

Experiences of supportive care when waiting for a lung re-transplantation

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Abstract

Objectives: Lung transplant patients and their next of kin share the experiences of illness but little is known in the face of a lung re-transplantation. To describe patients' and next of kin's experiences of supportive care while awaiting lung re-transplantation and the objective was to highlight a small group with special circumstances and needs.

Methods: Using qualitative content analysis, seven adult patients and seven next of kin were consecutively selected from a regional lung transplantation centre and individually interviewed shortly after decision about lung re-transplantation.

Results: The experiences of supportive care were captured in one main category: 'once again haunted by death' and three sub-categories: 'when life turns and death once again snorts down your neck', 'the importance of information', and 'perceptions of support'. A complex interaction between the experience of waiting, and communication patterns, emotional states, and social support was shown.

Conclusion: This study provides insights into the complex interaction between the experience of waiting for a second lung transplant and communication patterns, emotional states, social support and social roles between patients, next of kin, healthcare professionals, and the health and social welfare system. There is a need for developing supportive care programme to achieve the best possible care.

Keywords

Advanced lung disease, chronic illness, experiences in everyday life, family, pulmonary re-transplantation

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Introduction

To be accepted for the waiting list for lung transplantation is life-changing for the patients¹ and for their relatives,² and it may be assumed that a second pulmonary transplant (re-LTX) may be even more special.

The main reason for a patient being in need of primary lung transplantation is obstructive pulmonary disease, restrictive lung disease, lung disease with chronic infection or pulmonary hypertension, and a lung transplant may be the only way to survive.³ Regarding re-LTX, bronchiolitis obliterans syndrome is the most commonly reported diagnosis.⁴

After the primary lung transplantation, life for most patients returned to relatively normal, but was lined with life-long medication and regular follow-up visits in healthcare.⁵ Although patients who have received a lung transplant have better physical and mental health after, compared to before, transplantation, their lives are still characterized by uncertainty and anxiety and they are in need of continued support

from the healthcare system.⁶ The patients are often also in need of practical support and assistance from, for example, the municipality and the social insurance services.^{7,8} Frequently, problems occur in contact with or between agencies that are not directly involved in patient care,^{7,8} and patient's relatives experience an increased workload.⁹ Serious complications such as early or late organ dysfunction or rejection, infection, respiratory problems, or pulmonary embolism are not uncommon in both early and late after lung

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transplantation.^{5,10} Physicians have reported that patients and their families have unrealistic expectations of lung transplantation.¹¹ On the other hand, lung transplant patients lacked information about the risks and complications.⁷

Re-LTX represents a small sample of all lung transplants performed worldwide, but has been increasing in recent years.¹² In the Nordic countries, 75 re-LTXs occurred between 1992 and 2013.⁴ The need for re-LTX depends on the medical disease,¹² but there are discussions regarding whether or not the patients' own adherence to the treatment contributed to the need for a re-LTX.¹³ There are also ethical discussions.¹² Selection criteria for re-LTX are similar to those for the initial lung transplantation. The survival rate after re-LTX has improved over time, but is worse than after the primary lung transplantation.^{4,12} Healthcare professionals, patients, and families may feel uncomfortable about discussing end-of-life care when patients are waiting for the first lung transplant. There is also plenty of uncertainty regarding the timing of such discussions and regarding who among the healthcare professionals is best suited to be responsible for them.¹⁴ Unmet palliative care needs have been found in the cardiopulmonary transplantation care and palliative care are proposed to take place in parallel with active management.¹⁵ Naturally, these difficulties also exist when facing a re-LTX. Supportive care is a broad definition that covers all support and information that patients and their next of kin (NoK) would need in connection to a disease and treatment. The concept supportive care is often used synonymous with palliative care and is in many ways comparable.^{16–18} Supportive care aims to relieve suffering and provide information, communication, and support in order to ensure the best possible quality of life for patients and NoK alike.^{16–18} Studies that illustrate how supportive care is perceived by patients, awaiting re-LTX, and their NoK are missing, and this study is a first step on the road towards a greater understanding thereof. The care strategy for these extremely ill patients, and their NoK, should instil hope for the future but also, in parallel, include all aspects of supportive care. Hence, the aim was to identify and describe patients' and NoK's experiences of supportive care while awaiting re-LTX.

Methods

The study has a descriptive qualitative design, using interviews, conducted between 2009 and 2013, and analysis according to content analysis. The study was approved for ethical permission from the Regional Ethical Review Board, Lund, Sweden (Ref. No. LU 638/2008).

Setting and sample

The study was performed at Skåne University Hospital in Lund, which has one of Sweden's two lung transplant centres with approximately 15 patients per year receiving either

a single or bilateral lung transplant. Inclusion criteria were lung transplanted patients, and that 2 weeks should have elapsed since they were again placed on the waiting list for a second transplantation. Participants should be able to read and understand the Swedish language. The patients were identified through the transplant waiting list and they received an information letter sent home by ordinary mail. Then, the first author (B.I.) called the patients to provide information about the study and invited them to participate. The patients also chose their NoK for interviews. Seven patients (three women, four men) and seven NoK (seven women, whereof four partners, one sister, one daughter, and one friend) have been interviewed individually (Table 1). Participation in the study was voluntary and participants could, throughout the process, cancel any involvement without this affecting the care. Informed consent was obtained through oral and written information, and the free will to participate was emphasized.

Data collection

The data collection method has been that of recorded interviews made in the patients' or NoK's home (5), at hospital (1), or by phone (8). An interview guide was used with questions about the patient's and NoK's experiences, thoughts and needs, and about the implications of the transplantation associated with supportive care. The opening questions were as follows: How would you describe the support related to your situation? How would you describe information/communication related to your situation? Probing questions were also asked. The interviewer (B.I.) was not involved in patient care but was skilled in dealing with sensitive subjects. The interviews were digitally recorded and then fully transcribed and critically analysed.

Data analysis

The answers were analysed by means of qualitative content analyses, inspired by Graneheim and Lundman.¹⁹ The process of analysis of the content consisted of several steps. First, in order to provide a sense of the whole, the raw material was read through several times, looking for similarities, differences, and extremes. Second, statements made by the respondents were identified as expressions in the form of relevant words, sentences, and paragraphs related to the aim. Third, the statements were systematised and coded into sub-categories and an abstraction and condensation of the result was carried out. This developed categories of description. Graneheim and Lundman¹⁹ found increasing reliability of the analysis examined by persons who are familiar with the topic and research based on text content, and who are familiar with the interpretation of the text, hence the co-author's (T.S.) involvement in the analysis. Representative quotation was used to illustrate the respondents' experiences.

Table 1. Demographic data and other characteristics of patients and next of kin.

	Patients (n = 7)	Next of kin (n = 7)
Gender		
Women (n)	3	7
Men (n)	4	
Age		
Mean \pm SD	49 \pm 13	44 \pm 13
Median (range)	52 (28-65)	40 (26-64)
Relation		
Wife/partner		4
Sister		1
Daughter		1
Friend		1
Civil status		
Single (n)	1	1
Married/cohabiting (n)	6	6
Education		
Elementary school (n)	1	1
High school (n)	2	3
College/university (n)	4	3
Diagnosis		
Cystic fibrosis (n)	2	
Pulmonary fibrosis (n)	2	
α 1-Antitrypsin deficiency (n)	1	
Pulmonary hypertension (n)	1	
Pulmonary emphysema (n)	1	
Time between the first transplant and the decision on a second transplant (month), mean (range); median	61 (36-97); 59	
Survivors of the waiting time for a second lung transplant (n)	3	
Waiting time on the waiting list for the survivors of a second lung transplant (weeks), mean (range); median	23 (7-34); 29	
Death on waiting list (n)	4	

SD: standard deviation.

Results

The patients stated that they cheated death with the first transplantation and that life took a new turn. In addition to their breathing improving considerably they could once again perform physical activities, such as climbing stairs, biking, and carrying things, which meant that they gained their independence since they did not need to ask others for help. Some patients had also been able to work again but when their strength ran out and they were bound to oxygen therapy they stopped working. The NoK were also positively influenced by the first transplantation. However, the unexpected had happened, the patients had once again become so sick that they had to be placed on the waiting list for a second lung transplant if they were to survive. This also affected the

NoK negatively. One main category emerged from the analyses: "Once again haunted by death": In this category three sub-categories were identified: "When life turns and death once again snorts down your neck", "The importance of information" and "Perceptions of support".

When life turns, and death once again snorts down your neck

Patient perspective. The patients had thoughts, both from a medical and an existential perspective, about why they were once again so hard hit. Several patients wondered whether higher powers wanted to test them. They expressed gratitude for the years they had received after the first transplant. They also expressed great hopefulness about having an active life again, but thoughts of death lured in the background. One person blamed himself for the deterioration and said it was due to travelling to countries with different climates, but this was not supported by the physician:

I've found a great deal of consolation from a book about the soul and not a whole lot about death ... I like to believe that the soul is beautiful and loving if things were to go all haywire ... (Patient 6)

The patients also had concerns about whether organs would be accessible to them in time. Opinions on current Swedish legislation were given and the patients could not understand why Sweden did not strictly follow the donation law and, without talking to NoK, just use organs from people if they had not previously registered their negative will concerning organ donation:

We're about seven to eight hundred people in the country sitting waiting for new organs ... on the day it happens [that someone dies and can become a donor] it's not so easy for the next of kin to make a decision about organ donation. I think people often say no because there's just so much else going on. (Patient 7)

NoK perspective. The NoK described that they experienced that patients regained their physical performance and a more positive state of mind after their first transplant. Thus, it now felt hard to see how the patients once more gradually deteriorated. They had questions regarding how many times a person could get a new lung and whether there had been progress in research which would make it possible to match the lung with the recipient to better fit this time. Most of the NoK had a scientific or fatalistic attitude towards the necessity of a re-LTX; they felt it was important to live in the here and now. The NoK were concerned about organ shortage, but they kept this concern to themselves. Most of the NoK stated that they used the strategy of never showing that they were sad in the proximity of the patients because they wanted to avoid burdening them. They also expressed some concern that relatives in the surroundings ignored the seriousness of the situation.

The importance of information

Patient perspective. Most patients had saved the information brochure they received before the first transplant and this written information was also used after the first transplantation, mainly for raising awareness of signs of rejection.

The patients expressed that healthcare professionals almost apologized that they were obliged to inform the patients orally once again before the re-LTX, but the patients said that they needed the updating. They were to some extent surprised that they received the same written information as the last time, even though in some cases, several years had passed since the first transplantation. There was an expectation that the written and oral information would be more focused on the special circumstances regarding a re-LTX, but this was missing:

Would have liked to know more about the risks involved. They say that retransplantation is more difficult. If they could tell you in what way, is it because it's hard to transport the new lungs or is it the actual operation that's more difficult? (Patient 1)

Patients told of how, before the first transplantation, the NoK had had difficulties accessing information from both the healthcare staff and the patients themselves. Last time it was the healthcare staff who had propagated for the involvement of the NoK in the information process as opposed to this time; now the patients were supposed, to a greater extent, to decide for themselves. Patients felt that this time they had come to realize the importance to having well-informed and involved families:

It was more like ... if you want we can (healthcare staff) give the information to your relatives and quite frankly, I think there's actually a greater need for information than you'd imagine. Because, I mean ... you're so in the middle of it all ... I don't think so much about how much deterioration that there really has been ... in, say, the last six months. But I think the next of kin do, I've seen that. And I suppose there're many questions that our next of kin would like to ask. (Patient 2)

NoK perspective. Patients lived in different family constellations and several of the NoK had concerns about the healthcare's view on the family members. In some families, where communication about the patient's illness and the upcoming transplant was sparse, the NoK respondents would think that maybe others in the family had received more information from the healthcare staff than they had. In spite of this, the NoK expressed that they had knowledge of the upcoming transplantation, and the time afterwards, from the former transplantation, which they felt was satisfactory. In contrast, they felt deeply worried about how the patients would fare until the transplant and would have appreciated being given detailed information from the physicians about just that. Some NoK described the feeling that patients knew more about the illness and prognosis but kept it to themselves:

It's not the actual operation I'm interested in, but rather the condition of the patient before and after the operation. (NoK 2)

The NoK expressed the understanding that healthcare professionals are bound by confidentiality and should not go behind the backs of patients with information. There was a desire for written information specifically designed for relatives, which would include the names of anyone in the transplantation team who would be able to answer general questions. In addition, data on patient associations and useful links on the Internet were requested. The relatives experienced that they used the Internet to access information to a greater extent than the patients did. They expressed that the information they found on the Internet regarding lung transplantation and aftercare was the same as that received from the transplant centre. They found it supportive to take part of positive experiences of previously lung transplanted patients on different chat forums, blogs, and so on. On the other hand, it was negative for the NoK not to be able to avoid others' negative experiences. However, on the Internet, they had not found anything about re-LTX or families with experiences of re-LTX:

To get some kind of confirmation that it's ok to feel like I do. It can also be a bit awkward to talk to someone who's having a tough time ... it can be misery and more misery. (NoK 2)

Perceptions of support

Patient perspective. The patients experienced that they were given support by specialist medical services at the transplantation centre after the first transplantation. However, they expressed that once it was determined that the patients were accepted and placed on the waiting list for a re-LTX, they felt that physicians and nurses were less available.

As the patients' physical strength decreased, most of them needed more and more help from the local authorities. The needs could for instance be to have help with oxygen, a wheelchair, toilet elevations, shower chairs, and so on, and this worked well. When it came to parking permission for the disabled or special medical transportation, the patients had different experiences. Some of these matters worked well, while others had great problems despite the fact that they even had trouble getting out from their homes on their own. Windy weather affected their strength greatly, and this was hard for people who had no knowledge of the disease to understand:

... I thought they [the municipal assistance administrators] went too far sometimes ... (Patient 1)

Some patients needed help in the home with personal hygiene, cleaning, cooking, and other activities. There was a great fear of being infected and therefore the patients wanted control over who would help them in their homes. This was

an obstacle regarding municipal assistance and some patients, despite their needs, waived help. There were also patients who waived help because they could not afford to pay for it. Most of the patients were worried about their strained economy:

Whoever's here needs to be free from infection, even the slightest little infection means that I'll be taken off the waiting list and can miss getting an organ. The municipality didn't know how to deal with this. I fixed it myself, with private assistance ... The municipality wanted to avoid paying ... That whole hassle isn't so easy. (Patient 4)

The NoK were very important for the patients, both when it came to getting practical help and emotional support, and also if there were underaged children living at home. Friends and colleagues were connected with the patient mostly by phone and social media and most often on initiative of the patients. This was due to the risk of infection and a lack of energy. Some patients also felt that it was hard to find topics of conversation when they were not in their normal social situations:

If they phone me from work I've got nothing new to say. I can't handle going through the whole story every time someone phones me. It's just too exhausting. (Patient 7)

NoK perspective. NoK felt that the support from the transplant team was better before the first transplantation. Now they lacked the connection to make questions both to physicians and nurses.

Some NoK were disappointed about the support the patients had received from the municipality and social insurance. Most NoK complained, to a greater extent than the patients, about a fragile economy because of the disease. One NoK said that his relative could not afford to buy the nutritious food that a transplanted person should eat. Some NoK had helped patients seek financial support when the patient's economy was too weak because of the disease. One NoK said that the insurance fund was responsible for the relapse of the patient because the patient lost the temporary economic disability support and therefore had to take on a heavy job:

... you wonder how long your body [the patient's] can put up with an uphill struggle ... and then we [the patients and the NoK] have to put up a fight with the authorities on top of that, it's just too much. (NoK 1)

The NoK expressed a great deal of concern when the patient had dependent children, and they felt that the patients needed more support, both in terms of informing the children and of gaining knowledge about the opportunities they had for getting help from the healthcare or society in general:

... could've needed more support in knowing how she [the patient] should speak to her children. Someone should've taken

the time to sit down and say our experience is that you should do like this and then followed up on that. (NoK 6)

Discussion

Summary of main findings

This study investigates the perspectives of both patients' and NoK's experiences of supportive care while awaiting re-LTX. It is well known among patients and NoK that waiting for a re-LTX can lead, on one hand, to a relatively normal life or, on the other hand, death. This study showed that after entering the waiting process again with its known perspective, patients and their NoK preferred talking about the future in an optimistic way rather than about the possibility of death. Existential emotions and fears of dying related to shortage of organs, and the eventuality of not getting new organs in time, were expressed by both patients and relatives.

Interpretation in light of existing literature

For the patients in this study, the waiting period terminated differently; three patients underwent a re-LTX while four patients died during the waiting period. This outcome stresses the fact that the transplant teams should embrace the World Health Organization's (WHO)²⁰ position of palliative care:

Palliative care is an approach that improves quality of life for patients and their families facing problems associated with a life-threatening illness. This is provided through the prevention and relief of suffering by means of early identification, accurate assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Colman et al.²¹ have recently stated that palliative care, including opioid therapy, can be given safely during the wait for lung transplantation. This study showed that a transparency of thoughts surrounding death did not exist and one contributing factor was that the NoK did not want to increase the burden on the patients with their anxiety. In contrast, it has been shown that patients awaiting lung transplantation want to protect families from emotional stress.²² For healthcare professionals, good communication is important in order to give hope to patients and family members alike and to meet realistic needs.²³

This study describes that both patients and NoK received oral and written information when the patient was accepted for a second transplant, the re-LTX. However, they lacked specific information from the healthcare organization on what a re-LTX means regarding risks, access to organs, and prognoses. It has been suggested that a multidisciplinary transplant team must discuss opportunities, risks, quality of life, and ethical issues with the patient and the NoK even before the decision to re-transplant is taken.²⁴ A review showed that re-LTX can now be performed safely for

carefully selected patients,²⁵ and it is very important that this is communicated to patients and their families. The patients in this study stated that a second transplant is not a personal matter and should include family members in the communication process with the healthcare professionals; also, there were some NoK who felt sidelined. Social media, which can be used by health professionals, patients, and relatives, has a great potential in terms information and support. It has been shown that the majority of adult lung transplant patients are willing to use Internet resources.²⁶ Apart from immediate access to peer support, the healthcare organizations can offer secure meeting platforms with personal logins for patients and NoK. In addition to providing a platform for patients to learn more about the illness and receive support, healthcare professionals can use social media to collect data for studies and thus improve the care.²⁷

In this study, the experiences of both the patients and their NoK regarding support from the healthcare, the social insurance offices, and the health insurance system were usually very diverse. Yet the authorities did not always take into account the patient's perspective, nor the fact that patients and NoK did not have knowledge of the types of resources that were available. Therefore, it is important that all officials from different organizations, who come into contact with the vulnerable and dependent transplant patients and their families, are responsive and take into account the patients' medical and financial needs. It is conceivable that a specifically dedicated nurse, who would secure for continuity and availability, could, by acting as coordinator, enable an adequate response to the wishes and needs for information and support of patients and relatives alike. Moreño²⁸ argues that the use of care navigation models can bridge the gap and amend failures in the care of patients.

This study confirmed that the patients' illness affects their everyday lives, which can include being a parent, a partner, the head of a household, a relative, a friend, and so on. The patients and their NoK struggled to maintain as comfortable a life as possible. To avoid misunderstanding and to reinforce the development of reciprocity, patients may need help in conveying the nature of the disease and in maintaining their preferred contact with their environment. Above all, ill parents with dependent children need extra support and it has been demonstrated that children are affected emotionally and also need information and support in connection to a parent's lung transplant.²⁹

Strengths and limitations of the study

To provide good quality throughout the research process, it is important to achieve the reliability that comprises credibility, trustworthiness, and transferability.¹⁸ A scattering of patients and their NoK that included different diagnosis, ages, and relationships meant that informants had different experiences and made it possible to highlight the supportive care from different angles, which strengthens the credibility. However, it would have been desirable that male NoK had been involved in the

study, but patients could freely appoint relatives. Trustworthiness was strengthened by that all the informants were given the same information about the study and that the same initial questions were asked all informants according to the interview guide. This was made to avoid inconsistency which easily can occur when data collection is done over a long time period.¹⁸ Since this study was based solely on data from seven patients and seven NoK, the described findings are limited in terms of generalizability. However, the study appears to give a reasonably comprehensive picture of the experiences that can exist while waiting for a second lung transplantation (which is very rare) and, in this, we believe that the study can serve to inspire patient organizations, healthcare professionals, and social agencies to improve the supportive care for both patients and their NoK in the present situation.

Conclusion

Patients in need of a lung re-transplantation are extremely ill. It is essential to instil the patients and their NoK with hope for the future, but in parallel to support them with all facilities of palliative care. This study provides insights into the complex interaction between the experience of waiting for a second lung transplant and communication patterns, emotional states, social support and social roles between patients, NoK, healthcare professionals, and the health and social welfare system.

Relevance to clinical practice

This suggests the need for developing better coordination between different healthcare actors and social agencies in order to achieve the best possible health for patients and their families despite their living within the confines of illness. One way is to developing supportive care programme to further improve the way in which care is offered to patients waiting for a second lung transplant.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval

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Informed consent

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