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## Relative's experiences before and after a heart or lung transplantation

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## **Abstract**

### **Background:**

Relatives take on great responsibilities during patients' heart or lung transplant process and a understanding for their situation is required.

### **Objective:**

To describe relative's experiences before and during the patient's hospital stay as well as during the first 6 months after a heart or lung transplantation.

### **Methods:**

Using qualitative content analysis, 15 relatives (eight women and seven men) aged 36-65 years were interviewed within 6 months of a heart or lung transplantation.

### **Result:**

Three categories that illuminate relatives' experiences have been identified: "Navigate specific circumstances", "Facilitate throughout the transplantation journey" and "Experiences of strength and weakness of information and support". The relatives reported involvement in the transplantation decision, peer support, information seeking, burden and coping.

### **Conclusion:**

Greater awareness about relatives' experiences with identification of appropriate support and information exchange between healthcare professionals and relatives is important. This awareness could provide benefits for heart or lung transplant patients, families and healthcare organizations.

**Keywords:** caregiver, communication, family, social support, spouses

## **Introduction**

Relatives play a major role supporting the patient undergoing a heart or lung transplantation. It is indeed stressful for the relatives when they realize that being listed for transplantation is a reality (1). Most patients make the decision to undergo the transplantation in collaboration with their relatives (2). During 2008-2010, at the time of this work, 11,411 heart transplantations and 9,778 lung transplantations were reported from more than 200 centers worldwide (3). It is widely known that patients waiting for heart or lung transplantation are worried about their relatives (4-6), and this concern is mutual (1). Research has shown that relatives of patients waiting for heart or lung transplantation worried about a rapid disease progression and death while the patient was waiting for new organs (7, 8). Most relatives suffer from uncertainty, fear and stress (7-9). These emotions persist after the transplantation, during the recovery period, and in some cases for years because of the risk of acute, or in the long term, chronic organ rejection and death (10).

The quality of life of relatives is strongly influenced by how the patients master their daily life and how the relatives experience the burden of being informal caregivers both before and after the transplantation (11-13). The relatives have an important role, and they are influenced by the state and progression of the illness (7, 8). During the waiting period, relatives tend to forsake their own needs, activities and friends in their daily life (8, 14, 15) and they experience an increased caregiver burden (16, 17). Studies have shown economic strain for more than half of the relatives of patients on the waiting list (18, 19). Therefore, different types of support and information are a matter of great importance for the relatives (8, 20, 21).

For patients, having undergone surgery, the postoperative recovery process, including the physiological, psychological, and social aspects were demanding (22). Transplant patients and their relatives felt that they had experienced something unique at the same time, which might contribute to a positive connectedness (9). Therefore it is important that healthcare professionals understand that patients and relatives undergo the process together (19). Despite the importance of relatives, healthcare professionals, to a great extent focus only on the needs of the patient (23). Relatives play a significant role for patients undergoing transplantation and there is a growing need for knowledge regarding the relative's experience before and after a heart or lung transplantation.

The aim of this qualitative study was to describe relative's experiences before and during the hospital period as well as during the first 6 months of recovery after a heart or lung transplantation.

## **Methods**

### **Design and participants**

A qualitative, descriptive and retrospective design was used. Serving as informants were fifteen relatives with a close relation to patients who had undergone a heart or lung transplantation about 6 months earlier. The relatives were chosen by the patients' themselves. The same patients had previously participated in studies regarding their own experiences in connection with the transplantation (6, 24). Demographic and clinical characteristics of the relatives and patients are shown in Table 1. The investigation conforms with the principles outlined in the Declaration of Helsinki (25). The Ethics Committee of Lund University, Sweden, approved the study (LU 638/2008).

### **Data collection**

Contact with transplanted patients was initiated via a letter of introduction. One of the investigators then called the patient and asks for permission to contact their relatives for an interview. The relatives were informed by letter about the purpose and methodology of the study, that their participation was voluntary and that they could withdraw from the study at any time. The relatives were later contacted by phone and asked whether they agreed to participate, and if so, where they preferred the interview to take place. Before the interview, the patient and the relative gave their written consent and were guaranteed confidentiality

The interviews were semi-structured and used a conversational approach. Demographic data such as age, education and profession was collected as a part of the interviews as well as information relation to relatives' experiences of information and support. The opening question asked about their experience of information during the waiting time until the present

followed by a question about their experience of support during the same period. Follow-up questions were also asked for clarification and to continue the conversation. The interviews, conducted between August 2008 to November 2009, took between 13 and 59 minutes to complete and were conducted either in their home [6], at the patient hotel of the hospital [5] or done as telephone interviews [4]. The interviews were undertaken in a dialogue form and all interviews were audio-recorded and professionally transcribed.

### **Data analysis**

A qualitative content analysis of the text was performed as proposed by Burnard (26). The analysis was carried out in five different steps according to Graneheim & Lundman (27). First, the text was carefully read through as a whole to capture an overall understanding. Second, the text was read through focusing on identifying meaning units that were related to the purpose. The number of meaning units provided by each relative varied between 12 and 27. Third, the meaning units were extracted from the text and condensed. Fourth, the condensed meaning units were abstracted into codes and subcategories that met the study aim. Three overall categories were formulated (27). The concept of validity in qualitative research is illustrated through credibility, authenticity, criticality and integrity (28). To ensure credibility, one researcher (TS) made a detailed examination of the first researcher's (BI) coding and categorization, and adjustments were made until consensus was reached as Graneheim & Lundman advocates (26). Authenticity pursued by depictions in form of quotations to exemplify the findings. Criticality and integrity are achieved by repetitive checks of interpretations, critical analysis and reflexivity.

## Results

Relatives' retrospective experiences could be extracted as three main categories and eleven subcategories. The main categories are labelled "*Navigating through specific circumstances*", "*Facilitating the transplantation journey*", and "*Experiencing information and support*".

Table 2 provides an overview of the main categories and subcategories.

### *Navigating through specific circumstances*

The first main category was separated into four subcategories describing experiences of relatives' involvement in the transplantation decision, reaction to the call for transplantation, how they were influenced by the patients' condition and the circumstances regarding the patients' dependent children.

#### **Involvement in decision-making about the transplantation**

Relatives were able to participate in the discussion with the patient regarding whether the patient should accept to be a candidate for transplantation or not. However, the relatives pointed out that they wanted the patient to make the final decision by themselves, since they did not want to feel guilty should the outcome be poor. When a patient finally made the decision the relatives were pleased because they realized how sick the patient was.

*"I said to her [the patient], that I could not say yes or no ... Should something go wrong, would I be able to bear it?" R 6*

#### **Reaction to the call for transplantation**



A crucial point for the relatives was the transplantation call, regardless of whether they had the possibility to follow the patient to the hospital or not. The relatives described the call as a positive surprise and as a start of something new and vital for both themselves and the patient.

*“Another [patient’s] mother said that when it was NNs turn, ‘Good luck with the future.’ I thought: Exactly. I understood on a deeper level that it wasn’t over . . . Our journey in some ways is ahead of us.” R 12*

### **Influenced by the patient’s condition**

Before the transplantation, the relatives worried and closely followed the patients’ health status. After the transplantation, relatives of patients with uncomplicated transplantations experienced great relief, and even allowed themselves to think about the future. The awareness of what could be ahead for the patient regarding rejection, cancer and medication side effects were described as difficult. Relatives to patients suffering from complications in connection to the transplantation were anxious about the outcome and subsequent treatment. They expressed uncertainty regarding the patients’ present and future health.

*“Sometimes one has a positive outlook. But when he [the patient] doesn’t feel well I worry. Will his organ be rejected? One has to be prepared that that can happen at any moment, so it can be very hard.” R 14*

### **Circumstances regarding dependent children**

Relatives with underage children, who are parents together with the patients, lived under special circumstances. They described the importance of adequate information from healthcare professionals, given in an educational, age-appropriate and individual way without

scaring the children. The relatives pointed out that the children's well-being had priority over their own need of support. The relatives stated that they received support and help with the children from other next of kin and friends, including practical assistance. However, some relatives described that they had not received any help from health services because the municipality's assistance was limited only to the sick.

*“I have a fantastic mother-in-law.... She has helped me to manage practical matters.... I drove our children to school and then NN to the hospital and my mother-in-law picked them up and fixed food. Towards the evening I came home and took over.” R 11*

### ***Facilitating the transplantation journey***

This main category shows a variety of conceptions, ranging from peer support, information seeking, burden and coping in connection with support from local authorities, family and friends.

### **Meeting patient/family with experiences of transplantation**

Few relatives had met someone with personal experiences of transplantation, but those who had were very positive that they were given the opportunity. They found it helpful to talk to someone with personal experience and felt inspired, hopeful and confident of the future. Only a few relatives had received assistance in getting this contact. The relatives expressed that it was most important that the patients themselves were given the chance to meet with previously transplanted patients.

*“I would like to speak with someone who has undergone a transplant. My wife met a transplant patient but it was wasn't the same. It was hard for her whereas I was curious.” R 7*

### **Active information seeking**

Among the relatives, some sought information from other sources than through the healthcare system. Sufficient information from healthcare services and lack of time was the usual explanation from those who did not seek any information on their own. For those who actively sought information about transplantation, in addition to the information they received from healthcare professionals, it was by means of the Internet, newspapers or television.

*“I have visited the Swedish Heart and Lung association’s website. I have read about others that have undergone transplantation and how well Sweden is doing, that the Swedish system rates statistically well”. R 1*

### **Being preoccupied with practical and mental support**

The relatives described limited possibilities in their daily life compared to the life they had enjoyed before. Now the relatives spent significant time assisting the patient physically, psychologically or socially. Support given to patients in the form of parking permits, transportation services, shower chairs, wheelchairs, and house cleaning were described as a support to relatives in their role as informal caregivers.

*“I was unable to work full-time ... we wouldn’t have been able to manage it. NN [The patient] wouldn’t have been able to stay home as much. Of course, work has suffered”. R 9*

The relatives described their social networks, including family, neighbours, friends and colleagues, as being of great help and support in the form of social and practical assistance. Even though the relatives experienced important support from the social network, the network

of friends shrank because of their own lack of energy to maintain the contacts or the fact that the network retired. Sometimes the support was via letters and social media. At the same time, they described that they had high expectations of being able to invest in both work and private life, now that the transplantation was completed.

*“When I came home during the day, our neighbor came out. We didn't say much to each other, that was not necessary, but I knew he was thinking on us.” R2*

### **Handling the consequences of life-threatening situations**

Relatives described how they felt they got support from various kinds of activities, such as keeping pets, gardening, walks, choir and meeting other people than the patient. Most relatives felt support in some kind of faith or spirituality, in the form of a strategy to master the situation related to the transplantation. Regarding receiving an organ from another human being, it was described as a gift and they expressed that it was most important that the new heart or lung worked in the recipient.

*“It was a great sorrow for them [the donator's family] and a happiness for us. I try not to think where it [the organ] comes from actually. It's fantastic that one can do these kinds of things.” R 3*

### ***Experiencing information and support***

The third main category was separated into three subcategories, which describe experiences of support and information received or not received from the transplant team and other healthcare professionals, as well as the in-hospital time.

## **Receiving support and information from the transplant team and other healthcare professionals**

The relatives were pleased by the information they and the patient received from the multidisciplinary transplant team before the transplantation. They had also read the written information provided and used it as a reference during the recovery period. The relatives valued that they or the patient were allowed to contact the transplantation team and felt trust in and support from the team. Few relatives expressed that they had received emotional and practical support from social workers or any other healthcare professionals.

*“I read the information provided about the rate [of recovery] after a transplant ... It matches pretty well with our experience, that setbacks can happen, that recovery can go up and down. It was pretty good information.” R 5*

## **Feelings of being uninformed or unsupported**

The relatives missed information about the long-term prognosis both before the transplantation and afterwards. In retrospect, some relatives lacked contact with a social worker, although some expressed that they declined this assistance. Some relatives were frustrated with the way information was conveyed between the home hospital and the transplant center and most experienced problems around licenses, insurance and other paperwork. A few employed relatives felt that they did not receive sufficient support from their employer or their insurance. Some foreign-born relatives felt that although they and the patients could understand spoken Swedish, they had difficulty reading the information.

*“I have used up all of my vacation time when the situation was at its worst. I would have liked to have been able to take sick days instead. One needs a vacation when everything has calmed*

*down after the transplant. One is psychologically tired as one has worried about the situation for such a long time". R13*

### **Impression of the in-hospital time**

The relatives were thankful for the information, support and trust they received from the healthcare professionals during the patients' hospital stay before, during and after the transplantation. This applied to both personal contact and by phone. The relatives felt that they received adequate and straightforward information and explanations during the postoperative stage, even in cases where several complications occurred. They also felt that the nurses, surgeons and anaesthetists were available to talk to, and most relatives were pleased with the care, reception and support provided by nurses, assistant nurses, physicians, physiotherapists and social workers. They felt support in that they could call and come at any time without getting the impression that they were disturbing. All had been offered to stay at a hospital hotel but some had declined.

*"No one could have foretold ... health services could not have warned us of every possible scenario we might encounter. Complication after complication came ... The health professionals kept us informed the whole time about what they were doing and why. We received fantastic care at the hospital." R13*

## DISCUSSION

This study emphasizes the importance of relatives for the patients during the pre- and postoperative phases of a heart or lung transplantation and the results contribute to the understanding of the significance experienced by relatives. When the patients were given the possibility of a heart or lung transplantation most relatives wanted to play a supportive but not an advisory role. The relatives were afraid of feeling guilt if they strongly had advocated transplantation and the outcome then was bad. They did not want to live with that feeling the rest of their lives. Dominguez-Cabello et al. (29) found that relatives to liver transplant patients had significantly more anxiety and depression before the transplantation than afterwards. They associated this finding with the decision process and care of the patient in combination with responsibility for the home as well as other members of the family. In the present study the relatives felt that they, to a great extent, had to carry the heavy burden of the patients' physical, psychological or social needs. This is in line with Xu et al. (30) who showed that family caregivers to lung transplant patients actively supported the patients with healthcare more than seven hours every day.

The relatives in the present study expressed that they had positive feelings regarding the transplantation but also worried about possible complications, side-effects and the patients' overall health. This is in line with previous research in lung transplantation showing that an onset of chronic rejection is associated with serious concern for the relatives and reminds them negatively of the pre-transplant stage (31).

Earlier research has shown that patients, waiting for heart transplantation, with dependent children felt concern that their partner largely had to take responsibility for children's well-

being during the patients' illness (20). Regarding children of heart or lung transplant patients, studies have revealed that these patients lacked specifically age-dependent tailored information and support from healthcare services (6, 24, 32). Patients also had concerns about how much the particulars of the transplant affected their children but had no forum to address these concerns (24). Findings in the present study indicate that relatives had the same concerns as the patients. A previous study also showed that children of lung transplantation patients showed a "rollercoaster" of emotions from the first symptoms of illness up to their parents' follow-up appointments at the clinic after the transplantation (33). These findings indicate the need for a more holistic approach to patient care, taking into consideration the patient's family members.

In the present study, the relatives found strength when they or the patient were given the chance to meet persons with personal experiences of transplantation. Researchers in lung transplantation (15, 21), confirm this, suggesting a strong benefit to intensifying this form of support.

This study indicates that patients and their illness put a strain on the relatives physically, mentally and/or socially, but the relatives accept the responsibility. In addition, the relatives received social, practical and emotional support and assistance from people in their surroundings although it was apparent among the studied relatives that less time was spent with friends and acquaintances. Ziegert (34) highlighted that if a relative wants to provide support they must also focus on their own needs and the healthcare professionals have a challenge in inspiring, giving hope, and teaching relatives to live with the uncertainty. Consistent with other studies in heart or lung transplantation (14, 17) some relatives in this



study stated a financial strain due to the illness. Financial difficulties were partly due to the family budget but also to the national insurance system.

Overall the relatives in this study felt that they received support and information from the transplant team and other healthcare professionals. Most relatives had mainly good experiences of the encounter with the healthcare professionals during the in-hospital time. The relatives felt encouraged to call if they had questions or were anxious, and mostly the information was given in a clear and concise language which was of great value for the relatives. This is gratifying, as correct and respectful support and information requires that the healthcare professionals have sufficient understanding and knowledge of both patients and their relatives' situation and all their problems.

### **Methodological limitations**

One limitation was that it was impossible to do face-to-face interviews with all the relatives since they lived in a geographically wide area. The data in this study were collected from relatives at one cardio-thoracic center. With the purpose of strengthening the credibility of the analysis the interviews were conducted by one researcher (BI) and the analysis was conducted with (BI) and another researcher (TS), who hadn't participated in the interviews and thereby had the opportunity to see the text with unbiased eyes. This way of seeking agreement with co-researchers strengthens the credibility according to Graneheim & Lundman (27). Because of the study's qualitative nature, our aim was not to generalise the findings to apply to all relatives to heart or lung transplant patients. However, it is reasonable to assume that the findings can show a part of the reality of relatives' experiences in connection to heart or lung

transplantation and give a better understanding of the interaction between patients, relatives and healthcare professionals.

## **Conclusion**

In conclusion, various descriptions about information and support were given and the key findings were three different categories: Navigating through specific circumstances, facilitating the transplantation journey and experiencing information and support. Relatives play a crucial role in the patients' life, and it is therefore important to use a holistic approach and to identify strength and weaknesses regarding the support and information exchange between healthcare professionals and the relatives. This study shows that there is more to be done in this field. The result can also be used to design and build up an intervention program to improve the care and attention for heart or lung transplant patients and for their relatives including children.

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