are the ones that patients view as the most important, and thus encourage their participation in decision-making (Hsiao & Fraenkel, 2017). According to the World Health Organization (WHO Quality of Life Assessment Group, 1996) the assessment of the benefits of clinical interventions should include the patient's subjective perception of life in the context of their value systems, goals, expectations, and standards. An awareness of the patients' expectations can increase their participation in care, identify more realistic outcomes and influence the impact of an intervention on their quality of life, thus aiding the design of new strategies for improvement adapted to real needs.

There are numerous studies on quality of life before and after LT (Ochman et al., 2019; Seiler et al., 2016; Singer et al., 2013; Staçel et al., 2020; Thabut & Mal, 2017). Few of them, however, have explored patients' expectations. Studies using qualitative methodologies remain relatively rare in the transplant literature, but this approach brings unique strengths to many research areas by providing insights into people's behaviours, attitudes, beliefs, and values (Bogue Kerr et al., 2018; Tong et al., 2013), managing to personalize the attention and improve the quality of the care offered. The main aim of the present study is to examine the expectations and feelings of people awaiting LT.

## 2 | METHODOLOGY

Exploratory descriptive qualitative study of people with advanced lung disease, refractory to medical treatment, who are candidates

for lung transplantation, at a Hospital in Spain. Patients were recruited by purposive sampling technique in order to achieve sound results. Inclusion criteria were age over 18 and no language difficulties, while patients with particularly severe conditions or pending retransplantation were excluded. Finally, a sample of 16 patients was obtained, sufficient to reach data saturation. The expression of feelings and thoughts by the participants was favoured. The sensitivity of the data being collected was taken into account. Therefore, one of the main investigators, a psychologist, who was able to guide on how to approach possible emotional situations arising from delving into the experience of the patients, and in selecting the questions. There were no other risks associated with conducting the study. Approval was obtained from our hospital's Research Ethics Committee (PR 490/2019).

The main researcher (OMS) works as a nurse in the hospital. She contacted the participants on the day they agreed to join the waiting list. Patients received oral and written information about the study, and they were able to ask any further questions. After confirming their willingness to participate, they provided signed written consent and a date to conduct semi-structured interviews was agreed and scheduled. The first author conducted all interviews following a semi-structured interview guide based on four thematic areas (Table 1). Interviews were conducted at the outpatient consultation, lasted approximately 45 min and were recorded and transcribed verbatim by OMS. The first interview was used to validate the content of the questions. Interview transcripts were returned to participants to check for accuracy with their experiences (Guba & Lincoln, 1994).

The analysis was carried out by RGI between January and March 2021. Information was collected and analysed simultaneously

**TABLE 1** Script of the semi-structured interview

### 1. KNOWLEDGE

What meaning do you give to the transplant?

What do you know about the transplant?

Who has informed you? With the knowledge you have of the lung transplant process, how do you feel about it?

What do you need to know?

### 2. FEARS

How do you feel about the transplant? What are the emotions associated with the transplant?

Are you afraid of the transplant? Why?

What worries you most about the transplant? Why?

What motivations do you feel before the transplant?

### 3. QUALITY OF LIFE

How would you describe your quality of life right now?

How did you feel when you decided to go on the LT list? How did you make that decision?

How do you imagine the transplant process?

### 4. EXPECTATIONS

What do you expect from life after the transplant?

And your expectations? How would you like the whole process to evolve? How do you see your life in the future?

(Sandelowski, 2008) using the thematic content analysis proposed by Braun & Clarke (2006), with the support of the software Atlas.ti® version 8. Data were collected until information saturation was reached, that is, when the data collected were repetitive and did not add anything new to the results (Taylor & Bogdan, 1984). The interviews were read once in order to identify the main meaning, and after that coded according to the content found, and later grouped into categories. Verbatim extracts from the interviews were used to illustrate the results. The reporting guideline COREQ was used (Booth et al., 2014). In order to ensure the trustworthiness of the qualitative methodology, an exhaustive analysis of data collection and processing was carried out (Guba & Lincoln, 1994; Shenton, 2004). In this line, to guarantee the rigour of the study, we followed the methods outlined by Guba and Lincoln (1994). These included: (1) Ensuring credibility by having two participants review the data and confirm the accuracy of the themes and sub-themes in relation to their personal experiences; (2) Ensuring dependability by consulting with two experts with a background in qualitative research to verify the meanings we had formulated; (3) Ensuring transferability by accurately transcribing the verbatim text of each interview for presentation in the study; and (4) Ensuring confirmability by carefully storing the original materials for future reference and verification.

### 3 | RESULTS

Interviews were conducted with 16 participants, eight women and eight men, with a mean age of 56.7 years. Their expectations about the transplant are summarized under the four categories and ten subcategories displayed in Table 2.

#### 3.1 | Reasons for undergoing transplant

The main reason for patients to request lung transplant is the impact of their pulmonary pathology on their daily lives. Among the severe disabling symptoms they mention, cough, sensation of permanent suffocation, extreme mucus, pain, tiredness and fatigue stand out.

*"The feeling is that I am always exhausted and out of breath. I don't want this; I've always been very active and now I can't do anything. If I think what I used to be able to do... now I can't walk 100 meters without getting tired"* (P 013).

*"I'm exhausted, I can't walk, I get tired, I'm short of breath, I have a lot of pain when I cough. I am 65 years old, and I feel as if I were 80"* (P 016).

The treatments prescribed to deal with the symptoms have entailed a great physical and emotional burden for patients for many years. They find the situation overwhelming. The treatment they find most tiresome is the need to inhale oxygen and to carry the cylinder around them.

*"I've been in hospital so often, I've had some terrible years, always under medication, always catching infections"* (P 016).

Their pathology makes them feel dependent on other people and on their medication. They want the transplant in order to feel free and to fend for themselves. Some describe themselves as prisoners, and report feelings of uselessness. The limitations are so extreme that they do not recognize themselves and say that they have lost their identity.

*"Now I need a machine to go out and another to be at home. And that's right, you can't do anything by yourself. Without the machine I would die"* (P 006).

| CATEGORIES                           | SUBCATEGORIES                  | CODES   |
|--------------------------------------|--------------------------------|---|
| Reasons for undergoing transplant    | Severe symptoms                | Cough, choking, mucosity, pain, tiredness, fatigue  |
|                                      | Treatment overload             | Feeling overwhelmed, oxygen, medication, wearout  |
|                                      | Loss of freedom and identity   | Dependence on people and objects, prisoners of the disease, feeling of uselessness, do not recognize themselves |
| Expectations of life post-transplant | Live better                    | Happiness, second chance  |
|                                      | Live longer                    | Only option, family   |
| Emotional state                      | Fear                           | Intervention, complications, waiting times, organ rejection, death  |
|                                      | Feelings towards the new organ | Uncertainty, new organ, different sensations  |
|                                      | Motivation                     | Strength, fight   |
| Relationship with healthcare team    | The importance of information  | Resolve doubts, individualized care   |
|                                      | Gratitude                      | Proximity, excellent treatment, resolution  |

TABLE 2 Categories of qualitative analysis

### 3.2 | Expectations of life post-transplant

Most participants hope that the transplant will improve their quality of life and allow them to live longer. They are not happy as they are, and the transplant is their only hope for a better life. They see it as a second chance, an opportunity to do everything they want, without feeling sick and limited.

*"I want to be born again, a new beginning, I am getting worse and worse and I see it day by day. Born again. The other day I had an appointment and I wondered whether they'd tell me I was going to have the transplant"* (P 015).

*"To improve my quality of life and get back to normal, after what I've been through. It's like being born again"* (P 007).

The testimonies show that participants regard the transplant as the only way to continue sharing their lives with their families.

*"In the end, I'd prefer to die on the operating table than to live like this, every little extra bit of life is important. And I hope it will last a few more years"* (P 007).

### 3.3 | Emotional state

Fear is the emotion most frequently mentioned by the interviewees: fear of the surgery itself, fear of complications, concern about being able to resolve family and work issues before the intervention, concern that the call confirming that there is an available organ will not arrive, but above all, the fear that the transplanted organ will be rejected and that they will die.

*"I am afraid for my family, I have three small daughters and my husband died a year and a half ago. They only have me and if something happens to me... It is a major operation [...] I am afraid that after a while something will happen to my immune system and that it will reject the lung. I am afraid of dying"* (P004).

*"Well, I'm worried they won't call me, or that it'll be too late when they do. I am 40years old and I think about my children and about whether my wife will be able to handle everything alone... That scares me a lot. I don't sleep well thinking that it will take a long time to find a lung for me, or that in the end they won't be able to"* (P 011).

The fact that they will be carrying an organ that is not the one they were born with, or that it comes from a deceased person, can also generate discomfort and uncertainty; they do not know what they will feel, or how they will react in this new situation. They feel they may need psychological support to deal with this emotional maelstrom.

*"It makes you feel uneasy to think that someone has to die so that I can go on living and that they've put a piece of that person in me. I don't know how I'll react afterwards, if I'll accept it, I mean psychologically"* (P 012).

Despite the emotional toll of the situation, most of the participants state that they have the strength to continue; they have the motivation to go on fighting.

*"I've already cried enough, I cry inside, I allow myself the luxury of crying one day because I feel bad, but the next day I dust myself off and*

*go forward. I have to be positive and think that everything will be fine"* (P 004).

*"I'm so excited about being able to resume my normal life, thinking about this motivates me and gives me strength. For me it's everything, to live again, this is what the transplant can give me"* (P 007).

*"I feel motivated to enjoy life, after all I've been through, and take advantage of what life gives me. I am 100% sure that my life will change—well, if not 100%, 99%"* (P 009).

### 3.4 | The relationship with the healthcare team

The participants stress the importance of feeling informed throughout the process. They report that the health care team has always been very willing to answer questions and offer all the necessary information. The ability to share those moments with the health care team makes them feel that they are being treated as people, not just as patients.

*"Yes, faced with an unknown situation, obviously I have my doubts, but the health care team always explained everything to me. Information is power, and in my case it has been peace of mind"* (P 008).

All the participants report having received excellent, hands-on treatment; they continually thank health professionals for their commitment.

*"I've felt very supported as if they were my family, if I have a problem I call them. I only have words of gratitude"* (P 001).

## 4 | DISCUSSION

The results of this study identify the reasons why patients on the lung transplant waiting list want surgery: namely, the severity of their symptoms and the progressive decline in their quality of life due to the burdensome treatment that they endure.

It is well known that an illness forces people to adapt to a new reality (Sacks, 2009). Starting from self-determination theory (SDT) (Ryan & Deci, 2017), a recent systematic review exploring the experiences of people living with a chronic disease (Eassey et al., 2020) emphasizes as a key emerging theme the fact that people with a chronic disease basically yearn to "live a disease-free life", and suggests that living with disease puts to the test the three basic psychological needs posited by the theory of self-determination: the senses of autonomy, competence, and relatedness.

People on the lung transplant waiting list face specific problems because their physical condition and autonomy are compromised (Rosenberger et al., 2012). For example, having to depend on artificial oxygen for a large part of their daily activities (Ivarsson et al., 2011; Rosenberger et al., 2012), the frequent medical complications and recurrent hospital admissions, the demanding treatment they must undergo while on the waiting list and the need for social isolation to avoid infection place major limitations on their daily life (Skogeland et al., 2018). All these problems undermine their sense of autonomy, competence, and relatedness.

As outlined above, the participants in our study highlight the loss of freedom and identity as one of the reasons why they want a transplant. These results corroborate those of the narrative review of qualitative studies conducted by Skogeland et al. (2018), who suggested that precisely being on the waiting list offers the hope of a life without the limitations imposed by the disease, especially social withdrawal (Skogeland et al., 2018). Similarly, other studies use the term “life in limbo” to refer to the experience of the period on the waiting list (Macdonald, 2006), and suggest that during this time of waiting for a new organ, life is, in some way, on hold (Ivarsson et al., 2011). Indeed, a review of qualitative studies of patients on the waiting list for a kidney transplant identifies the restriction of freedom during this waiting phase as one of the key themes (Koons & Smeltzer, 2018).

For all these reasons, the present study suggests that for patients with severe pathology, the option of undergoing a transplant and the power to decide whether or not to proceed with it may favour their sense of autonomy, as it offers them a certain sense of personal control over their condition. In addition, it seems to offer them the opportunity to regain a sense of connection or relatedness with others because it mitigates their sensation of being isolated. Finally, it may improve their sense of competence, in terms of their perceptions of their capacity for self-care (Eassey et al., 2020; Ryan & Deci, 2017).

The opportunity of a lung transplant allows prospective patients to imagine a future with fewer limitations. The participants clearly stated that they hope to live longer and enjoy a higher quality of life. These findings are consistent with the results of a qualitative systematic review of the experiences of heart, lung, and heart-lung transplant recipients, which found that patients regard transplantation as a chance to lead a life with a much better state of health (Stubber & Kirkman, 2020). The testimonies recorded in that study recall those indicated by our patients, with expressions such as “second chance”, “back to normality” and “resumption of life”.

Indeed, one of the emotions most frequently mentioned by patients scheduled for a lung transplant is hope (Brügger et al., 2014), and the prospect of a better future. In that study, patients on the waiting list imagined what it would be like to breathe with healthy lungs and, like our participants, what everyday life would be like without the limitations imposed by their disease (Skogeland et al., 2018).

Patients on the waiting list also experience fear, as reported by a recent qualitative systematic review (Stubber & Kirkman, 2020) of the experiences of recipients of heart, lung, and heart-lung transplants. Those authors noted that their patients frequently reported feeling afraid both of the transplant and its implications and also of the disease itself.

The process of getting on the waiting list and staying there is recognized as a long, stressful experience (Macdonald, 2006) and a time associated with great psychological vulnerability (Magán-Uceda et al., 2015). The literature suggests that levels of anxiety prior to transplantation are higher than after it (Ågren et al., 2017). Coinciding with our findings, previous work has found that anxiety, fear and uncertainty are common emotions while waiting for the

transplant, as are doubts about how the process will unfold and what the results will be, including the fear of dying (Burns et al., 2017). The risk of organ rejection is another concern (Evangelista et al., 2003), and being on the waiting list causes unease (Koons & Smeltzer, 2018; Rosenberger et al., 2012), as patients worry about whether the organ will arrive and how long they will have to wait (Burns et al., 2017)—and also about the potential complications (Evangelista et al., 2003), the threat to survival posed by the disease (Magán-Uceda et al., 2015), fear and concern for their families (Evangelista et al., 2003) and, finally, apprehension about the surgery itself.

Among the other main categories or subthemes that emerged from the data analysis were the patients' feelings towards the organ and the donor. One of the common concerns reported by patients before transplantation is not knowing how they will feel about the new organ. These results are consistent with the issues reported by kidney transplant recipients, both before and after surgery (Amerena & Wallace, 2009); those authors noted that patients need to adapt to a changing sense of themselves and also to the “alien organ” in order to establish a positive relationship with it. Also coinciding with our findings, a study of heart transplant recipients stressed that participants needed to accept and adapt to the change of organ and bear in mind the possible complications deriving from its rejection and subsequent treatment (Sadala & Stolf, 2008).

About feelings towards the donor, the participants in this study are well aware that in order for the transplant to be carried out, it is necessary for someone to lose their life. In other studies, this finding has been associated with a feeling of “existential” guilt (Skogeland et al., 2018) arising from the ethical issues inherent to organ donation (Fedson & Siegler, 2010). Transplant recipients may experience a sensation of inadequacy, feeling responsible for the disease that requires the transplant or for awaiting the death of a suitable organ donor (Stubber & Kirkman, 2020).

In contrast, the participants in this study also expressed feeling motivated and strong enough to continue moving forward. This motivation is essential and it is important that candidates for transplant should have the resources needed to avoid maladaptive coping strategies that indicate emotional distress and depression (Yorke & Cameron-Traub, 2008).

As this and other studies have shown, from the very beginning the lung transplant process is accompanied by intense and complex emotional experiences (Brügger et al., 2014). The results suggest the coexistence of feelings of fear and unease alongside hope and motivation, describing the emotional situation typical of a liminal state (in this case, being on the waiting list) understood as an intermediate phase in their health-disease process. A previous study focusing on kidney transplant also highlights this paradox and internal conflict by juxtaposing the feelings of discouragement and anxiety associated with the disease process with the hope provided by the transplant and the opportunity of a new life (Amerena & Wallace, 2009). Another phenomenological study that focused on the experiences of kidney transplant recipients also bears out the paradoxical nature of these experiences, between health and illness, between self and other, and between life and death (Bogue Kerr et al., 2018). For this

reason, those authors propose using the concept of "transliminal self" to refer to the complexity of the experience of a transplant process.

In relation to the experience of the care received, this study underlines the importance of receiving comprehensible information, the rapid resolution of problems and doubts, and individualized and personalized attention. All participants felt that the information they received was appropriate for them. In contrast, a recent study of patients with cystic fibrosis undergoing transplantation identified the need to offer more detailed information to broaden their understanding of the situation, and also the need for greater coordination in treatment transition issues, earlier introduction of the transplant option, and broader social support (Smith et al., 2020). These differences are likely to be related to the point in the care process at which the study is carried out, since the perception of our participants may differ pre- and post-transplant. In parallel, in a study exploring patients' perceptions of care and their nursing care needs while waiting for a lung and/or heart transplant (Yorke & Cameron-Traub, 2008), information was identified as one of the key topics, alongside regular contact and familiarity. The clinical staff are an invaluable external source of both psychological and practical support, highlighting the value of appropriate information at all times (Stubber & Kirkman, 2020). Previous studies suggest that in patients awaiting transplant it is essential to pay attention to psychosocial factors throughout the care process, highlighting the key role of support, information, help and comforting (Ågren et al., 2017).

Similarly, Macdonald (2006) described emotional support from the healthcare team, and practical support as the disease progressed, as being essential. Those authors stressed the importance of the information provided by the medical and nursing team. The psychological support offered by nursing throughout the process, especially during the waiting phase, may help to alleviate some of the anxieties or fears experienced by patients, and it has been shown that the nurse-patient interaction can influence health outcomes and the general well-being of patients with severe chronic conditions (Yorke & Cameron-Traub, 2008). Finally, the participants in this study, in common with those in other reports (Ivarsson et al., 2011; Yorke & Cameron-Traub, 2008), felt close to their careers, were grateful for the attention received, and felt accompanied at all times.

## 5 | LIMITATIONS

Despite the small sample size, reaching data saturation ensured the rigour and transferability of the results in territories with similar health policies contexts. Therefore, the results cannot be generalized, which is a characteristic of the methodology used. While this is a single-centre study, it is a reference hospital as patients from various communities come to be attended.

## 6 | CONCLUSIONS

People on waiting lists for surgery have a very low perception of quality of life. They are obliged to live with their pain and endure

significant physical and social limitations; they regard transplantation as the only possible option and accept the risks involved. The expectations placed in the transplant are high and it is conceived as a second chance. However, the post-transplant future is uncertain. Finally, the health team is identified as a key part of the entire process, an element of support and a vital source of information.

These results suggest that the lung transplant process is a complex emotional experience, thus highlighting the importance of social and psychological support.

Future research should explore recipients' experiences of lung transplant at later stages, in an attempt to determine whether their pre-surgical expectations of quality of life are met after they have received the new organ.

## 7 | RELEVANCE TO CLINICAL PRACTICE

Our findings highlight the importance of adapting care through all the lung transplant process, which is accompanied by intense and complex emotions since the beginning. Being on the waiting list implies the coexistence of feelings of fear and hope, expectations about the transplant are high and the opportunity of a lung transplant allows patients to imagine a future with fewer limitations; thus, providing social and psychological support from the beginning may contribute to their health status, helping them deal with all the emotions and feelings experienced, and find balance between expectations and reality.

## 8 | IMPACT STATEMENT

**What does this paper contribute to the wider global clinical community?**

- Patients on the lung transplant list place high expectations in the transplant, as the opportunity of a lung transplant allows them to imagine a future with fewer limitations and the transplant itself is conceived as a second change.
- Being on the waiting list implies the coexistence of feelings of fear and hope and the lung transplant process is accompanied by intense and complex emotional experiences. Providing social and psychological support to potential recipients of a lung transplant from moment they are included in the waiting list may contribute to their health status, helping them deal with all the emotions and feelings experienced, and helping them to find balance between expectations and reality.
- Nurses and health team need to be aware that they are a key part of the entire lung transplant process, and are seen as an element of support and a key source of information.

### AUTHOR CONTRIBUTIONS

Study conception and design: (OMS, RGI, JLM, MAG, REF). Data collection: (OMS). Data analysis and interpretation: (RGI, CW). Drafting of the article: (OMS, RGI, CW, EZP, JLM, MAG). Critical revision of the article: (OMS, RGI, CW).

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**CONFLICT OF INTEREST**

The authors have reported no conflicts of interest.

**DATA AVAILABILITY STATEMENT**

Data available on request due to privacy/ethical restrictions.

**ETHICS STATEMENT**

This study was approved by our hospital's Research Ethics Committee (PR 490/2019).

**TOPIC/QUESTION: DESIGN/TYPE OF PAPER**

Exploratory qualitative study conducted in Spain. The study population comprised 16 patients awaiting lung transplant.


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