

ORIGINAL ARTICLE

Daily lives of pre-adolescents/adolescents and their parents after liver transplant

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Abstract

Aim: This mixed methods study describes the post-transplantation daily life of pre-adolescents and adolescents who had undergone living donor liver transplantation and their parents.

Methods: Nine parent–child dyads were enrolled and all children were living donor liver transplant recipients. Three participants were pre-adolescents and the six were adolescents. Five of the parents surveyed in this study had been the donors. Members of the parent–child dyads completed the questionnaires and participated in semistructured interviews. An inductive qualitative analysis of the interview data was conducted.

Results: The post-transplantation daily life of the parent–child dyads had four distinct patterns: (i) pre-adolescents who had undergone transplantation during infancy, who had no understanding of the transplant procedure, and whose care was managed by their parent(s) without any problems; (ii) adolescents who were aware that their physical condition had improved after the transplant and who managed and dealt with the situation on their own; (iii) adolescents who were dissatisfied with the transplantation and associated immunosuppression because transplant procedures were perceived as negative or because they could not remember the transplant procedure; and (iv) one participant could not be categorized because their liver function deteriorated post-transplantation and they were registered for re-transplantation. Patterns were identified that characterized the post-transplantation daily life of pre-adolescents/adolescents who underwent liver transplantation, and that of their parents. Further research for post-transplantation parent–child dyads is warranted.

Key words: children, daily life, liver transplantation, quality of life.

INTRODUCTION

Currently, liver transplantation is the key therapy for end-stage liver disease. Approximately 90% of the pediatric liver transplant patients in Japan have living donors. Eighty percent of these children underwent transplant surgery before school age (The Japanese Liver Transplantation Society, 2011). The survival rate of

children after living donor liver transplantation is higher than survival in adults (The Japanese Liver Transplantation Society, 2011). Therefore, children are expected to have long-term survival post-transplant.

There has been little research to explore social and psychological quality of life (QOL) of children after liver transplant (Fujita, Nakamura, & Sato, 2013). Most researchers have explored only the physical QOL after transplantation (Hashimoto *et al.*, 2002). Guidance for nursing interventions to improve QOL of post-liver transplanted children is limited in part because the number of transplanted children in Japan is low, between 100–150/year (Inomata & Hayashida, 2013). This lack of knowledge is particularly problematic when the child who was transplanted is transitioning to adult care as an adolescent. Berquist *et al.* (2006) pointed out

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the need for self-management of disease and children's changing needs due to growth and development. In a qualitative study about the experience of young people living with a liver transplant, Taylor, Franck, Dhawan, and Gibson (2010) found important issues related to relationship building, effect on schooling, tiredness and fatigue, acceptance of the burden of medication, and view of the future. The sample for their study was only children after transplantation. Parents are indispensable to a child's growth development and disease management but there does not appear to have been any study of the parent–child dyad in this group.

Living donor liver transplantation is the main treatment in Japan, which is different from other countries where cadaver transplantation is the primary treatment (Sugawara, 2013). Approximately 95% of pediatric living liver transplantation donors in Japan are from a parent of the recipient (The Japanese Liver Transplantation Society, 2011). Because both the donor and recipient are present in a family after living donation, the burden is large for the family. Little is known about the perceptions as well as nursing intervention for post-transplantation daily life issues of pre-adolescents and adolescents who have undergone liver transplantations and of their parents in Japan. This study describes the daily lives post-transplantation of pre-adolescents and adolescents and their parents who underwent liver transplantation. A goal of this work is to develop ideas for nursing support that would maintain and improve the QOL of these children and their parents.

METHODS

Setting and participants

Participants were recruited from a single center in Japan. A purposive sample of children and parents was invited to participate in face-to-face interviews after the research had been announced from doctors. The sample for this exploratory pilot study consisted of nine parent–child dyads. All children had undergone living donor liver transplantation. The parent subject of this study was the primary caregiver of children. Children's donors were all their parents. Four parents were not donors. The study was conducted from July 2011 to March 2013 at an outpatient clinic for children's surgery. All children and parents met the following inclusion criteria: (i) children had undergone living donor liver transplantation; (ii) their age was 10–18 years; (iii) they understood their diagnosis and disease; (iv) they had

a parent who was willing to participate, whether the parent had been a donor or not; and (v) the parent usually accompanied the child on outpatient visits. Pre-adolescent was defined 10–12 years old and adolescent as 13–18 years old.

Ethical considerations

The research ethics committee of the university that the researcher was affiliated with at the time of the study approved the study proposal and corroborated its ethical considerations. Children and parents were informed about the purposes and the methods of this study. Parents who agreed for themselves and their child to participate in the study provided signed written consent. Children assented to participate in the study after the agreement of their parents. Permission to audio record the interviews were obtained from parents and children.

Measures

Quality of life for pre-adolescent and adolescent liver transplant recipients is defined as age-appropriate growth and development, maintenance of liver function, and transition to self-management of the disease. It also includes satisfaction with daily life, including medical treatment, school life, social life, and everyday life and disease management. QOL for the parents includes: maintaining their own physical, mental and social function; having an appropriate relationship with the child; being satisfied with family life; and physical, psychological, social, and economic aspects of life.

Data collection

A mixed methods approach was used. Data were collected through questionnaires and semistructured interviews about their daily life experience. Demographic data and medical record data were collected through questionnaires. Questionnaires were administered before interviews, and interviews were based on the results of the questionnaires. Semistructured interviews with parent and child were separated. The interviews with the children ranged 6–26 min with an average of 12 min. It was difficult to interview some of the children because of their developmental stage or characteristics. The child with the shortest interview time seemed to be very embarrassed, and her interview was completed in such a way as to check the contents of the questionnaire responses.

Parental interviews ranged 10–50 min in length with an average of 31 min. Participants responded to questionnaires while waiting for their child's physical

examination, and responses were collected at the time of interviews, again while awaiting examination. The interview was based on the questionnaire responses and was digitally recorded. Children were interviewed about daily life experiences and perceptions of their disease. Daily life experiences and perceptions about the disease and themselves consisted of mainly current daily life and perception. Furthermore, children were asked when they became aware of the disease or transplantation, as well as how they were informed about the disease and transplantation, and change in their physical condition pre- and post-transplantation. For example, questions included: “What are you careful about in daily life?”, “Do you have anything else to express other than what has been asked of you in the questionnaires?”, “When did you become aware of your disease and transplantation?”, and “What were you told about your disease or physical condition?”.

Satisfaction with life was investigated using a validated questionnaire (Nakamura *et al.*, 2002, 2004, 2007). The Satisfaction with Life questionnaire measured daily life satisfaction for primary, junior high, and high school children. The version for primary and junior high school children consists of six subscales: (i) anxiety; (ii) family; (iii) friends; (iv) school; (v) general health; and (vi) strength/diligence/self-esteem. The published Cronbach’s alpha coefficient for the questionnaire was 0.90, and for the subscales ranged 0.59–0.81. The high school version consists of eight subscales: (i) friends; (ii) school; (iii) mental health; (iv) parent/economic states; (v) self-esteem related to relationship with boyfriend/girlfriend; (vi) vitality; (vii) anxiety regarding admission to higher school/employment; and (viii) sibling(s). The published Cronbach’s alpha coefficient for the questionnaire was 0.91, with subscale values ranging 0.53–0.83 in the past study. These questionnaires have been validated for the Japanese general population (Nakamura *et al.*, 2002, 2004, 2007).

Parents were interviewed and responded to a questionnaire about attributes and daily life of their child and their own daily life, and experiences and perception of the child’s disease as well as liver transplantation. Parents were interviewed about current daily life and their lives before transplantation and difficulties or experiences post-transplantation. For example, questions included: “What are you careful about in daily life since your child’s transplantation?”, “What are you careful about in the disease management of your child?”, “What are the differences in your daily life pre- and post-transplantation?”, and “How do you perceive your child’s current disease and treatment?”. Health

related QOL of parents was evaluated with the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36; Fukuhara, Bito, Green, Hsiao & Kurokawa, 1998; Fukuhara & Suzukamo, 2004; Fukuhara, Ware, Kosinski, Wada & Gandek, 1998). The SF-36 measures general health status. One item assesses perceived change in health status, and the remaining 35 items contribute to a score on one of eight scales: (i) physical functioning; (ii) role–physical; (iii) bodily pain; (iv) general health perception; (v) vitality; (vi) social functioning; (vii) role–emotional; and (viii) mental health. Scores on these eight scales can be used to compute a summary index of physical health and a summary index of mental health. The published Cronbach’s alpha for each subscale and summary score in the present study ranged 0.71–0.87.

Data analysis

Children’s satisfaction scores were scaled based on the standard deviation (SD) of each developmental stage (average reference value, 0; SD, 1; Nakamura *et al.*, 2002, 2004, 2007) and were compared with the reference value (Nakamura *et al.*, 2002, 2004, 2007). Parental QOL scores measured by the SF-36 were compared with a norm-based score from the Japanese population according to the SF-36 manual (Fukuhara & Suzukamo, 2004).

Descriptive statistics and questionnaire scores were used to look for patterns. Patterns identify characteristics of recipients’ QOL, stage of development, comprehension of transplantation and its implications, perception, and disease management practices and liver function status.

Interviews were transcribed verbatim after each interview. Each child’s qualitative data was analyzed individually and as a group. The data were analyzed for perception of daily life, school life, disease management, satisfaction with daily life, and experience of liver transplantation. In the individual analyses, daily experiences of parents and children were organized by similar content and expressed in a concise sentence representing a meaning for the dyad. Scale scores for the QOL measures were calculated.

The relationship between daily life and QOL were synthesized from the results of qualitative data and instruments that measured satisfaction with daily life. The credibility of the data was established with two nursing PhD candidates as a peer check. The coding, categorization, and extraction of patterns were supervised.

RESULTS

Participants

There were nine parent–child dyads (Table 1), including three male and six female children with a mean age of 14.2 ± 3.0 years (range, 10–17). The mean age at the time of transplantation was 8.2 ± 5.4 years (range, 2–17). The post-transplant period ranged from 7 months to 12 years and 1 month (mean, 5.7 ± 3.6 years). All children were receiving immunosuppression therapy, but one adolescent needed i.v. albumin infusion; he was registered for a cadaveric donor liver transplant. Three children had lower scores of daily life satisfaction than the reference values (Nakamura *et al.*, 2002, 2004, 2007) of the same age (Table 2). The sample included one father and eight mothers aged from the late 30s to the early 40s. The five parents who had been donors included one father and four mothers. Three parents had lower than standard value scores (Fukuhara & Suzukamo, 2004) on physical component summary, and five had lower scores on the mental component summary (Table 2).

Patterns and aspects

The extracted patterns from the interview data demonstrated multiple dimensions, including developmental stages; children's perception about transplantation, perceptions and actual status of disease self-management, and presence or absence of liver function deterioration were reflected in the extracted patterns. Four thematic patterns were extracted based primarily on the children's data. There was a difference in the stage of development of the pre-adolescent compared with the adolescent. Characteristics of the disease management were different for primary school children and high school students (Table 3). Four patterns were synthesized from the interviews and questionnaires that synthesized the child's historical or current situation.

Pattern 1: naive to transplant

Pattern 1 consisted of pre-adolescents who underwent transplantation during infancy, who had no understanding of the transplant procedure, and whose care was managed by the parent(s) without any problem post-transplantation ($n = 3$).

These children knew that they had experienced an operation in their childhood, but did not understand about the transplantation itself. For example, one said, "I do not know what [a] transplant is", "I [did] not know that I got the liver". Pre-adolescents were similar to other elementary school students, and there were no

limitations to daily life. They recognized the importance of disease self-management, the use of immunosuppressant medications, and they took medicine from their parents or on their own. Sometimes they forgot to take their medicine. Disease management was maintained by parents. Satisfaction with daily life was greater than or the same as children of the same age (Nakamura *et al.*, 2002, 2004, 2007). Body development was a little less than that of the children's growth curve, but there was no obvious difference of more than -2 SD.

Parents recognized their children as "No different from other children" except for the use of immunosuppression, and parents identified positive change for children post-transplantation such as "I feel a change in [my child's] physical condition post-transplant". Parents left some physical management to their children. They informed the children about oral medications, and they were quite careful about immunosuppressant use and health status of children. In addition, parents worried about the future of their children, saying, for example, "[The] future is a concern" and "It is a concern about [what my child will be able to do on] his/her own in the future".

Pattern 2: positive experience

Pattern 2 consisted of adolescents who were aware that their physical condition had improved because of the transplantation and managed and dealt with the situation on their own ($n = 3$). These adolescent children were high school students, and they had undergone a transplant after the age of 10 years. The children perceived that their physical condition had improved by undergoing transplant and that they had undergone a transplant surgery. One noted, "It was easy to become tired before transplantation, but the body becomes normal after transplantation". There was no perceived limitation of daily life for these children. Children attended school, and they perceived their school life as no different from ordinary high school students. The children built normal friendships. Satisfaction with life was substantially the same as children of the same general age. Physical growth was approximately the same as other children. However, satisfaction with physical vitality was lower than the reference value (Nakamura *et al.*, 2002, 2004, 2007). Although the use of immunosuppression was perceived as cumbersome, they knew immunosuppression was necessary for their disease management. They sometimes forgot to take their medicine, but they coped with forgetting to take their medicine by themselves.

Table 1 Demographic and status of participants

Case	Children			Parents		Family makeup, number of people (relationship)	
	Age/sex	Post-transplant period	Diagnosis	Height (SD)/obesity index (%)	Age (relationship)		Donor
A	10/male	5 y 9 m	Congenital absence of the portal vein, hypergalactosemia	-0.4/-6.8	Mid-30s (mother)	Mother	Two (mother)
B	10/female	7 y 3 m	Congenital absence of the portal vein, hypergalactosemia, subglottic stenosis	-1.2/-7.9	Early 40s (mother)	Father	Five (mother, brother, grand mother, aunt)
C	11/female	8 y 2 m	Biliary atresia	-0.4/15.7	Early 40s (mother)	Father	Four (mother, sister, brother)
D	15/male	2 y 11 m	Biliary atresia	-1.7/-9.5	Early 40s (father)	Father	Five (father, mother, brother, young sister)
E	17/female	7 m	Biliary atresia	-2.46/28.1	Early 40s (mother)	Mother	Four (father, mother, sister)
F	15/female	1 y 11 m	Biliary atresia, hepatopulmonary syndrome	-1.6/61.5	Mid-40s (mother)	Father	Seven (father, mother, four young brothers)
G	17/female	7 y	Fulminant hepatitis	-2.1/7.1	Mid-40s (mother)	Mother	Three (mother, sister)
H	17/male	7 y 4 m	Biliary atresia (complete registration of cadaveric transplantation)	-0.07/1.5	Early 40s (mother)	Father	Seven (father, mother, three young sisters, young brother)
I	16/female	12 y 1 m	Biliary atresia	-0.1/2.1	Late 30s (mother)	Mother	Three (mother, young brother)

m, month; SD, standard deviation; y, year.

Table 2 Questionnaire scores

Case	Children Satisfaction with daily life	Parents SF-36 summary score, PCS/MCS
A	0.44	55.5/70.6
B	0.43	44.2/25.6
C	1.33	58.2/57.3
D	−0.05	60.2/43.1
E	1.14	51.0/58.5
F	1.39	43.0/47.9
G	−0.39	60.4/48.8
H	0.31	60.4/48.8
I	−0.32	40.0/36.5

Satisfaction of daily life of children score are normalized scores. Reference value is 0 (range −0.39 to 1.39); adapted from Nakamura *et al.* (2004, 2007). MCS, mental component summary (range, 25.6–70.6); PCS, physical component summary (range, 40.0–60.4); SF-36, 36-Item Short-Form Health Survey (the score component summary of parent are standard value of 50.0); adapted from Fukuhara & Suzukamo (2004).

Parents perceived health management as more difficult as the child's age increased. On the other hand, parents orally confirmed the child's immunosuppression use, but left some of the management to the child as suited their age and characteristics. Parents perceived that their child was not feeling changes in physical condition post-transplant, but parents worried about the course or deterioration of liver function in the future.

Pattern 3: negative experience

Pattern 3 consisted of adolescents who perceived transplantation as a negative experience ($n = 2$). Children with pattern 3 were both adolescents; one had undergone the transplant in early childhood and the other while in junior high school. Both of them experienced complications after transplantation. Both children attended high school with no particular limitation of daily life and spent school lives depending on their physical condition. They were building relationships with friends at school, such as talking to close friends. One child did not perceive any improvement in her physical condition after liver transplantation because she underwent transplant in early childhood and did not remember the surgery. She was not able to understand the need for immunosuppression and had a negative perception about side-effects, saying, "I do not understand the need for medicine". The other child perceived the improvement in her physical condition after transplantation and recognized that immunosuppression was needed for her physical condition. On the other hand, she had a negative perception about taking medicines.

She had taken many medicines pre-transplant because of complications, and the situation did not change after the transplant. Disease management for both was maintained by involvement of the parents. Satisfaction with life was not different substantially from average children of the same age in the general population.

Parents perceived their children as no different from other children other than use of immunosuppression. Parents left some physical condition management to their children, considering their adolescent age. However, parents told the children that they should pay attention to taking medicine. In addition, parents worried that there might be deterioration of liver function in the future. Parents enlisted cooperation of the children's siblings. At any time of worsening of liver function of sick children, parents urged the understanding of their siblings of transplantation and disease. The physical and mental QOL of parents was lower than the standard value (SF-36; Fukuhara & Suzukamo, 2004).

Pattern 4: treatment failure

Pattern 3 consisted of an adolescent whose liver function deteriorated post-transplantation and who was registered for re-transplantation ($n = 1$). He did not show any of the previous characteristics due to deteriorating liver functions and could not be categorized into the other three patterns. This adolescent child had undergone a transplant during elementary school, but had adjusted to the need for re-transplantation because of deterioration of the graft liver function. He was registered for cadaver transplantation. He required daily outpatient visits for albumin infusion therapy, but he could not be absent from school if he wanted to graduate on time. Therefore, he spent every day balancing outpatient visits and school, saying for example, "I spend school life according to my physical condition and I take it easy". He was not able to build friendships after transplant well in elementary school, but he was enjoying himself in high school life, depending on his physical condition. His disease was managed with immunosuppression and i.v. albumin therapy. His immunosuppression was self-managed, beginning in junior high school. He forgot to take his medication at times because he found it cumbersome, and it caused side-effects. He perceived his physical condition as poor at the time of the study, recognizing that it was important to self-manage medicine, and he understood the need for re-transplantation. His satisfaction with life was substantially the same as average children of the same age (Nakamura *et al.*, 2002, 2004, 2007). Satisfaction with physical vitality was slightly higher than that of similar

Table 3 Characteristics of each pattern

Pattern	1	2	3	4
Children				
Transplant age				
Childhood		After school age	Childhood/school age/adolescent	School age
Developmental stage				
Pre-adolescent		Adolescent	Adolescent	After late school age
Experience of liver transplantation				
Children knew that they had experienced an operation in their childhood, but did not understand about the transplantation itself: “I do not know what a transplant is”, “I did not know that I received a liver”.		Children perceived that their physical condition had improved by undergoing transplant and that they had undergone a transplant surgery: “It was easy to become tired before transplantation, but the body becomes normal after transplantation”.	Children do not understand having undergone transplant surgery, or even if they understand, there is a negative perception of transplant: “There was no surgery because I do not remember that surgery”, “Although I heard of the transplant, I was fine anyhow”.	The child perceived that their physical condition had improved by undergoing transplant and that they had undergone a transplant surgery: “Before worsening, it was an ordinary life, but the current situation is not good”, “It was easy to become tired before transplantation, but the body becomes normal after transplantation”.
Daily life				
Everyday life				
No limitation: “My life is not in trouble”, “There is no limitation to daily life”, “I have no physical restrictions in my daily life”, “I don’t eat food that is prohibited”, “I’m careful about cleanliness and food, lifestyle”.		No limitation: “My life is not in trouble”, “It is a normal life except for the medicine”, “Spend while moderate”, “I perform infection prevention behavior in my own way”.	No limitation: “My life is not in trouble”, “I have no particular concerns”.	Limited associated with deterioration of liver function: “It is not difficult when my condition is bad”, “There is a limit to activities and foods”, “I cannot conform to activity restrictions”.
School life, social life				
Children were similar to other elementary school students: “School life is fun”, “Relationships with friends are going well”, “I go to school every day”.		Children perceived their school life as no different from ordinary high school students: “School life is fun”, “It is not unreasonable to meet the physical demands of my school”.	Children perceived their school life as no different from ordinary high school students: “School life is fun or not inconvenient”.	It is a life frequently requiring repeated hospitalized or outpatient treatment: “School life is fun”, “I spend my school life according to my physical condition and take it easy”.
Disease management				
Disease management was maintained by parents: “I’m careful to drink the medicine”, “Drinking daily medicine is necessary for the body”, “Although I take medicine by being told to my family, medicine has been forgotten to be taken occasionally because of carelessness”.		Children sometimes forgot to take their medicine, but they coped with forgetting to take their medicine by themselves: “Drinking daily medicine is necessary for the body”, “Sometimes I forget to take medicine”, “It is troublesome to take medicine every day”, “I’ve coped when I have forgotten to take medicine”.	Children are responsible for some part of their management. Understanding of the necessity for immunosuppression is insufficient. Management is maintainable by relationship with parents. “There are side-effects to the medicine”, “I do not understand the need for medicine”, “Taking medicine does not change both before and after transplantation”.	Intravenous treatment in an outpatient unit is required. Management of immunosuppression is different depending on experience and developmental stage: “It is troublesome to take medicine every day”, “There are side-effects to the medicine”, “Although taking medicine and intravenous drip are troublesome, they are unavoidable”.
Parents				
Perception of the child				
No different from other children except for the use of immunosuppression: “No different from other children”, “I feel a change in their physical condition post-transplant”.		No different from other children except for the use of immunosuppression. Health management is difficult as the child gets older: “Health management becomes more difficult as age increases”, “I feel a change in their physical condition post-transplant”.	No different from other children except for the use of immunosuppression. Health management is difficult as the child gets older: “No different from other children”, “Health management becomes more difficult as age increases”, “I feel a change in their physical condition post-transplant”.	Conditions are bad. The child also understands: “The child understands the bad current situation”.
Disease management				
Part of the management is left to the child, but parents are careful about the disease management of the child: “I take care to prevent infection”, “I carefully manage medicine daily”, “I always attend the outpatient visits”.		Part of the management is left to the child, but parents are careful about the disease management of the child: “I manage my child’s health to match their characteristics”, “I’m careful in the management of medicine”, “I always attend the outpatient visits”.	Part of the management is left to the child, but parents are careful about the disease management of the child: “I tell them that they have to be careful”, “They neglect management because they are naughty”, “I’m careful in the management of medicine”.	Part of the management is left to the child, but parents are careful about the disease management of the child: “I manage my child’s health to match their characteristics”, “I’m careful in the management of medicine”.
Concerns				
Child’s future (self-management, liver function). Perception of child’s future: “Their future is a concern”, “It is a concern about what my child will be able to do on his/her own in the future”.		Liver function in the future: “The course or deterioration of liver function in the future is a worry”.	Liver function in the future: “The course or deterioration of liver function in the future is a worry”.	Anxiety symptoms worse. Presence or absence of donor: “The course or deterioration of liver function in the future is a worry”, “I cannot be a donor twice”.

Example of category “ ”.

children. Satisfaction and physical condition of deterioration of liver function did not coincide.

His parents were tired because of the work it took to take care of the family, the daily outpatient visits, and the poor condition of the child. They found the child's situation difficult to understand, but cared about the physical condition of the child and careful management of medicine. The parents worried about the progress of the child in the future, saying, "I can't be a donor twice". Mental QOL (SF-36) was lower than the standard value.

DISCUSSION

The post-transplantation daily life of pre-adolescents/adolescents who underwent living donor liver transplantation, as well as the characteristics of post-transplantation daily life for the transplant recipient's parents, are described. Four patterns of liver transplanted children and their parents' QOL were found and defined. From the patterns extracted, several nursing interventions have been identified that may improve the QOL of these children and their parents.

Pattern identification and extraction

The extracted of pattern was reflected by children's developmental stage, perception of disease management and transplantation, depending on liver function. Four patterns that reflected the families' QOL were extracted. Pre-adolescents of pattern 1 underwent the transplant in early childhood, and they knew that they underwent transplant surgery but they did not understand the meaning of the transplantation. Iba (2005) reported that children's perceptions of illness were affected by their cognitive development, their characteristic experiences related to congenital heart disease (surgery-related scars, awareness of symptoms, and activity restrictions), information provided by mothers, and interaction with friends. This study confirms Iba's findings that pre-adolescents' disease management occurred through the involvement of the surrounding environment and experiences of the past. Early transplantation was related to positive QOL for these participants.

Children with patterns 2 and 3 were adolescents and the difference between pattern 2 and 3 was children's positive or negative perception of transplantation. Adolescents with pattern 2 had had liver transplantation when they were more than 10 years old, and they understood that experience. They perceived the improvement of their physical condition after transplantation; satisfaction with life was not low. Adolescents with pattern 3

negatively perceived transplantation. One did not understand the need for immunosuppression and its side-effects, and did not remember the transplant in infancy. The other child perceived no change pre- and post-transplantation. Adolescence is an unstable period when identity is established (Ninomiya, 2014). Adolescence is a stage in which children are likely to have insufficient understanding of illness and conflict with illness, be conscious of the disease, and feel uneasiness and strong dislike for the side-effects of the medicines. As a result, medical treatment, mainly internal, tends to be insufficient (Fujishiro, 2010). Therefore, experiences of transplantation as well as developmental stage for children are important to evaluate patterns.

Patterns 1, 2, and 3 were extracted from developmental theory, children's perception of transplantation, and disease management. Pattern 4 was not associated with transplant age or developmental stage but rather with treatment failure. For pattern 4, the child physical management was a priority because of the deterioration of liver function and uncertainty.

No studies were located that focused on the daily life of Japanese pre-adolescent/adolescent children after living donor liver transplantation and their parents. Children have a longer period post-transplant than adult recipients and experience their own growth and development into adulthood. The history of post-transplant changes in the liver graft due to aging and lifestyle is unknown. Adjustment of daily life and disease management post-transplant is very important. The symptoms of the liver function aggravation are sometimes incomprehensible and it is hard for the parent to grasp their child's condition. Symptoms of deterioration of liver function are expressionless, and controlling life is difficult. Parents are also aware that the only treatment for liver failure after transplantation is re-transplantation, and parents who were a donor once cannot be a donor again.

Implications for nursing practice

Several unique characteristics of daily life of pre-adolescents and adolescents and their parents after living donor liver transplant have been described. The extracted patterns can be a useful tool for the assessment of children and their parents. Nursing interventions often depend on pattern recognition in order to set goals for each patient and determine the support required. A different support model could be designed depending on children's developmental stage and their perception of disease.

Implications for future studies

Few studies explain the differences in experiences due to the difference of the original disease and its treatment (Taylor et al., 2010) for adolescent liver transplant recipients and their families. In the study of other chronic diseases, therapeutic behaviors of parents have been demonstrated to correlate with the therapeutic behaviors and lifestyle of the children (Nakamura, Kanematsu, Keiko, Konno, & Tani, 1997), and several factors had effect on the involvement of parents such as perception of the disease and treatment, perception of the reaction of children to treatment and disease, emotionally supporting children, perception of the parent on the child's physical condition change, medical condition and treatment of children, and the outlook for the time of renal transplantation (Utsumi, 2011). Therefore, further studies are needed about these patterns to determine their relationship with health development and family dynamics. These findings suggest that further research should include differences in child developmental stage, primary versus cadaveric liver transplantation, and support given pre-transplantation.

Limitations

The sample size was very small, and all cases had received living donor liver transplantation and one pattern extracted had only one case. The patterns need to be further substantiated.

CONCLUSIONS

Analysis of this pilot data revealed four patterns based on recipients' QOL, stage of development, comprehension of transplantation and its implications, perception, disease management practices, and liver function status. Patterns were divided by the perception of disease, age at transplant, and developmental stage of the child. Extraction of the patterns showed some potential to suggest nursing intervention for maintaining and improving QOL in the daily life of parents and children after liver transplantation.

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CONFLICT OF INTEREST

The author has no financial conflicts of interest to disclose concerning the manuscript.

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