



A Descriptive Qualitative Study of Home Care Experiences in Parents of Children with Tracheostomies

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ABSTRACT

Purpose: The number of pediatric patients who require a long-term tracheal tube at home is gradually increasing. Studies have demonstrated that the parents of these children report high levels of stress, anxiety and other negative emotions as early as shortly after discharge from the hospital. The purpose of this study is to describe the home care experiences of parents of children with tracheostomies during the transition from hospital to home in China to more effectively address their needs.

Design and methods: This study used a qualitative descriptive design and face-to-face interviews with semi-structured questions to learn about the home care experiences of parents whose children had undergone a tracheostomy.

Results: Thirteen parents were recruited from the otorhinolaryngology outpatient ward of Xinhua Hospital in Shanghai, China. These parents described three categories of home care experiences: “direct care overload,” “psychological overload,” and “personal growth.” Subcategories included parental “role change,” “from helplessness to skillfulness,” “lack of professional support,” “anxiety and depression,” and “social isolation.” They also reported personal growth, which was mainly reflected by “changing their perspectives” and “developing potential.”

Conclusion: Although the findings of this study indicate that the physical and psychological overload reported by parents of children with tracheostomies during home care is inevitable, a better understanding of parents' caring experiences among professionals may facilitate clinical practice and promote continued community nursing care in China.

Practice implications: Parents hope to receive systematic education during hospitalization, including web-based video education for skills training after discharge. In addition, parents desire public recognition so that they can participate in normal family and community activities.

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Introduction

Tracheostomy is a surgical procedure performed to create a long-term or temporary channel in the middle of the normal respiratory tract for effective respiration and the removal of tracheobronchial secretions (Feber, 2006; McPherson et al., 2017; Nakarada-Kordic, Patterson, Wrapson, & Reay, 2017). Tracheostomy is becoming an increasingly common treatment for children with complex and critical health conditions who go home with a long-term tracheal tube (Davis, 2006; McPherson et al., 2017; Schweiger et al., 2017). Complications of tracheostomy include airway obstruction, mucus blockage, tube displacement,

bleeding, and infection (D'Souza, Levi, Park, & Shah, 2016; Johnson Obaseki, Veljkovic, & Javidnia, 2016; Shah et al., 2012). Some of these complications can lead to difficulty breathing and even death (D'Souza et al., 2016; Feber, 2006). During long-term home care, parents are responsible for providing basic tracheostomy care, such as sputum suctioning, cleaning, and tube changes (Flynn, Carter, Bray, & Donne, 2013; McCormick et al., 2015; McDonald, McKinlay, Keeling, & Levack, 2015). Thus, parents must master the skills involved in necessary tracheostomy care and demonstrate competency.

Studies have demonstrated that parents of children with tracheostomies reported high levels of stress, anxiety and other negative emotions as early as shortly after discharge from the hospital because they worried about their ability to provide tracheostomy care at home and to address accidents, such as tube displacement (Callans, Bleiler, Flanagan, & Carroll, 2016; Flynn et al., 2013; Hartnick, Bissell, & Parsons, 2003;

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Hopkins, Whetstone, Foster, Blaney, & Morrison, 2009; Joseph, Goodfellow, & Simko, 2014; Montagnino & Mauricio, 2004; Nakarada-Kordic et al., 2017). Flynn et al. reviewed the experiences and perspectives of parents of children with tracheostomies and found that these parents were likely to be isolated because of uncertainty about leaving the home due to the technical aspects and social stigma of having a child with a tracheostomy (Flynn et al., 2013). To date, there has been no investigation into the home care experiences of Chinese parents of children with tracheostomies. This is an important gap because it cannot be assumed that these parents' home experience is the same as that of parents in different cultural and social contexts.

This study aimed to describe parents' short-term experiences of caring for children with tracheostomies at home and to clarify their physical and psychological responses and transitional care needs in Mainland China.

Methods

Study design

Institutional review board approval was obtained before the implementation of this study (XHEC-D-2016-040). A qualitative description approach was used to learn about the home care experiences of parents whose children had undergone a tracheostomy (Lincoln & Guba, 1985; Miles, Huberman, & Saldana, 2014). Content analysis is a qualitative method for linking data to a main theme, and its final product is a set of concepts and categories describing the phenomenon under study. Therefore, this study, which sought to obtain descriptive categories from the participants' real experiences, adopted this methodology (Pope, Royen, & Baker, 2002).

Sampling method

A purposive sampling method was used to select potential participants with different levels of education through the otorhinolaryngologic outpatient clinic or the ward providing care services for children with tracheostomies in one hospital. These pediatric patients had visited the otorhinolaryngologic department and had undergone the procedure of tracheostomy electively. After discharge from the hospital, they visited the outpatient clinic or ward again for follow-up care within one month to observe any general short-term changes.

Based on clinical experiences, we thought that the emotional reactions and care needs by parents who were new to home care with the tracheostomies children would differ from those of parents who had the home care experience for a longer period. Thus, the inclusion criteria for potential participants were as follows: parents must have been taking care of a pediatric patient with a tracheostomy at home for less than 1 month, the respondent must have served as the primary caregiver and been responsible for the majority of the child's care, and the participant must have signed the informed consent form. Parents were excluded if they had received or were receiving mental health services or any psychological treatments or if they were health care professionals. Information was given to potential participants via posters or face-to-face contact between professional staff and parents. If parents were interested, they could contact the first author for more information and to receive a verbal description of the study.

Data collection

Semi-structured interviews were conducted to collect data. Guided by a literature review, one researcher developed an initial outline of primary questions to use as a guide. Then, the six-member research team discussed and developed the primary question guide outline, which was reviewed by a pediatric psychologist to ensure that the questions should not cause psychological trauma to the parents. One researcher

conducted all of the interviews in the otorhinolaryngology ward's meeting room.

The purpose and significance of this study were explained to the participants before the interviews, and the participants were assured that their privacy would be protected. After the informed consent form was signed, the interview was recorded and supplemented with notes taken during the interview. The participants were allowed to leave the study at any time. The interviews began with questions about the general condition of the pediatric patient and gradually transitioned to the following questions:

1. Can we talk about the patient's disease progression?
2. What role do you play in home care? What do you need to do every day?
3. Can you completely address the patient's needs? How did you learn tracheostomy care?
4. How did you feel when you were told to return home after the hospitalization?
5. How did you feel in the first 2 weeks after the patient was discharged?
6. What changes have you and your child experienced after returning home?

The semistructured interview method enables the interviewer to improvise follow-up questions based on the participant's responses (Kallio, Pietilä, Johnson, & Kangasniemi, 2016). Interviews lasted 28 to 63 min depending on the level of detail in the participants' responses to the individual questions.

Data analysis

All of the interviews were audio-recorded and transcribed verbatim. The data analysis began with a reading of each transcript from beginning to end. Then, each transcript was read word by word. Codes were derived by highlighting key words or phrases from the text that captured key ideas or concepts (Callans et al., 2016; Huberman & Miles, 1994). Then, a content analysis was conducted following three major steps (Elo & Kyngäs, 2008):

- (a) Open coding: the researcher made notes of first impressions and performed an initial analysis while reading each transcript. Next, the written material was read again, and as many headings as necessary were written in the margins to describe key concepts. The headings were collected from the margins and recorded on coding sheets. Categories were freely generated at this stage.
- (b) Creating categories: after open coding, the categories were grouped under higher-order headings. These data were compared with other observations in different categories.
- (c) Abstraction: this step involved formulating a general description of the research topic by generating categories. Each category was named using content-characteristic words. Subcategories with similar events and incidents were grouped together into categories, and these categories were grouped into main categories.

Validity and reliability of the findings

The following measures were employed to improve the validity and reliability of the findings (Beck, 1993; Graneheim & Lundman, 2004; Lincoln, 1995):

1. During the interviews, the interviewer used various interviewing techniques, such as questioning, feedback, and confirmation, to ensure that the participants understood the questions correctly.
2. Two researchers separately and independently analyzed the data; subsequently, the research team members compared the results and discussed them together.

3. A summary of the main findings of all the interviews was given to the participants to ensure that the results accurately described their experiences.

Results

After 13 parents (2 fathers and 11 mothers) were interviewed, the interviews were stopped because no additional new information emerged and data saturation occurred. The parents' average age was 27.85 years (standard deviation (SD) = 3.36 years), and their education level ranged from high school to a master's degree. Six children were diagnosed with congenital laryngomalacia, three children were diagnosed with acute laryngeal obstruction, two children were diagnosed with laryngostenosis, one child was diagnosed with recurrent respiratory papillomatosis, and one child was diagnosed with a subglottic hemangioma. Details about the parents and their children are presented in Table 1. After the analysis, parents' experiences of caring for children with tracheostomies at home were grouped into three main categories and other related subcategories, which are detailed in Table 2.

Direct care overload

This category reflects the daily tracheostomy care that the patients required (i.e., sputum suctioning, cleaning, and tube changes). The parents had to spend extensive time taking care of their children at home, and they experienced heavy care loads, as reflected in the categories "parental role change," "from helplessness to skillfulness," and "lack of professional support."

Parental role change

This concept refers to an additional caregiver role apart from the parental role. Some parents could not successfully address this change in their role, and parental role conflict appeared. Most of the participants were new mothers or young adults with limited experience addressing life challenges; they often adopted passive coping styles that were not conducive to adjusting well to the changes in their parental roles. For example, B said, "Sometimes I felt like I was not a mother; instead, I felt more and more like a nurse." Father F mentioned, "Many times, I carried out my responsibilities, and I felt completely trapped by this matter (child care). I didn't know how to cope with this situation. I felt distressed." Young mothers like E and L experienced a daily struggle when they returned home early from the hospital.

However, some parents adapted to this change in role by developing a routine living schedule with reasonable planning, hiring a professional caregiver to take care of the child, or receiving care assistance from grandparents. For example, G said, "When my baby was hospitalized, the charge nurse gave me a very good suggestion to make a daily plan. As I am a full-time mom, if I followed the schedule and learned these professional tracheostomy nursing skills, I could handle the situation

Table 2
Categories and subcategories identified.

Categories	Subcategories
Direct care overload	Parental role change From helplessness to skillfulness Lack of professional support
Psychological overload	Anxiety and depression Social isolation
Personal growth	Changing their perspectives Developing potential

very well." "My mother volunteered to take care of my baby when we returned home from hospital, and she certainly helped me a lot. I have to go to work and make more money to support my family so my family can handle everything," C said.

From helplessness to skillfulness

This concept means that when medical personnel informed parents of the importance of home care for a tracheostomy child, parents often reported higher anxiety and tension than other parents and worried that they were not qualified to perform these additional responsibilities. However, they became more skillful over time when appropriate coping strategies were developed. For example, A stated, "I had no medical knowledge at all. Especially when I just returned home, I was afraid I was not doing it right, of causing harm to my child. Time passed, and I am familiar with what I have to do every day, so I am not green anymore." Mother D said, "The nurse encouraged me to care for my baby by myself before discharge, but I was scared. I always needed their supervision and assistance. However, two weeks later, I could do it (care for the tracheal tube)." Mother G said, "I had thought it was a very complicated job. I had been very anxious and even didn't sleep. However, I often went to the hospital to learn and watched professional videos on Youku. I am now more skilled."

Lack of professional support

Studies have revealed that professional support from clinical nursing experts or community nurses is invaluable (Kirk & Glendinning, 2002). However, professional support in community settings is currently lacking in China. The parents indicated that obtaining professional support in a timely manner was very important. For example, Mother A said, "When my child was hospitalized, I often asked the medical staff for some professional guidance and took a video while they were doing sputum suctioning. However, I dared not change it (the tracheostomy tube belt); I was worried that the tube might get dislodged or even come out. Therefore, I have not changed it yet, and there is no hospital nearby that can help me. All of them rejected helping me." Mother B said, "The doctors and nurses were out of touch after my child was discharged. We did not know where to find help and worried about increasing the burden on them if we called the professionals at the

Table 1
Biographical data of the research participants (n = 13).

Participant	Parental role	Age (years)	Level of education	Occupation	Child with tracheostomy		
					Sex	Age (months)	Time in home care (days)
A	Mother	25	High school	None	F	4.5	30
B	Mother	26	Associate degree	None	F	3.4	28
C	Mother	29	Associate degree	Self-employed	M	5.03	16
D	Mother	30	Bachelor's degree	Accountant	M	6.53	28
E	Mother	25	High school	None	F	4.7	15
F	Father	28	Associate degree	Self-employed	F	19.7	22
G	Mother	31	High school	None	M	15.07	28
H	Father	35	Master's Degree	Teacher	M	22.07	27
I	Mother	29	Bachelor's degree	Civil Servant	M	35.67	20
J	Mother	22	High school	None	F	8.47	26
K	Mother	27	High school	None	M	35.67	26
L	Mother	25	High school	Self-employed	M	3.87	27
M	Mother	30	Associate degree	Self-employed	M	3.73	25

hospital. If we could get some professional support on the web, it would be helpful for us.”

Psychological overload

This category describes the high level of distress the parents reported, which usually caused them to stay in a relatively closed-off interpersonal space for a long time. The parents were prone to psychological overload which mainly manifested as anxiety, depression and social isolation.

Anxiety and depression

The parents were overloaded with care and exhibited high levels of anxiety, depression, or other negative emotions during the early stage after the child with a tracheostomy was discharged. K and J reported high levels of anxiety and feelings of depression, and they said they could not escape from these negative emotions.

K said, “I worried that I was not able to take proper care of my child. What if I harmed my child? What if my child had difficulty breathing - what could I do? In short, I thought many things and worried a lot. How could I sleep well?”

Conversely, other parents used positive coping styles, such as listening to music to relax and problem solving, to address the negative emotions. A: “When I feel unhappy or distressed, music is a good way to keep me calm. By sharing my experience with other families who had a similar journey, I can release my negative emotions and could learn some lessons from them.”

Social isolation

Repeated hospitalizations due to the disease or its complications, changes in the anatomy and defensive functions of the respiratory tract, and low self-esteem among the parents and children caused by changes in the child’s image in relation to other children resulted in fewer social interactions or the passive acceptance of social isolation. For example, B said, “The doctors advised us not to take my child to public places or crowded areas too much, which would increase the chance of infection. Therefore, we seldom go to public places. I have not been shopping with my friends for a long time.” Mother D said, “I once took my child to play in the park nearby, but many strangers stared at us. They were curious about what happened to my boy. I felt very uncomfortable, so I have not gone out since. I had to make a choice to stay home.” Mother I said, “Every time my child’s uncle and aunt wanted to visit him, I refused because I felt increased strain from their excessive attention.”

Many parents (G, H, I, K, and J) expressed concerns about their children attending school. For example, mother I mentioned, “My child will go to kindergarten soon. I consulted many schools, but no kindergarten accepted him due to his situation. We tried many kindergartens and were rejected by all of them. They worried about what to do if my child had an accident at school. They have no experience. This is very upsetting. When my child grows up, he will slowly learn that he is somewhat different from other people. I worry about its impact on his psychological development.”

Personal growth

This category indicates the considerable personal growth that the parents displayed after struggling with complex difficulties, as represented by the categories “changing their perspectives” and “developing potential.”

Changing their perspectives

This concept indicates that since the child became sick, the parents’ attitudes toward life, their values, and their worldviews changed and became more universal and peaceful. The family gradually become a priority among the important affairs of life. For example, C said, “My

husband and I made so many plans when I was pregnant, such as making more money to provide a good living environment for my baby and expecting that he would become an excellent person in the future. However, now I feel that the most important thing is that he is healthy and happy. I abandoned all of my old ideas.” Mother I said, “Previously, I thought there was nothing I couldn’t do as long as I wanted to do it and I tried to do it. However, now...I realize that health is not something you are able to get because you want it. I used to be so naive!” G also mentioned, “In the past, I thought money was very important. Now, I realize that money is indispensable, but it is not irreplaceable.” M said, “Before my child was sick, we believed that career and money were very important. For these things, we sacrificed time with our family and forgot many important anniversaries. We made many plans for the unborn child and even registered for a very expensive prenatal education course to ensure that my child was not behind at the starting line. However, after he became sick, these priorities changed. Nothing is more important than family. Although we still work hard to make money now, the purpose of making money has changed. Making more money is just for the better survival of my child, and family members can gather and share our happiness.”

Developing potential

This subtopic reflects the parents’ ability to develop their potential in times of hardship and accomplish what they originally thought was impossible. For example, mother F said, “I never learned any medical knowledge, and I never heard of these skills (tracheostomy care skills) before. Although I worried about it very much at the beginning, I learned how to manage in the end. I’m proud of myself. I did what I used to think was impossible. My husband even praised me. I believe that I will be able to do many other impossible things in the future.” When caring for pediatric patients, parents can also discover potential in their children. For example, H said, “Human potential is infinite, and I believe in it very much now. Regarding my child, I think he must feel more pain than a normal child. Although he truly suffers from the pain, he still lives life happily and tries very hard. I admire him very much. I believe he will have a different future.”

Discussion

Discussion of the findings

This study provides evidence that the parents of children with tracheostomies face many challenges during home care, especially in the early stage of discharge, which is consistent with the experience of parents of children with tracheostomies in other countries (Callans et al., 2016; Hartnick et al., 2003; Hopkins et al., 2009; Joseph et al., 2014; Montagnino & Mauricio, 2004). However, this situation is more stressful in China because of the one-child policy, which has changed the family structure (FAN, 2016). That is, a husband and wife raise one child and must support four parents. The parents of ill children in particular face a greater care overload and financial burden.

The results of this study, such as the finding of parents experiencing a sense of fear with helplessness in the early stage after the child is discharged, are consistent with the findings of Flynn’s review (Flynn et al., 2013). For most parents, the tracheostomy was the most significant medical intervention that their child underwent (Flynn et al., 2013; Nakarada-Kordic et al., 2017; Woodgate, Edwards, & Ripat, 2012); particularly during the postdischarge period, the parents were often exhausted because they worried that they were not qualified to provide necessary tracheostomy care (Callans et al., 2016; Hartnick et al., 2003). Their lack of home care knowledge and skills led to an inability to provide necessary tracheostomy care due to concerns about their own insufficiency.

This group of parents reported anxiety and depression, which provides evidence that parents of children with tracheostomies have a higher level of psychological burden than normal controls, as reported

by Montagnino and Mauricio (2004). Moreover, two different coping strategies with two opposite psychological responses were adopted by the parents of children with tracheostomies. Montagnino and Mauricio (2004) revealed that parents who adopt passive coping styles are unable to escape from their negative emotions. However, other parents use positive coping styles, such as problem solving, to successfully adapt to this life or role change (Hopkins et al., 2009; Montagnino & Mauricio, 2004).

The results of this study demonstrate that social stigma is the most common reason that parents of children who require a long-term tracheostomy limit their participation in everyday life. Studies have reported that the incidence of social isolation is significantly higher for parents of children with tracheostomies than for parents of children with obstructive respiratory sleep syndrome (Cohen, Suzman, Burstein, Riski, & Montgomery, 1998). There are two possible explanations for this difference. After a tracheostomy, the natural barrier that prevents airway infections can be damaged to varying degrees; thus, the pediatric patient is more susceptible to lung infections in crowded surroundings (Berry et al., 2011; D'Souza et al., 2016). Therefore, some parents or the patients themselves may limit their social activities, stay at home, or communicate only with a small group of people, which exacerbates the social isolation. Additionally, stigma makes parents reluctant to let their children come in close contact with others (Flynn et al., 2013; Woodgate et al., 2012). The changes in image among children with tracheostomies cause low self-esteem in the children and their parents, which in turn leads to a decrease in active social behaviors (Gilony et al., 2005; Nakarada-Kordic et al., 2017).

However, the parents in this study expressed the desire to receive support and recognition from society so that they could participate in normal family and community activities. Woodgate et al. (2012) reported that meaningful participation contributes to normal family and community activities for parents and their children. Having a normal life allows families to feel like they belong, are accepted and are able to contribute to the environment in which they participated. Moreover, studies have demonstrated that participating in a variety of social activities promotes the acceptance of groups of patients with a tube (tracheostomy), reduces social isolation (Flynn et al., 2013; Woodgate et al., 2012), and positively affects the health and emotional well-being of parents and children.

The finding that parents self-adjusted their outlooks on life, their values, and their worldviews and developed their own potential are consistent with some recent positive psychology theories. For instance, posttraumatic growth theory (Tedeschi & Calhoun, 1996; Tedeschi & Calhoun, 2004) suggests that the parents of a children with a tracheostomy experience positive changes as they actively respond to difficulties. Positive psychology theory believes that negative emotions can be relatively reduced when individuals can perceive their own growth and change (Tedeschi & Calhoun, 1995; Tedeschi & Calhoun, 1996; Tedeschi & Calhoun, 2004).

Limitations of this study

This study has the following limitations. First, the interview samples were selected from one hospital and therefore did not reflect all home care experiences of parents of children with tracheostomies. There may be differences in experience due to different treatment options or health education programs. Second, we analyzed experiences in the early stage of discharge, which could not reveal longitudinal changes among parents. Consequently, a cross-sectional survey and longitudinal study, both with large samples, will be conducted in the future to understand parents' psychological status, influencing factors, and change curves to fill relevant gaps in knowledge and provide scientific evidence for clinical practice.

Implications for practice

Although the findings of this study indicate that the physical and psychological overload reported by parents providing home care was

inevitable, a better understanding among nurses of parents' caring experiences may facilitate nurses' clinical practices and the care they provide during the hospital discharge program (Fenwick, 1979). This in turn connects the hospital and the community and incorporates the care provided during hospitalization with professional support after discharge. During hospitalization, systematic training and education plans should be developed. Nurses must recognize the care needs of parents and evaluate their emotional states. Furthermore, nurses must develop individual teaching plans in the form of oral directions, written papers, and videos. However, it is difficult for parents to master these professional skills in a very short time. Thus, parents benefit greatly if they can obtain professional support outside of the hospital, such as via the internet, which has been demonstrated to be an important source of social support for parents (Fiske, 2004; Flynn et al., 2013; Nakarada-Kordic et al., 2017). Parents and their children are encouraged to participate in meaningful activities that can contribute to the overall objective of increasing the public's understanding. The recommendations might be for nurses in those hospitals that don't provide any supports for parents caring for tracheostomy dependent children at home.

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