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WAITING FOR A HEART OR LUNG TRANSPLANT: RELATIVES' EXPERIENCE OF INFORMATION AND SUPPORT

Short title: Relatives' experience of support before a heart or lung transplant

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Abstract

Objectives

To describe the relatives' experiences of information and support while the heart or lung transplant candidates were waiting for a heart or lung transplantation.

Methodology/design

The critical incident technique was used. Incidents were collected via interviews with 18 relatives (28-73 years old) of heart or lung transplant patients within four weeks of the patients being accepted onto the transplant waiting list.

Findings

A total of 286 important events, both positive and negative, were identified and divided into two main areas: "Experiencing information and support" and "Reflecting upon information and support." "Experiencing information and support" was associated with "dissatisfaction with the health-care system", "being relatively satisfied", "supporting patients" and "the role of social networks." "Reflecting upon information and support" was associated with "finding strength" and "uncomfortable with emotions". Relatives experiences suggest that needs can be met through specific targeted information and support for them as well as mediating contact to previously transplanted persons.

Conclusion

The findings indicate a gap between the information and support that relatives need and receive, and that more attention should be paid to information and support for this group. By increasing awareness among healthcare professionals and the community, interventions can be developed that benefit relatives.

Keywords

Chronic illness, communication, family, spouse, transplantation, waiting list

Introduction

Before 2012, a total of 1,630 heart or lung transplantations (HoLTX) had been performed in Sweden: 884 patients had received a donor heart and 746 had received donor lungs (Swedish Transplantation Register, 2013). During the waiting time candidates for heart and lung transplantation have shown similar psychosocial and behavioural characteristics (Dobbels et al., 2010). It is well known that patients waiting for a HoLTX are concerned about their relatives (Jalowiec et al., 1994, Porter et al., 1994), and the concern is mutual (Ivarsson et al., 2014).

The patient faces the risk of dying before the transplantation can be done, and this often results in uncertainty, fear, and stress in relatives (Collins et al., 1996, Meltzer and Rodrigue, 2001). The relatives' quality of life is strongly influenced by how patients master their daily life (Myaskovsky et al., 2005). Patients must spend considerable time at the hospital during this waiting period as they require different forms of healthcare interventions (Sadala and Stolf, 2008), such as oxygen therapy (Cullen, 2006) or mechanical cardiac assist devices (Liden et al., 2007). As a consequence, many relatives act as informal caregivers to these patients both in hospital and at home (Kurz, 2002, Akbarin and Aarts, 2013, Rodrigue and Baz, 2007) with the risk of experiences of stress and burden as a result (Goetzinger et al., 2012). In addition, relatives of patients with cardiac assist devices may fear malfunction, pain, infection, and stroke (Bunzelet al., 2007), generating uncertainty and anxiety (Akbarin and Aarts, 2013).

Most relatives also report economic strain because of loss of income, extra costs of transportations and accommodation associated with medical visits during the period of care (Lefaiver et al., 2009, Rodrigue and Baz, 2007, Ulrich et al., 2004). While waiting, relatives tend to disregard their own needs, hobbies, and friends (Bohachick et al, 2001, Kurz, 2002, Meltzer and Rodrigue, 2001) and relatives experience an increased workload (Kurz, 2001,

McCurry and Thomas, 2002). Although being a caregiver often imposes increased workload and psychological strain, it can also promote well-being and satisfaction (Poulin et al., 2010). Different kinds of support, as personal care, administration of medications, transportation and household maintenance performed by relatives are important for patients waiting for a transplant (Kurz, 2002, Wang et al., 2006). Support and information for caregiving relatives are also important (Haugh and Salyer, 2007, Meltzer and Rodrigue, 2001, Ullrich et al, 2004). Healthcare professionals must be aware that most patients do not undergo the process alone but also have relatives and therefore healthcare professionals must give these persons targeted information and support (Lefaiver et al., 2009). In the nursing process, Travelbee (1971) stated that it is important to pay attention to relatives, acknowledge their significant support and the importance of their presence. Ziegert (2011) emphasized that the quality of information is important for relatives in their efforts to provide support and that healthcare professionals must adapt to the relatives' needs and ability to receive information. Communication with and support for relatives need to be intensified and repeated during the transplant waiting period (Akbarin and Aarts, 2013, Rodrigue and Baz, 2007). However, little is known about relatives' experiences of information and support during this vulnerable period of life.

The aim of this study was to describe the relatives' experiences of information and support in the form of important events, while the heart or lung transplant candidates were waiting for a HoLTX.

Methods

Design

This study uses a descriptive design with a qualitative approach, incorporating a critical incident technique (CIT). CIT, described by Flanagan (1954), is a method used to obtain

records of specific behaviors from those in the best position to formulate an event. It is a systematic, inductive, highly flexible method and that gives concrete, descriptive data of real-life events and is aimed at solving practical problems (Kemppainen, 2000). In this study, the term “event” was used with the same meaning as “critical incidents,” and this change of term is not intended to change the process of the procedure, as described by Flanagan. Instead, it highlights the recollection of appropriate events (Schluter et al, 2008). These events do not always have a clear beginning or end, and may be composed of the overall experience of a situation but are considered by respondents as meaningful and important (Norman et al 1992). Flanagan’s requirements for CIT are that the activity investigated should have a well-defined aim and that both positive and negative aspects of the activity, i.e. “information and support,” are elicited. The extent of the data is based on the nature of the problem and hence the number of critical events, and not on the number of participants (Flanagan, 1954; Schluter et al., 2008).

Participants

The investigation was conducted in accordance with the Helsinki Declaration (WMA, 2008) and was approved by a Regional Ethics Board. Twenty-one patients newly accepted for the HoLTX waiting list, described in a previous study (Ivarsson et al., 2011), were invited to nominate relatives to this study. The patients were questioned by telephone for permission to contact their relatives for an interview. There were three who declined: one patient wanted to spare the relative, and two patients have been transplanted quickly after they have been accepted for the waiting list. An introductory letter informed all relatives that their participation was voluntary and that they could withdraw from the study at any time without explanation. They also received oral and written information about the aim of the research and signed a written consent form before the interview. To ensure that relatives would not feel compelled to participate, the interviewer (BI) was not involved in the patients’ clinical care.

Demographic and clinical characteristics are presented in Table 1. All data were collected between March 2009 and June 2010.

The transplant team

In this study, the term “transplant team” is used broadly. It includes the cardiologists, pulmonologists, surgeons, immunologists, coordinators, nurses, therapists, counsellor etc., who came into contact with the patients and their relatives at the transplant center.

Data collection

Because of long travel distances and times, a mixed data collection design was used, including face-to-face and telephone interviews. In order to facilitate data collection, a semi-structured interview guide was developed (Table 2) based on previous research (Ivarsson et al., 2005, Ivarsson et al., 2011) and a review of the literature. One pilot interview (not included in the study according to the informant's wishes) was conducted to evaluate whether events were verified satisfactorily in response to the questions. The interviews began with one example of an event that can be perceived positively or negatively. As data was collected through semi-structured interviews in dialogue form, it was possible for the relatives to describe, in their own words, events around information and support while the candidates were waiting for transplant surgery. The recorded interviews lasted from 12 to 40 minutes and were conducted in the relatives' homes (n=6), or by telephone (n=12). A verbatim transcription of each interview was made.

Data analyses

The analyzing process, which is an inductive classification, started after the transcribed interviews were read thoroughly several times and decisive events in the relatives' statements

were identified. A decisive event is considered as a specific experience (critical incident) described by the relatives in a positive or negative way in relation to their experience during the waiting time. A total of 286 events were found. Each relative provided between 11 and 22 events. Some relatives reported more than one incident for a specific question, whereas some did not report any incidents for a certain question.

To categorize the incidents, they were abstracted from the text, assigned labels, and then sorted into groups. The identified behaviors were sorted systematically into clusters according to what united them as most qualitative analysis (Norman et al 1992) and resulted in 17 subcategories. These were allocated into six categories, based on similarities, and two main areas mirroring the overall structure of the events. In the last two interviews, no new subcategories emerged, indicating saturation of the model. During the analysis process, a continuous discussion regarding the analysis was held between the researchers BI and TS. To avoid subjectivity, TS placed the events into the determined subcategories and a large consensus prevailed. To ensure that the classification was as free from bias as possible, could be replicated, and was reliable, the classification into subcategories and categories was discussed until total consensus was reached (Sharoff, 2008). Events have been illustrated by selected quotations.

Results

Two main areas emerged from the analysis of the incidents. 1. “Experiencing information and support” describes how relatives were dissatisfied with the health-care system, were relatively satisfied, gave support to patients, and thought about the role of social networks. 2.

“Reflecting upon information and support” describes how relatives found strength or were uncomfortable with their own emotions. An overview of the main areas, categories, and subcategories is shown in Table 3

Experiencing information and support

Dissatisfaction with the health care system

Relatives expressed concern over fragmented and insufficient information when the patient was considered for a transplant. A number of relatives felt that they would have benefited from information much earlier than was actually the case, i.e. in close connection with the decision to offer the patient a place on the waiting list. Of these, some experienced that patients had withheld information from them. For some of the relatives the information about a forthcoming transplantation was shocking, especially when the patient rapidly progressed into a life-threatening condition and became dependent on hospital care and, in some cases, could not take part in any information exchange or discussions or decisions.

“The period before the decision was worst. However, the message that she would not survive without a transplant was honest, even if it felt brutal. I guess I was shocked even if the content of the information was okay” (R14).

Because of economic strain some relatives were disappointed by the lack of support from the health insurance system in connection with the transplant. *“My husband needed to see the dentist before the transplantation. When we asked who was going to pay we were told*

that it was our own responsibility. I mean.... what benefit is a donor heart when you cannot afford to chew?” (R4).

Being relatively satisfied

The relatives stated that they received written information from the transplant team. This information was perceived to be useful but sometimes difficult to understand and even frightening. The relatives described how they had been invited to a face-to-face meeting with the transplant team and felt trust in and support from the team. *“We have had meetings with doctors, physiotherapists, and nurses who made everything very clear, and one didn’t feel any question was stupid” (R13).* Some relatives had been in contact with a counsellor who was part of the transplant team and had found this valuable, mostly discussing insurance matters and other kinds of paperwork. However, they felt a sense of security in knowing that this help was available. *“Before, I hardly knew what a counsellor did or what kind of help she could provide, and that even I could get support. – I am going to talk to her. It feels really nice” (R14).*

Many relatives got information via alternative sources such as the Internet or television programs. Most of them found this information interesting, but they had difficulties handling the complexity and the amount of information. *“I have surfed on the Internet. However, I am a little bit hesitant due to the risk of exposing myself to too many negative stories” (R8).* Relatives appreciated the opportunity to meet previously transplanted patients or their relatives in meetings arranged by the transplant center or on their own initiative. Some of those who did not have that opportunity missed it and felt that healthcare providers should arrange such meetings. *“I would have liked to have met someone who had gone through a transplant, preferably someone close to the patient who stood by that patient’s side” (R4).*

Supporting patients hands-on

The relatives expressed their sense of sacrifice when the patients were in need of help of a physical, psychological, or social nature. Conversely they also described a kind of pride in being able to help. *"I sleep here, that's why I spend so much time here (with the patient).... he does not want to be alone during the nights. So I do not get much sleep"* (R13). Some relatives described how their assistance was necessary in seeking help for patients from local social services with regard to, for example, handicap parking permits, house cleaning, and public organizations. Some relatives related to the experience that public organizations were not supportive, showed no empathy, and had no knowledge about particular transplant patients. *"The local authorities offered cleaning services every other week for two rooms and a kitchen. That didn't help at all. You could only get help to just above poverty level.... He has two young children and would need help with cleaning, washing, possibly cooking...."*(R15).

The social network's role

The relatives felt that, because of the patient's illness, their own social contacts had become increasingly distant, relying on telephone or social media. They felt support from next of kin and friends. Employed relatives felt support from their employer and colleagues. They had the opportunity to temporarily stay home from work without feeling guilty. *"I have been present at all doctor's appointments (the patient's) and on occasion, I have reduced my work hours. My employer says that I can feel free to do what I need to do, and take it week by week. They are very understanding"* (R15).

Of necessity, the patients decreased their social activities. This situation also had an impact on their relatives, who described not wanting to blame the patient or other people but sometimes feeling betrayed by others in the environment. *"He is tired; that's why we are not seeing many friends and they are also holding back a bit"* (R4).

Reflecting upon information and support

Finding strength

Some relatives described feeling support from various kinds of activities, such as working, physical exercise, volunteer work, and meeting other people less involved with the patient. Instead of thinking about the future transplant they expressed the positive effect of participating in various activities, both alone and together with the patient. *"I sometimes do volunteer work. I feel that it helps us both. When I get home I can talk about what has happened. You can't just think about the illness all the time"* (R5). There were relatives who felt some support and comfort from a life philosophy, either a strategy to master the waiting, or a religious faith. *"My faith has helped.... You know there is hope"* (R18). The relatives reflected on organ donation and the fact that their next of kin would receive an organ from someone who had just died. Some relatives encouraged their friends to make a decision regarding their own organ donations. *"I think about the fact that someone is actually going to*

lose a relative to make it possible for him to get well. When I get these thoughts I need to remind myself.... This person is not going to die because of him” (R8).

Uncomfortable with their own emotions

Some of the patients waiting for the transplant suffered from hereditary diseases, and a few of their children had concerns about this. None had undergone genetic testing and they felt that it was difficult to talk with healthcare professionals about it, because they did not feel any support from the patient. *“We briefly talked about it ... since it is a hereditary disease. However he was very annoyed since he felt that life had been good anyway” (R5).*

Some relatives felt tension in their relationship with the patient and it affected their ability to communicate. Few relatives linked this tension to the patient’s decline in cognitive ability. *“He can really confuse things, and get somewhat paranoid, and I only mean well ... but he can interpret it the wrong way and then I just have to decide to keep my mouth shut” (R12).* There were relatives who described experiencing fear and anxiety, and had had thoughts concerning their own life situation. Some relatives living in a relationship with the patient described that their sexual cohabitation had ceased because of the patient’s illness. *“Our sex life does not work. We have had ours. But I did not think life would be like this. My life is over” (R4).*

The relatives felt well informed but ambivalent about the moment the call for the transplant would come, expressing both uncertainty and expectation. They also expressed concern about the future, whether the patient fully grasped how much was required afterwards regarding nutrition, exercise, and medication as well as potential side effects. *“Afterwards he really has to make every effort to manage his medication and training. He hasn’t understood the seriousness of this yet and we are trying to encourage him.... We feel that he hasn’t understood that it will take a lot from him as well” (R16).*

Discussion

The findings of this study have illuminated different aspects of the information and support requirements and benefits for relatives waiting for HoLTX. "The results revealed comprehensive experience of being ' *dissatisfied with the health care system,*' to be " *relatively satisfied with the health-care system* " and also to be pleased with themselves by " supporting patients" and detecting " *the role of social networks.* ". Furthermore the relatives were " *finding strength*" through human or non-human support and had to face "feeling *uncomfortable with emotions*"

When a patient was accepted on the transplant waiting list, the relatives were informed both orally and in writing by the transplant team. However, some relatives wished that they had received information earlier because of the patients' inability or unwillingness to share information. With the exception of a sudden emergency illness, one explanation can be that it was in accordance with the wishes of the patient, and the healthcare professionals considered the patient's autonomy. In a previous study, patients described wanting to spare their relatives worrying about their illness (Ivarsson et al., 2004), and this could be an explanation. In addition, healthcare professionals may take for granted that patients give their relatives the information they need, in cases where patients can communicate. However, it is imperative that relatives become involved because patients may either forget what they have been told or misunderstand the information they have received. The healthcare professionals should not forget that one-third of all patients with end-stage heart or lung disease have cognitive impairment while waiting for a transplant (Olbrisch, Benedict, Ashe, and Levenson, 2002), which affects both the relationship and communication skills of relatives and patients.

Consistent with the findings of Bohachick et al (2001) and Kurz (2001) some relatives, in this study, stated that waiting for HoLTX caused significant financial strain. The difficulties may be due to the family budget but also to the country's insurance system. Some relatives had become informal caregivers, and those with employment highlighted that they

were allowed to stay home from work temporarily, which they experienced as a form of support. Nevertheless, it must be remembered that caregiving can lead to reduced work hours entailing fewer job benefits and lower wages, which in the long run can culminate in impaired physical health and depression for the relative (Alspach, 2009).

How relatives respond to their situation may depend on which coping strategy they use. Passive coping strategies such as resignation and avoidance are associated with emotional distress (Claar et al., 2005). In a study of HoLTX patients' spouses, planning was a frequent coping strategy, which may lead to an increased feeling of control and less depression (Burker et al., 2005). The relatives in the present study experienced support from counsellor but, in line with a study of Burker et al (2005), strategies targeting relatives who need help with planning or with psychological support, social work, or nursing interventions need to be developed.

While waiting for a transplant, many relatives in the present study searched independently for information through the Internet and other media sources. Information that is publicly generated and made available on the Internet may be incorrect or misleading, and may cause harm (Hanif et al, 2009). Consequently, it is important that responsible healthcare professionals provide information, preferably from the actual transplant center. One study showed that top-ranked hospitals in the United States had a variety of Internet-related (e-health) tools that enhance health education and communication (Gallant et al., 2011). For relatives who wish to seek information on their own, such as those who are geographically remote from the transplant center, it may be valuable to provide a list of reliable websites.

In this study, relatives felt strengthened and encouraged when they had contact with previously transplanted patients. These findings are in line with a previous study on patients waiting for a transplant (Ivarsson et al., 2011). Some relatives in the present study expressed the desire to connect to other relatives and the Internet could again serve as an information

channel where both patients and relatives can communicate and interact with other patients, their relatives, and others, as Gallant et al. (2011) described.

The patients' physical condition had a profound impact on the relatives' relationships and social lives, in line with findings by Bohachick et al. (2001). Relatives also took responsibility for communication and acted as an intermediary between the patient and friends, social agencies, and healthcare professionals. However, the results reveal that providing help and care to a patient waiting for a transplant, although burdensome for the relatives, can also be positive and rewarding. A previous study showed that it is important for patients and their relatives to work together and provide mutual support (Macdonald, 2006) and as the relatives pointed out in this study, support early on is important.

The relatives in this study contemplated the issue of organ donation and felt some satisfaction from advocating it to their friends. This is in line with a study of cystic fibrosis patients' perception of organ transplants, that is, no perceived ethical or moral dilemma surrounding transplant but rather a desire to increase the availability of organs (Lowton, 2003).

Relatives in the present study who had concerns about genetic and heredity issues reported that they had an open communication with the patients but felt conflicting obligations regarding the patient and their own children. Gallo et al.(2009) stated that healthcare professionals must work with patients and their relatives to better understand genetic disclosures and to provide the whole family with accurate, appropriate, and current information, as well as support to facilitate disclosure decisions.

Claaret et al. (2005) found that only 2.4% of the caregivers of patients waiting for lung transplant reported anxiety. In contrast, Bohachick et al. (2001) found that 61% of the spouses of patients waiting for a heart transplant reported anxiety. The findings of this qualitative study are in line with the study by Bohachick et al. (2001), reporting that patient caregivers

experienced anxiety during the time the patient waited for a HoLTX. These results suggest that both quantitative and qualitative studies are needed to achieve an optimum coverage ratio, which has been described in a context of heart transplant patients and their quality of life (Abbey et al., 2011).

Methodological considerations

This study used a degree of rigor to control research quality, including applicability, credibility, dependability, and conformability (Lincoln and Guba, 1985). Applicability was established by the chosen method, i.e., CIT was chosen for its credibility in promoting reflection and its focuses on personal behaviour (Kemppainen, 2000, Sharoff, 2008). The researchers have an understanding of the research area and of qualitative studies, and they have extensive experience in transplant care and were constantly aware of this preunderstanding, establishing the credibility of the research content and findings. As we have described the method, subject recruitment, and procedure for data analysis, we allow the study to be independently repeated to show consistent results, providing dependability.

Interpretations of the findings were clearly derived from the research subjects and not from the researchers own motives, interests, or prejudice, ensuring conformability. It would have been desirable to conduct face to face interviews with all relatives but telephone interviews were logistically simpler, because of time constrains and living in a geographically distant location. Although the use of a phone can give participants a feeling of anonymity and thus tell more, lack of face-to-face interview could have prevented the development of the study (Novick, 2008).

Conclusion

In conclusion, the results indicate that information and support needed and received by relatives of HoLTX patients varies, and there are plenty of gaps where interventions would be welcomed. More attention should be paid to the information and support provided to relatives,

and a holistic approach must be taken in connection to heart or lung transplants. This study will help the transplant team and other healthcare professionals and institutions to better understand the experiences, resources (or lack thereof), and challenges faced by patients' relatives and to provide better clinical practice and support.

Implications for Clinical Practice

- Before acceptance for transplantation relatives only received partial information and additional measures from healthcare professionals are necessary to support relatives of patients facing a fatal and chronically condition.
- Internet should be used to a greater extent as a source of targeted evidence based information as well as practical and psychosocial services.
- Relatives of patients waiting for a lung or heart transplant respond favourably to information and support provided by previously transplanted patients and their families. Such communication should be emphasized and fostered.

Contributions

Study design: BI, BE, TS

Data collection and analysis: BI, TS

Manuscript preparation: BI, BE, TS

Conflict of interest

None.

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