

## Original Article

# Concerns of and coping strategies by parents of pediatric liver transplant recipients: a qualitative study from China

Wen-Xin Zhang<sup>1\*</sup>, Hong Wei<sup>2\*</sup>, Zhong-Yang Shen<sup>3</sup>, Xiao Peng<sup>1</sup>, Xin-Guo Chen<sup>3</sup>, Wei Li<sup>3</sup>, Fan Wang<sup>3</sup>,  
Shu-Ping Zhang<sup>1</sup>, Hong-Xia Liu<sup>1</sup>, Yu-Jian Niu<sup>3</sup>

<sup>1</sup>School of Nursing, Beijing University of Chinese Medicine, Beijing, China; <sup>2</sup>Department of Nursing, Affiliated Hospital of Hebei University of Engineering, Handan, Hebei Province, China; <sup>3</sup>Institute of Organ Transplantation, The General Hospital of Chinese People's Armed Police Forces, Beijing, China. \*Equal contributors.

Received September 17, 2014; Accepted November 24, 2014; Epub December 15, 2014; Published December 30, 2014

**Abstract:** Parents of liver transplant recipient children have to face complicated health issues of their children. Coping strategies of parents as major care providers not only impacts on their handling of stresses on themselves but also on the recipients' quality of life. In this study, we sought to investigate the coping strategies of parents of Chinese pediatric liver transplant recipients at a single tertiary care institution in China. Twenty-five parents of liver transplant recipients were selected by the purposive sampling method and data was collected using qualitative semi-structured interview. Interviews were conducted until thematic saturation was achieved. We extracted 5 major themes: 1) guilt and self-blame for not giving a happy life to the sick child; 2) seeking social support for helping to treat the sick child; 3) standing firm by not giving up on treating the sick child; 4) cautious caretaking; 5) compromise: a helpless acceptance of truth. In summary, parents of transplant recipients present 5 major coping strategies. Proper assessment of stresses on parents of liver transplant recipient children and their coping strategies may help the medical staff and social services to provide more targeted support, and help and promote the balance of the family function.

**Keywords:** Liver transplant, children, parents, coping, qualitative study

## Introduction

Pediatric liver transplantation has a history of more than half a century, and now it has become a conventional therapeutic modality for children with terminal liver diseases [1, 2]. In the 1980s, pediatric liver transplantation yielded a survival of only 30% to 50%, and good long-term survival is now anticipated in most pediatric liver transplant recipients. A 2006 report by the Liver Transplant Center at Cincinnati Children's Hospital showed that the 5-year survival increased from 80% in the past to 90% [3]. Pediatric liver transplantation surgery started in 1993 in China and by December 31, 2011, 540 pediatric liver transplant surgeries had been performed in mainland China according to a report by the China Liver Transplant Registry (CLTR) [4]. The major source of pediatric liver transplants is living donors

(64.81%), and the cumulative 1, 3 and 5-year survival of pediatric liver transplant recipient is 78.13%, 65.81% and 59.25%, respectively [4].

Children who had received liver transplant since 1990s in China have now entered adolescence and adulthood, but they are required to take lifelong medication with immunosuppressants and undergo periodic physical checkup. They also have to deal with issues related to compliance with medication, potential graft rejection and complications. As the major care providers of pediatric liver transplant recipients, parents have to take responsibilities beyond those of ordinary parents and have to handle complex health issues of their children, which may exert great pressure on them [5]. Apart from their negative effects on the quality of life of the recipient children, these pressures often exert negative effects on the family, resulting in dys-

functional family, increased negative psychological experience by parents, increased stress, predisposition to anxiety and depression [6]. Despite the myriad of issues above, there has been scant literature on the concerns of and coping strategies by pediatric liver transplant patients and their parents in China. A search of publications from major Chinese databases including CNKI, Wangfang and Weipu failed to find any literature on the concerns and coping strategies of parents of pediatric liver transplant recipients.

Health issues of children often exert great impact on parents and the coping behavior of parents in turn affects the coping ability of children and their sense of happiness [7]. The coping behavior by parents towards their caretaker role and their approach in handling emotion and feeling may affect the quality of care for children [8]. Lazarus *et al.* proposed that a person may use two coping strategies in face of pressure: problem-focused coping and emotion-focused coping [9]. Barbarin *et al.* showed that the coping strategies of parents of sick children include information-seeking, problem-solving, help-seeking, maintaining emotional balance, being optimistic, denying, and accepting [10]. It is important to investigate the coping strategies by parents of pediatric liver transplant patients as the coping strategies by parents not only impact on the management of children's illness but also the balance of family function.

During the liver transplantation and post-transplant process, the accompanying parents become an active participant in their children's care through effective coping. Descriptive qualitative studies allow investigators to obtain data to the fullest extent possible and can unravel answers to and lead better understanding of the coping strategies of parents of pediatric liver transplant recipients [11, 12]. By using the qualitative approach, we may gain insight into parental coping behaviors and uncover important issues for further research [13]. In this qualitative descriptive study, we sought to investigate the concerns and coping strategies of parents of Chinese pediatric liver transplant recipients at a single tertiary care institution in China September, 2013 and February, 2014.

### Subjects and methods

#### *Methodological orientation*

We used a fundamental qualitative descriptive approach based on the following two major considerations: 1) The CLTR reported that the number of pediatric liver transplant recipients currently stood at 540 in China and they were widely distributed throughout the country, making it infeasible to carry out a quantitative study of a large population [4]; 2) there have been few reports on the coping strategies of parents of pediatric liver transplant recipients. The current study used a qualitative descriptive approach and drew heavily from naturalistic inquiry to allow the emergent themes to present themselves in their natural state [13, 14]. The narratives of the study participants were categorized and summarized instead of being theorized [11, 15].

#### *Ethical issues*

The study protocol was approved by the local institutional review board at the authors' affiliated institution and written informed consent was obtained from the parents or legal guardians of all study participants.

#### *Participants*

This qualitative narrative interview-based study was carried out between September, 2013 and February, 2014 at a reference center for transplants, in China. The major care provider (defined as the parent who had provided the longest care for the sick child) of a pediatric liver transplant recipient was chosen using the purposive sampling method [11, 12]. A subject was recruited 1) if he or she understood the questions by the interviewers and was capable of communicating with the investigators without any difficulty; 2) if his or her child was in convalescence post liver transplant surgery and within 3 years of the transplant surgery; 3) if the subject was willing to cooperate with the investigators after being informed of the subject of the study.

#### *Qualitative semi-structured interview*

Qualitative semi-structured interview was carried out by two research assistants who have received qualitative research method training

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and digitally recorded with permission of the participants. The interview guideline was prepared before interview, which consisted of two parts: the 1<sup>st</sup> part consisting of structured questions, including age, gender, marital status, education, profession and baseline data of liver transplant recipients and the 2<sup>nd</sup> part consisting of in-depth interviews. The interview guideline of the second part was based on the theory of stress and coping by Folkman et al. [9]. Key questions in the 2<sup>nd</sup> part asked participants to describe: 1) the condition of the sick child, 2) coping strategies by parents during the period of transplantation, 3) the living condition of parents during the period of transplantation, 4) the impact of the child's illness on the health, work, family and social life of the parents, 5) current stresses and coping strategies, and 6) plan for growth and development of the child. Questions were open ended to avoid patient coaching and suggestion. The interviewers were guided by the pre-prepared guideline and to flexibly adjust the questioning sequence and method according to the response of the participants. Probes and reflective statements were used to encourage participants to provide additional details and to seek clarification. Subtle changes in facial expression were noted and recorded. Each participant was interviewed at least twice with each session completed within 30 to 60 min. The place for interview was agreed upon by participants to assure maximal privacy free of interference. Interviews were conducted until thematic saturation was achieved.

### *Data analysis*

We used conventional content analysis as our analysis strategy to generate coding themes [11]. Two transcriptionists independently reviewed the transcripts of the recorded interviews to ensure descriptive validity within 24 hours of an interview and to identify and define emergent themes. The transcripts were rendered anonymous during transcription. Team meetings were held to discuss the emergent themes to establish a consensus-derived thematic structure. Recurrent themes were coded and pooled and they were further categorized and conceptualized while maintaining fidelity to the original contents. General concepts were developed into major themes by the method of contrast, summarization and comparison and were further revised and refined through subsequent

data collection and analysis to vet the coding structure until theoretical saturation was achieved [16].

### **Results**

We interviewed 25 parents: 6 fathers and 19 mothers from 20 provinces or autonomous regions across China. Their mean age was 32 (range 24 to 41) years. Eighty percent of the children were diagnosed with congenital biliary atresia, and 95% of the liver allografts were from live parental liver donors. At the time of interview, the mean age of the pediatric liver transplant recipients was 4 years (range, 1 to 11 years) and the recipients lived with both parents. Twenty children were the only child of the family while 5 other children had siblings. The median duration from transplantation to the time of interview was 14 (range, 1-26) months. We carried out content analysis of the interview narratives of the parents of pediatric liver transplant recipients and extracted 5 major themes.

#### *Emotional coping: guilt and self-blame for not giving a happy life to the sick child*

The parents felt it to be their responsibility to give their children a happy life. They felt guilty and blamed themselves when first facing the diagnosis of illness in their children. The more severe the illness of the child had become and the more suffering the child had experienced, the greater the sense of guilt and self-blame in the parents who felt that they had failed their responsibility.

No. 1: I felt sorry; I gave birth to her, but with an illness. She had to be treated.

No. 8: The child came to this world and suffered so much. As a father (silence), I felt very sorry and also a rather failure.

No. 12: I felt that she had not got any happiness, not at all, though childhood is naturally a happy time. I had never thought that bringing her to this world would subject her to so much suffering (sobbing); if she had not been born, she would not have suffered that much.

#### *Seeking social support for helping to treat the sick child*

Good social support such as emotional support and financial support helped parents of recipi-

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ent children to proactively cope with children's illness and build their confidence in the care of their children. This also helped the resilience of the parents in face of stresses. All participants used seeking social support as a coping strategy by seeking financial assistance and emotional support from relatives and friends.

No. 7: Relatives and friends have all come to visit her and expressed their support in words and actions. They are very supportive and understanding, giving us the impression that everyone is very supportive. No one has told us to give up treatment. Support from our own parents, other relatives and friends is a source of confidence for us.

No. 12: I asked for help from relatives and friends during the surgery. All of them offered help. I felt happy about that.

No. 6: I went to the news media, hoping that they would offer some care and help to the child.

### *Stand firm-not giving up treating the sick child*

Parents felt it their responsibility to help their child to recover his or her health. Even though they faced multiple challenges in seeking medical care, such as opposition by family members against liver donation, financial stress and worsening of the disease of the child, the parents did not give up treatment for the sick child.

No. 1: Others told me to give up, but I cannot. It cannot be helped and things are as such. I have to find a way. For many things, one only knows the results after they are done. If the child does not recover well after surgery, at least we have tried. Giving us hope and giving him hope. It will move in the right direction. Do not give up. First of all, by not giving up, one may get a good result. If one has given up, one will not see the outcome even if it is a very good one.

No. 19: I am firm hearted. Since we had the examination results, I never thought about not seeking treatment for the child. I want him to be cured no matter where we go for treatment. Otherwise, I will feel guilty. Even though many people do not agree with me, I will not give up on treating the child. I am fully determined to have her cured. Even if doctors tell me that I need to be prepared for the worst and treat-

ment may not improve her condition, I will not give up. I have made up my mind and stand firm until the end.

No. 12: I brought her upon this world. If I cannot save her, who else can? She is still so young; if I do not persist, who else will? I can give up everything except her.

### *Cautious caretaking*

Parents secured liver transplant surgery after a strenuous process and were very sensitive to the health issues of the sick child. Meanwhile, because immunosuppressants may lower the immunity of the sick child and complications may occur at any moment, parents typically made greater efforts in taking care of the sick child.

No. 3: He has had surgery. I dare not let him go there (kindergarten). I fear that he might play too vigorously with others and that he might be harmed.

No. 4: We ourselves are very nervous. We pay particular attention to the sanitary conditions and avoid taking her out. What we fear most is that something happens to her after surgery, especially something that is irreversible. As to medication, we administer the medicines ourselves. We just hope that she remains alive. We have made all the decisions for her.

No. 12: I always worry that she might fall; I am definitely worried. I will follow her wherever she goes. Sometimes, I have a slip and she loses sight of me and I will rush out to run after her. Everyone thinks that I am crazy. I never cease worrying. This makes me nervous. What she eats and what she drinks and what happens if she has diarrhea? Whatever I do, I always think about her; the stress never seems to be off me.

### *Compromise: a helpless acceptance of truth*

Most participants were interviewed within one year post transplant surgery of the recipient children who were still in convalescence. The parents were still carefully monitoring the condition of the child and hoped that the child can recover and grow up in good health. The parents had no plan for future education of the child given the health status of the child. They coped with the situation by compromise.

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No. 22: Now we just want her to be alive. We have no other considerations. If she would like to go to school, we would let her. After all, since she has received the surgery, it does not matter if she chooses not to go to school.

No. 3: Question: do you have any plan for the child? Answer: No. I have to move on. What else can I do? I will see as I move along. Thinking too much is currently of no help. Even when the time comes, it still cannot be helped.

No. 13: I have no plan. As long as she is cured, nothing else matters. I do not want to think about anything else.

No. 25: But what should we say now? We will move along. Having such a child, I cannot afford to think too much. We as parents will try our best... to do what is within our capabilities to protect him.

The current study found that most interviewees showed a proactive approach in coping with the diagnosis, treatment and care of the child's illness. However, some parents showed a passive approach in coping with the treatment and care of their children in the future.

### Discussion

Family is the foundation of a society and the most important living unit, and it is also the first and the most intimate community for liver transplant recipient children. The value and expectation of a family impact on the health of each family member. Conversely, the health of family members also exerts great impact on the family. Illness in a family member may exert a heavy financial burden on the family [17]. Parents as major care providers of liver transplant recipient children have to tackle the financial burden as well as deal with enormous psychological pressure. Currently, there is no report on the concerns of and coping strategies by Chinese parents of pediatric liver transplant recipients in China. Nevertheless, it is necessary to study the concerns and coping strategies of this particular population to provide a basis for future investigation of the determinants of the coping strategies of parents of liver transplant recipient children. The psychological wellbeing of parents not only impacts on their coping behavior and quality of life, but also affects the emotion of the sick child as well as his or her treatment and recovery [18].

After a successful liver transplant, the life of the recipient child is saved and his or her quality of life is substantially improved. However, the child needs to take lifelong medication with immunosuppressants to ward off potential graft rejection reaction and thus he or she has to deal with issues related to infection and adverse drug reactions [19]. Parents have to face the uncertainty of the child's health over time and the possibility of death [3], and this in turn will impact on the feeling of the parents [20]. Meanwhile, coping by parents will also impact on the health of the liver transplant recipient [21]. Lazarus and Folkman define coping as constant adjustment of cognition and behavior in face of stresses and as a way of managing stressful states in the internal and external environment. Coping relieves emotional tension and maintains psychological equilibrium. Through coping, parents adjust their strategies to meet external requirement.

Coping serves as a mediating mechanism between stress and psychological health and plays a modulating role in psychological health [9, 22]. Different coping styles by parents exert different effects on liver transplant recipient children and the parents themselves [23]. This is the first qualitative study on the coping strategies by parents of liver transplant recipient children in China. In the current study, feeling guilty to the sick child was a common form of emotional coping by the parents, who felt being negligent for the child to develop the illness. Parents of liver transplant recipient children actively seek medical information, and communicate actively with medical staff and exchange information with parents of other transplant recipients. They are cooperative and maintain a positive attitude. They actively seek social support, maintain self-esteem and psychological stability, and build confidence in the treatment of the recipient children. These findings suggest active coping on the part of parents. Meanwhile, more consideration is given to the psychological health and future development of the recipient children while education of their children is still not on their priority list.

Parents have to face multiple challenges like substantial medical expenses following surgery, future education of the recipient child and conflicts in the family; this will lead to coping by compromise. Through emotion-focused coping, parents avoid or accept truth. Compromises by parents in their care of the recipient children

help lessen stresses on themselves. We found that parents hope for a healthy growth and development of their recipient children, but they have not given much consideration of education of the child and instead emphasize taking a natural course. This may be due to the young age of the recipient children in the current study and the short duration from time of surgery to time of interview. Parents focus more on the physiological health of recipient children. Education of the recipient child is still not on their main agenda.

Chronic illness is a major source of stress for recipient children and their family, which has to be faced by the recipient children or their parents and family. Parents of liver transplant recipient children take a proactive approach to cope with chronic illness by seeking social support and persist in the treatment of their sick child. This helps parents to maintain good psychological adaptation and the balance of family function [24, 25]. Litzeman *et al.* think that transplantation greatly threatens family stability of the recipient children, leading to changes in the role of family members [26]. Children with chronic illness and their parents need to constantly adjust themselves to adapt to the chronic disease state. Ratliffe found that parents of recipient children attempt to lower emotional conflict by seeking medical information and familial and social support [21], which is consistent with the current findings.

The current study is a qualitative descriptive study. This methodology enables investigators to obtain detailed information from the subjects and offers phenomenal explanation. This approach also can unravel answers to and lead better understanding of existing issues. We found that parents play a very important role in the recovery of liver transplant recipient children and they face multiple challenges in the care of their recipient children. Our study uncovered the coping themes of these parents such as compromise and seeking social support for helping to treat the sick child. However, we did not address the issue whether such coping strategies were efficient or effective in minimizing stress or reducing familial conflicts. We will tackle this important issue in future clinical studies. Furthermore, determinants of parental coping strategies will also be studied so that specific help and targeted intervention are provided for the family to improve family function.

### Acknowledgements

This study was supported by grants from the National High-tech R&D Program of China (863 Program): No. 2012AA021006, WZ2009042, WZ2011009, and WZ20130203. The study was also supported by the Project Sponsored by the Scientific Research Foundation for the Returned Overseas Chinese Scholars, State Education Ministry. We express our thanks to the staff at the Transplant Follow-up Center of the General Hospital of Chinese People's Armed Police Forces and School of Nursing, Beijing University of Chinese Medicine.

### Disclosure of conflict of interest

None.

**Address correspondence to:** Hong-Xia Liu, School of Nursing, Beijing University of Chinese Medicine (BUCM), 6#, Wangjing Zhonghuan South Road, Beijing 100102, China. E-mail: hongxia\_t@163.com; Dr. Yu-Jian Niu, Organ Transplantation Institute, The General Hospital of Chinese People's Armed Police Forces (GHCAFP), 69#, Yongding Road, Beijing 100039, China. E-mail: 13911723403@163.com

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