

Emotional and Psychological Support of Living Lung Donors Who Failed to Donate to their Child: A Case Report

Mikiko Nakamura¹, Chie Yokoyama¹, Noriko Akimoto² and Takahiro Oto^{1*}

¹Lung Transplant Unit, Okayama University Hospital, Japan

²Graduate School of the Health Sciences Okayama University, Japan

*Corresponding author: Takahiro Oto, Lung Transplant Unit, Okayama University Hospital, 2-5-1, Shikata-cho, Kita-ku, Okayama 700-8558, Japan, Tel: +81-86-235-7265; Fax: +81-86-235-7269; E-mail: oto@md.okayama-u.ac.jp

Received date: July 30, 2014; Accepted date: October 17, 2014; Published date: October 20, 2014

Copyright: © 2014 Nakamura M, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Abstract

Objectives: Living-donor lung transplantation (LDLT) is a real therapeutic option for pediatric patients in Japan. However, not all families with sick children can take advantages of a LDLT because of lack of suitable donors. Mental care for such a family becomes important when the parents cannot be donor candidates due to their own illness. The aim of this report is to describe the emotional and psychological status of donor candidates who could not be a lung donor due to malignancy.

Methods: A semi-structured interview was performed with a donor candidate who was unable to donate due to her own malignancy. The recipient was a 12 year-old girl, and the donor candidates were her parents. Results were obtained by a qualitative inductive analysis.

Results: Donor assessment revealed that the recipient's mother had malignancy. She was excluded from being a donor candidate and the planned living donor transplant for her daughter was cancelled. The mother's emotional responses when she failed to donate to her sick daughter were the major theme extracted from the data. In this context, nine codes were obtained and this theme was detected across three main categories including mood disturbances, anxiety symptoms, and affective reactions. A transplant team supported the donor's and recipient's emotional health. The donor developed a more positive attitude at overcoming her own disease and began to expect brain-dead donor could save her daughter's life. Three years later, the recipient underwent a successful lung transplant from a brain-dead donor.

Conclusion: These findings have the potential to help transplant nurses develop interventions to improve the emotional health of living donors who failed to have the ability to donate their organs. Mental health promotion, assessment, and treatment must become priorities to improve the overall domestic mental environment of having a sick child waiting for lung transplant.

Keywords: Mental support; Nursing; Lung transplantation; Living donor; Quality of life

Introduction

A living-donor lung transplantation is a real therapeutic option for critically ill pediatric patients due to the severe lack of organ donations from deceased donors in Japan [1]. However, not all families with sick children can take advantage of a living-donor lung transplantation to overcome the lack of suitable donors. Providing mental care for such a family becomes important when the parents are excluded from being suitable donor candidates due to their own illness. Donor mental quality of life (QOL) following a lung donation has been described elsewhere [2]. However, little is known about the mental QOL of potential living lung donors who failed to be able to donate while also facing the death of their loved one.

The aims of this report are to illuminate the mental, emotional, and psychological status of donor candidate who could not be a lung donor due to malignancy and to describe how nurses and other health professionals approached and supported families to facilitate their adjustments to unexpected donor evaluation results.

Patients and Methods

This study was conducted at the Lung Transplant unit at the Okayama University Hospital in Japan. Between 1998 and 2014, 76 living donor lung transplants were performed and 141 out of 163 potential donors were accepted as organ donors. One out of 22 potential donors was rejected, because their own malignant diseases were revealed in a donor evaluation. Other reasons for potential donor rejection in our facility have included various non-malignant diseases or positive cross-matches. This study was conducted using a qualitative descriptive study design. The participant included in this study was a potential lung donor who failed the donation evaluation due to her own malignant disease. A semi-structured interview was performed in our institution and at the participant's home by two interviewers. The interview was organized around a set of predetermined questions, with the flexibility of following the participant's responses. The interviews were based on the following questions: (i) Do you feel a physical burden? (ii) What are your exact symptoms? (iii) Now that you know that you are unable to become an organ donor for your daughter, how do you feel and what do you

think about that? (iv) What is your action? (v) What kind of help you need from the hospital and/or nursing staff?

The audio-recorded interviews were between 40 and 60 min in length. The interviews were later transcribed verbatim, providing written data that were ready for analysis. The data were obtained at one month, at two years and at three years after the donor evaluation results were explained in a privacy-secured room at our institution or at the participant's home. Under the approval of the Ethics Committee, the content of the interview was analyzed according to the content analysis instructions advocated by Krippendorff. An inductive approach to data analysis was taken which involved immersion in the data, coding, classifying, and creating linkages. The outcome of the intervention was scored using the K6 (2001) screening scale [3]. The K6 is widely recommended as a simple measure of psychological distress and as a measure of outcomes following treatment for common mental health disorders. The scale consists of six questions about depressive and anxiety symptoms that a person has experienced in the most recent 4 week period. The self-report style of questions assists in identifying current mental health problems and whether there is a need for treatment. The questions are responded to on a five-value self-reported scale as follows:

- None of the time - scores 0
- A little of the time - scores 1
- Some of the time - scores 2
- Most of the time - scores 3
- All of the time - scores 4

The questions were as follows:

- How often did you feel nervous?
- How often did you feel hopeless?
- How often did you feel restless or fidgety?
- How often did you feel so depressed that nothing could cheer you up?
- How often did you feel that everything was an effort?
- How often did you feel worthless?

The six questions were mandatory, and the total scores range from 0 (indicating no distress) to 24 (indicating severe distress).

Trustworthiness

Lincoln and Guba's four criteria of credibility, dependability, confirmability, and transferability were followed to ensure the rigor of this study. The interviewers participated in inpatient and outpatient activities prior to the interview. Member checks were used to review the final reconstruction. Dependability and confirmability were ensured by providing sufficient information about the research process, and the use of quotes to provide evidence of findings to enable an audit trail of the process. Transferability was addressed by providing sufficient background information regarding the study to enable the reader to determine the relevance of the findings to their own practice.

The recipient was a 12 year-old girl with idiopathic pulmonary fibrosis. The donor candidates were her parents. The donor assessment was performed at the outpatient clinic during the two weeks the recipient was evaluated. The donor assessment revealed that the recipient's mother had colon cancer and multiple liver metastasis. She was excluded from the possible donor candidates and the planned living donor transplant for her daughter was cancelled. The father of the recipient cleared the medical examinations but could not be a

donor because the estimated volume of his lower lobe was not enough for adequate donor/recipient size matching.

Results

After the donor evaluation results were explained, the mother of the recipient was stunned and could not sleep well for several days. She regretted that she could not save her daughter's life and also was fearful of her own malignant disease. The father of the recipient was also shocked to see the results. However, he decided that he had to be tough because he needed to support not only his daughter but also his wife. The recipient's mother could not overcome her depressive symptoms even with her husband's support. The mother's emotional responses after she failed to donate to her sick daughter were the major themes extracted from the data. In this context, nine codes were obtained from a mental health expert, and this theme was detected across three main categories including mood disturbance, anxiety symptoms, and affective reactions (Table 1). Emotional support by the transplant team including the transplant coordinator, ward nurses, and doctors was expected to support the emotional health of all of the family members. Strategies including counseling, frequent communications, stress management, and liaison nursing were used at the outpatient clinic or by phone during a three-year follow-up period. The transplant team also provided information about the recipient who had been thinking about her mother during her stay in the hospital. The recipient reported that she felt sad, because her mother had stopped smiling. Daily emotional support had been provided to the recipient's mother within one month after the transplant was cancelled. During the following two years, telephonic counseling was performed several times. The recipient's mother realized that she had hurt her daughter's feelings and that the donor evaluation process enabled her to have a medical examination and cancer treatments. It took three months for her to become more positive about overcoming her own disease. Two years later, she began to expect that a deceased donor could save her daughter's life. The recipient also remained motivated to receive a deceased donor lung transplant. Three years later, the recipient underwent a successful lung transplant from a brain-dead donor. The recipient stayed in the hospital for two months. The K6 scores before emotional support was provided, at two years after initiation of the support, and after lung transplant were 20, 12, and 4, respectively.

Codes	Categories	Theme
Feeling of blame	Mood disturbance	Emotional response
Self-blaming		
Despair		
Probability of daughter's adverse events	Symptom of anxiety	
Fear of daughter's future		
Fear of own future		
Being disturbed	Affective reactions	
Secret crying		
Sleeplessness		

Table 1: The process of obtaining theme from codes and categories.

Discussion

Little is known about the emotional health of mothers of children who are waiting for lung transplants. Emotional problems in mothers may increase the risk of emotional and behavioral problems in children and vice versa. When the recipient's mother failed to become an organ donor, it may be important to know how a sick child can influence family members and the nature of nursing support that may need to be provided. Disappointment, desperation, self-blaming, fear, self-crying, and sleeplessness were the mother's emotional reactions because she felt unable to rescue her daughter. When a mother is under pressure in a stressful and critical situation due to her own disease, resulting anxiety or stress will have an effect on her abilities, leading to a loss of control and subsequent decline in her efficacy and performance. Future research should incorporate an assessment of the family's relationship and ways of providing effective interventions for such families.

Conclusion

These findings have the potential to help transplant nurses develop interventions to improve the emotional health of living donors who failed to donate their organs. Mental health promotion, assessment, and treatment must become priorities to improve the overall domestic mental environment of having a sick child waiting for a lung transplant.

Acknowledgements

The authors gratefully thank Ms. Naomi Sunami and Aya Nakatani for their assistance.

Author Contributions

Concept/design (Mikiko Nakamura), Data analysis/interpretation (Noriko Akimoto), Drafting and Critical revision of article (Takahiro Oto), Approval of article (Chie Yokoyama)

References

1. Oto T, Okada Y, Bando T, Minami M, Shiraishi T, Nagayasu T, et al (2013) Registry of the Japanese society of lung and heart-lung transplantation: the official Japanese lung transplantation report 2012. *Gen Thorac Cardiovasc Surg*. 61:208-11.
2. Nishioka M, Yokoyama C, Iwasaki M, Inukai M, Sunami N, Oto T (2011) Donor quality of life in living-donor lobar lung transplantation. *J Heart Lung Transplant*. 30:1348-51.
3. Furukawa TA, Kessler RC, Slade T, Andrews G (2003) The performance of the K6 and K10 screening scales for psychological distress in the Australian National Survey of Mental Health and Well-Being. *Psychol Med*. 33: 357-362.