

A Qualitative Study on Nutritional Awareness Among Parents of Pediatric Recipients of Liver or Kidney Transplants

Ke Liu^{1,*}, Meng-Ying Zhang^{2,*}, Lu-Lu Sun², Qiao-Huo Liao², Yuan-Yuan Yi³, Yi-Ling Ji¹, Dan Ye¹, Qiu Yu¹

¹Department of Emergency, The Third People's Hospital of Shenzhen, Shenzhen, 518000, People's Republic of China; ²Department of Pediatrics, The Third People's Hospital of Shenzhen, Shenzhen, 518000, People's Republic of China; ³Department of Transplantation, The Third People's Hospital of Shenzhen, Shenzhen, 518000, People's Republic of China

*These authors contributed equally to this work

Correspondence: Lu-Lu Sun, Department of pediatrics, The Third People's Hospital of Shenzhen, No. 29 of Bulan Road, Longgang District, Shenzhen, 518000, People's Republic of China, Tel +86-13510332310, Fax +86-755-61238983, Email sunlulurainbow@126.com

Objective: The primary aim of this study was to examine the extent of nutritional awareness concerning dietary requisites within a cohort comprising pediatric recipients of liver and kidney transplants, along with their respective caregivers. The overarching goal was to establish a foundation for enhancing the dietary nutrition of this specific population.

Methods: This was a qualitative research study, involving in-depth interviews and subsequent qualitative data analysis. Our sample included pediatric patients in a specific age range who had undergone a liver or kidney transplant, as well as their parents. The data analysis technique we used was content analysis.

Results: The survey focused on knowledge of dietary requirements and restrictions, nutritional needs, and adherence to daily dietary requirements among pediatric patients and their respective caregivers. Approximately 30% of the parents lacked relevant nutritional awareness, 30% relied on a single source for acquiring nutritional knowledge, and 40% expressed a considerable need for nutritional guidance. Our findings revealed a deficiency in the understanding of nutritional and dietary requirements for children who have undergone a liver or kidney transplant. Their nutrient intake was unbalanced, and their dietary habits were irregular, highlighting the need for better nutritional guidance and monitoring.

Conclusion: The nutritional awareness and knowledge of dietary requirements among pediatric liver and kidney transplant recipients and their care providers are inadequate. Medical professionals are urged to tackle this concern by imparting comprehensive education to parents regarding the nutritional prerequisites essential for their children post-transplant. This approach empowers parents to implement requisite dietary modifications effectively. Furthermore, healthcare institutions should augment the nutritional proficiency of their medical staff through meticulously structured training initiatives.

Keywords: kidney transplant in children, liver transplant in children, nutritional awareness, nutritional support, qualitative study

Introduction

Liver and kidney transplants are among the most effective treatment options for severe liver and kidney diseases in children.^{1,2} Children undergoing a liver or kidney transplant are highly vulnerable to developing various postoperative complications, the most common among them being intestinal complications, undernutrition following the transplant, and infections.³ The occurrence of undernutrition in these patients may stem from inadequate nutrient intake, absorption disorders, and hypermetabolism following a liver or kidney transplant. This condition escalates the risks associated with the surgery and the incidence rate of postoperative complications, lengthens the duration of hospitalization, increases medical expenses, and ultimately affects the prognosis of patients.⁴

Parents of pediatric patients shoulder the responsibility for the recovery and care of their children after surgery, owing to the limited ability of children to manage their own health. The extent of parental awareness and capability to provide appropriate nutritional care directly influences the recovery of pediatric patients.⁵ In terms of preventing and treating undernutrition in children who have undergone a liver or kidney transplant and ensuring their healthy recovery, understanding the level of awareness of nutrition and dietary needs among parents of such children assumes significance. However, there is currently a lack of research regarding this aspect.

In this study, we aimed to investigate awareness regarding nutrition and dietary prerequisites among parents whose children have undergone liver or kidney transplants, employing a descriptive phenomenological research paradigm. The objective is to establish a foundation for formulating comprehensive plans aimed at delivering effective nutritional health guidance and nursing interventions tailored specifically for this cohort of children.

Methods of Data Analysis

Study Participants

A purposive sampling method was employed to select participants for this study. Through reference to medical records, a total of 26 pediatric patients within the age range of 0–14 years, who had undergone liver or kidney transplant procedures at the Third People's Hospital of Shenzhen, China, were identified for inclusion in the study. All organs were donated voluntarily with written informed consent and the procedures were in accordance with the Declaration of Istanbul. We selected the parents of these children to participate in the qualitative study.

Inclusion Criteria

Patients who ranged in age between 0–14 years; patients who had undergone a liver or kidney transplant; patients with complete medical reports; and patients and their parents who voluntarily participated in this study.

Exclusion Criteria

Patients who were unable to complete the research interview due to their physical condition; and patients whose parents were unable to complete the research interview. Parents of 26 children were included in this study in total. Details are given in [Table 1](#).

Study Methods

Development of the Interview Guide

The interview guide was developed based on the study objective, a review of literature, and consultations with experts. The interview consisted of two parts. The first part was parents' awareness of dietary care for children who have undergone a liver or kidney transplant, including basic dietary needs and restrictions as well as requirements for various nutrients. The second part was parents' concerns and opinions based on their experience of providing nutritional care for their children. The specific aspects of inquiry included in the interview guide were as follows: (1) How aware are parents about the importance of dietary requirements and nutritional support following a liver or kidney transplant? (2) How aware are parents of the special dietary needs of children who have undergone a liver or kidney transplant? (3) Do parents know how to select and prepare the appropriate prescribed foods for children who have undergone a liver or kidney transplant? (4) What are the difficulties and challenges faced by parents in providing the required diet for children who have undergone a liver or kidney transplant? (5) What is the parents' opinion on the kind of dietary support that is most essential for children who have undergone a liver or kidney transplant?

Data Collection Methods

Data was collected using semi-structured interviews. Interviews were conducted on the day of discharge, and the parents were interviewed in a pediatric consultation room to ensure a quiet and private setting. The interviewers selected for this study were healthcare professionals who had fulfilled nursing responsibilities during the children's hospitalization. These staff members were well-acquainted with the parents and had established a rapport, fostering a trustful relationship with them. Before commencing the interviews, the parents were briefed about the objectives and methods of this study. Interviews were scheduled in advance if the parents agreed to participate. Additional interviews were discontinued when data saturation was reached.

The entire interview was recorded after obtaining the consent of the interviewees. They also provided informed consent for the publication of anonymized responses. Two experienced supervisor nurses, each with over five years of

Table 1 Demographic Data of the Respondents (n = 26)

Number	Relationship of the Respondent with the Pediatric Patient	Age	Marital Status	Education	Gender of the Pediatric Patient	Age of the Pediatric Patient	Duration of the Disease (Months)
N1	Mother	35	Married	Undergraduate	Male	9	3
N2	Mother	30	Married	Vocational senior secondary school	Female	8	4
N3	Mother	40	Married	Graduate	Female	12	4
N4	Mother	37	Married	Three-year junior college	Male	11	3
N5	Father	33	Divorced	Undergraduate	Male	9	6
N6	Mother	32	Married	Undergraduate	Male	8	8
N7	Mother	35	Married	Academic senior secondary school	Female	5	9
N8	Mother	42	Married	Undergraduate	Female	8	4
N9	Mother	30	Divorced	Vocational senior secondary school	Female	2	6
N10	Father	36	Married	Undergraduate	Male	9	10
N11	Mother	41	Married	Graduate	Male	11	12
N12	Mother	35	Married	Academic senior secondary school	Female	5	6
N13	Mother	37	Married	Graduate	Female	6	2
N14	Mother	32	Married	Three-year junior college	Male	8	10
N15	Mother	36	Divorced	Graduate	Female	13	12
N16	Father	39	Married	Three-year junior college	Male	11	3
N17	Mother	43	Married	Undergraduate	Male	10	5
N18	Mother	39	Divorced	Undergraduate	Female	7	8
N19	Mother	40	Married	Vocational senior secondary school	Male	6	7
N20	Mother	29	Married	Undergraduate	Female	8	10
N21	Mother	30	Divorced	Undergraduate	Male	13	2
N22	Mother	35	Married	Academic senior secondary school	Male	10	5
N23	Mother	38	Married	Undergraduate	Female	6	8
N24	Mother	37	Married	Undergraduate	Female	10	4
N25	Father	45	Divorced	Graduate	Female	7	6
N26	Mother	36	Married	Academic junior secondary school	Male	12	9

clinical work experience, conducted the interviews. They remained neutral and did not interrupt the interviewees in between. When necessary, the interviewers clarified the content with the interviewee to ensure its authenticity and accuracy. Concurrently, the interviewers also observed and recorded nonverbal cues such as the interviewee's tone, facial expressions, and body language. No additional information was obtained during the interview with the 26th respondent. The duration of each interview in this study was between 35–90 minutes and averaged 50 minutes.

The interviews followed a predesigned process in which the questions and their sequences were clearly defined. The quality and accuracy of the interviews were ensured by training the interviewers, using audio recordings, and referring to interview notes for review, among other approaches.

The nutritional status of patients aged 0–2 was assessed according to the height-for-age z-scores/weight-for-age z-scores, and that of patients older than 2 was assessed according to the body mass index-for-age z-scores, proposed by the World Health Organization.

Methods of Data Analysis

We analyzed data in this study using Colaizzi's seven-step method.^{6,7} Audio recordings of the interviews were transcribed into texts within 24 hours of completing the interview. Nonverbal cues noted during the interviews were marked in the corresponding areas of the transcribed texts. Two researchers independently analyzed and coded the texts and then summarized the codes. In instances of disagreement, the research team engaged in thorough discussions to reconcile differing perspectives and achieve a consensus. This proactive approach aimed to mitigate the potential impact of personal biases and subjective interpretations, thereby enhancing the objectivity and reliability of the study results. Through this methodology, notable statements and their underlying meanings were systematically extracted, and thematic patterns were consolidated. The resulting interpretations were shared with the participants for their feedback and verification. We carried out the relevant modifications as required and finalized the results.

Results

About 30% of the parents lacked appropriate nutritional awareness, 30% acquired their nutritional knowledge from a single source, and 40% expressed a high need for nutritional guidance. None of the patients had any other underlying diseases.

Theme 1: Patients and Their Parents Lacked Correct Nutritional Awareness

One of the primary factors affecting the nutritional status of children who have undergone a liver or kidney transplant is a lack of correct nutritional awareness among patients and their parents. Based on the interviews, we identified a lack of awareness mainly in the following aspects: inadequate knowledge about diets and dietary nutrition. A considerable number of patients and their families believed that increasing food intake was equivalent to good nutrition. They paid no attention to nutritional balance in the diet. In addition, they were not aware of the function of nutrients. They lacked information about nutrition and were unaware of the nutrient content of various food items. For instance, respondent N1 mentioned in the interview that "I only know that if we eat more, our bodies will get enough energy". Another respondent, N16, said, "I'm unclear about the specific aspects that need to be improved after surgery". This indicated that N16 was unclear about post-transplant nutritional needs and dietary requirements.

In most cases, instead of scientifically tailoring their diets to match their nutritional requirements, patients and their parents believed that there would be no problems as long as they were eating. Most patients lacked knowledge of the dietary requirements, restrictions, and supplementation of various vitamins and nutrients and were thus unable to properly plan their diets and nutrition supplementation. Respondent N8 said, "Some vegetables, fruits, and meats are likely to be more nutritious, but I'm not very clear about the specific nutrients and their quantities". Respondent N11 stated, "Sometimes I feel confused and unsure if I have provided enough nutrition for my child". This indicated that N11 had inadequate knowledge about diet-related diseases and deficiencies.

A significant number of patients and their families were unaware of the restrictions on the intake of specific foods. This is important as it could lead to further deterioration of the patient's condition and affect recovery and rehabilitation. Respondent N5 said, "I believe that as long as patients eat well, they will be in good condition and recover fast". Another respondent, N17, said, "I failed to realize that there are restrictions on specific foods". In the interview, respondent N13 said,

Generally, during hospitalization, I would pay great attention to the treatment of the disease but pay little attention to the specifics of nutritional supplementation.

In our analysis, we found that these issues are related to two aspects: one is a lack of knowledge on dietary nutrition, and the other is the insufficient dissemination of specific information. Therefore, medical personnel should be encouraged to educate patients and caregivers about nutrition and provide them with detailed nutritional counseling to ensure that they are equipped with comprehensive and practical information pertaining to nutrition and dietary requirements.

Theme 2: Patients and Their Parents Had Limited Access to Nutritional Knowledge

After a liver or kidney transplant, patients and their parents had limited access to nutritional knowledge. This was a factor that potentially influenced their nutritional knowledge and decision-making abilities. During our research, we found that patients and their families had limited sources from which they accessed information about nutrition, which are listed below: Their first source of nutritional knowledge was their relatives and friends. Some patients and their families obtained information about foods and nutrition based on the experiences of their relatives and friends. A respondent, N3, said, “Generally, my knowledge of nutrition comes from the explanations of my close relatives”. Respondent N25 said, “I don’t know exactly how to supplement the nutrition. Mostly, I ask parents whose children suffer from a similar disease about their experience”.

Their second source of nutritional knowledge was online platforms. As respondent N7 said, “I usually search on the Baidu website for nutritional knowledge and read dietary and health magazines”. Respondent N18 said, “I like scanning videos on the Douyin app”. However, the information available on such platforms is diverse, and controversial opinions are common. Respondent N21 said in the interview, “I read popular science articles. However, I usually find it difficult to understand the articles as there is too much information”. These cases showed the limited access of patients and their families to information about nutrition. They primarily relied on the Baidu search engine and dietary and health magazines to obtain information pertaining to diet and nutrition.

However, these sources have their drawbacks, such as exaggerated and misleading content on the internet, which leads to inaccurate and unreliable information. Therefore, it is essential for patients and their families to consult credible institutions and professionals, such as nutritionists, and read authentic health magazines and nutritional textbooks to obtain more comprehensive and trustworthy nutritional information.

Some respondents also said that they were willing to improve their knowledge of nutrition by participating in the educational events organized by the hospital. However, they were frequently absent from these sessions as the timing of these activities did not match their schedule. As respondent N2 said, “I know that the hospital has organized courses in popular science, but I often did not participate due to conflicting schedules”. Respondent N12 said,

The popular science courses organized by the hospital are professionally run but are of a short duration, so I’m unable to get all the relevant information I need.

Hospitals are credible institutions that can authoritatively provide authentic information. The knowledge they disseminate is focused and practical, providing vital support for patients and their families to make informed nutrition-related decisions and properly plan their diets.

Theme 3: There is a High Demand for Nutritional Guidance from Patients and Their Families

Nutritional guidance/counseling was much sought-after by patients and their families. Probable explanations for this are that the health condition of the patient necessitates close attention to diet and nutrition and that patients and their families are cognizant of the gaps in their understanding of dietary and nutritional information. We recommend that physicians and nutritionists evaluate the nutritional requirements of the patients during the treatment process, offer individualized guidance on their diets and nutrition, and help the patients and caregivers make relevant adjustments and diet plans in accordance with their specific requirements.

The patients and their families are open to receiving nutritional guidance from a qualified source. To quote respondent N6, “I know little about diets and nutrition. How can I determine what diet is suitable for me?” Respondent N9 asked, “Will you turn to a nutritionist if you encounter a nutrition-related doubt that you don’t know?”

Additionally, to improve their dietary conditions, patients can inform themselves with dietary and nutritional knowledge from various other credible sources, such as reading books on nutrition, taking courses on nutrition, consulting nutritionists, and so on, all of which will help them plan more suitable diets.

Meanwhile, it is vital that patients and their families engage more with medical personnel and remain in contact with and interact with their physicians and nutritionists. Patients can manage their diets and nutrition better by partnering with professional medical personnel, thereby improving treatment efficacy, and promoting their own recovery.

Discussion

The Need for Improving Parents' Awareness of Nutritional Care for Children Who Have Undergone a Liver or Kidney Transplant

The parents of children who have received a liver or kidney transplant are the primary care providers and decision-makers for these children. Cultivating their awareness of health needs and nutritional information is crucial to the recovery, growth, and development of such children.⁸ Given the specialized nutritional needs and dietary restrictions for children who have undergone a liver or kidney transplant, there is a dire need to develop personalized dietary plans and ensure strict adherence to such diet plans.⁹

The extent of parental and familial awareness of nutrition is a factor that directly affects the formulation and implementation of dietary plans for such patients. Following a liver or kidney transplant, patients encounter several challenges, such as the use of immunosuppressants,¹⁰ inadequate nutrition,¹¹ and heightened stress levels. In such circumstances, it is important that patients and their families are able to maintain the prescribed dietary pattern for optimal physical and mental health.

We found that in most cases, the parents of pediatric patients lacked knowledge about post-transplant nutritional requirements. They were confused about what nutrition was required to be supplemented following the surgery and how to supplement it. Some parents equated increasing food intake with good nutrition. Other parents were of the opinion that it is important to supplement the diet with vegetables, fruits, and meat. Nevertheless, a shared deficiency in awareness was identified concerning the precise dietary constituents recommended for increased consumption and those foods that necessitated avoidance. Such gaps in nutritional awareness can hinder the implementation of postoperative nutritional plans for these children.

A thorough grasp of nutritional information can help parents make more informed choices when selecting foods, allowing them to identify dietary plans that match their child's condition and promote the post-transplant recovery of the child. Nutritional knowledge can also help reduce the risk of adverse reactions to medications, prevent diseases, improve immunity, and optimize the absorption and digestion of nutrients. Moreover, an enhanced grasp of nutritional knowledge can aid parents in more effectively managing the daily responsibilities and challenges associated with caregiving, thereby mitigating the occurrence of "caregiver fatigue".

Therefore, improving parental nutritional awareness is a fundamental prerequisite for fostering post-transplant health, rehabilitation, and recovery, as well as ensuring the subsequent growth and development of pediatric recipients of kidney or liver transplants. Education, guidance, counseling, training, and other approaches are imperative in strengthening their nutritional cognition, with the ultimate goal of enabling them to integrate this knowledge into their daily dietary habits.

Reasons for Inadequate Nutritional Awareness Among Parents of Children Who Have Undergone a Liver or Kidney Transplant

Potential causes of inadequate parental awareness of nutrition among parents of pediatric recipients of liver or kidney transplants include the following aspects:¹²

- 1) Insufficient dissemination of nutritional knowledge in medical institutions by clinical personnel: When sharing information associated with liver and kidney transplants, there appears to be a predominant focus among medical personnel on the treatment efficacy of the surgery, inadvertently overlooking the crucial emphasis on the importance of nutritional support. This suggests a lack of effectiveness among clinical teams in medical institutions in offering comprehensive dietary guidance for patients and their families.

- 2) Lack of basic nutritional knowledge among the families of the patients: Most families of the patients we interviewed did not have basic medical or nutritional background knowledge. Devising a proper post-transplant dietary plan posed a significant challenge for them. Professional knowledge is credible, but parents were at a loss as to how to access such sources. Even if they located professional sources of nutritional information, they found it hard to comprehend, as evidenced by the experience shared by respondent N18, highlighting the overwhelming technical content in articles. Therefore, we recommend that nutritional guidance for patients and their families be designed such that the content is simplified, easily understood, and acceptable for the layperson.
- 3) Physical and mental exhaustion experienced by family members: In the later stages of liver or kidney transplants, caregivers experience substantial physical and mental fatigue due to the extensive care they provide for the patients. This exhaustion can impede their ability to fully engage in nutritional learning and diet management. Respondents N2 and N12 were instances of this predicament, demonstrating eagerness to acquire the required information yet grappling with managing it well due to various challenges encountered in their caregiving responsibilities.
- 4) Insufficient support systems within the households: In some households, the caregiver may not get the support needed to make healthy food choices and prepare healthy meals. The absence of relevant resources, guidance, or help can pose practical challenges in determining nutritional and feasible diets.

In summary, multiple factors contribute to the insufficient parental understanding of dietary nutrition among families of children with a liver or kidney transplant. This highlights the need for establishing systems for information support and guidance for accessing scientific knowledge. Comprehensive educational inputs and targeted training, in particular, should be provided for the families of patients to equip them with the requisite nutritional knowledge and skills in this area.

Recommended Solutions to Improve the Awareness of Dietary Nutrition Among Families of Children Undergoing a Liver or Kidney Transplant and to Address Their Nutritional Needs

We advocate an intensified approach by medical personnel to delivering nutritional education inputs to patients and their families. This can be achieved by providing simple and easily understandable nutritional guidance via both oral and written educational materials and by strengthening the educational resources of families and communities through improving their nutritional awareness. Medical personnel can utilize various strategies to reach out to family members who are unable to participate in the educational sessions or for those who find the educational content difficult to understand. These include the online sharing of recordings of sessions, educational videos, posters, and articles. This multifaceted approach ensures accessibility to nutritional knowledge through alternative means for families unable to participate in formal educational courses.

Establishing online consultation services of nutritionists and dietitians as a means of providing professional guidance for patients and their families. These professionals can assist and guide families in formulating personalized dietary plans and provide practical suggestions with respect to selecting the appropriate food items and optimal food preparation techniques. Online accessibility can enable families to directly communicate with nutritionists for professional recommendations on specific foods that need to be supplemented, cooking methods, quantity of intake, and so on.

Implementing early stage nutritional assessments and nutritional interventions prior to formulating dietary plans can ensure that patients and their families have sufficient nutritional knowledge and skills to comply with the plans.¹³ This proactive approach can serve as a strong foundation for post-transplant recovery.

Improving the living environments of patients and reducing the caregiving burden of families. This can be realized by improving living conditions, expanding rehabilitation facilities, mobilizing and optimally utilizing the resources available in local communities, and other means.

Leveraging the potential of the internet and mobile communication technology to widen the reach, and utilizing online resources for providing medical services and disseminating nutritional information. On the one hand, these measures offer families with a child undergoing a liver or kidney transplant the opportunity to consult professionals and access relevant knowledge at their convenience, regardless of location. On the other hand, these measures promote

information sharing within the families of the patients. In this way, entire families are able to actively engage in and collectively understand the post-transplant rehabilitation process.

To summarize, improving the nutritional awareness and knowledge of families of children with a liver or kidney transplant and effectively addressing their nutritional needs necessitates concerted efforts and collaboration among multiple stakeholders. This will ensure better support for the rehabilitation of the patients while concurrently reducing the burden of caregiving faced by families and communities.

Conclusion

In conclusion, the provision of professional guidance pertaining to dietary and nutrition-related considerations is imperative for caregivers and families of pediatric patients who have undergone kidney or liver transplants. This guidance serves as a crucial component in fostering the cultivation of healthy eating habits within this specific demographic. This includes widening their access to nutritional information, consulting nutrition experts for personalized inputs on diets and nutrition, and strengthening their engagement with professionals in medical institutions. Such collaborative efforts can offer a more informed and supportive approach to the rehabilitation and overall health of patients.

Data Sharing Statement

The datasets used during the current study available from the corresponding author on reasonable request.

Ethics Approval and Consent to Participate

This study was conducted in accordance with the declaration of Helsinki. This study was conducted with approval from the Ethics Committee of the third people's hospital of Shenzhen. A written informed consent was obtained from legal guardians of all participants.

Consent for Publication

Consent for publication was obtained from legal guardians whose data are included in this manuscript.

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Disclosure

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