



Home care experiences of mothers of children with tracheostomies – a qualitative study

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ABSTRACT

Introduction and aim. Parents of children who are addicted to technology have many problems in home care. This study aimed to describe the home care experiences of mothers of children with tracheostomies.

Material and methods. The study adopted Husserl's phenomenological method, a qualitative research design. The sample consisted of 23 mothers of children with tracheostomies followed up in the pediatric pulmonology outpatient clinic of a university hospital. All participants cared for their children at home. Data were collected using a sociodemographic questionnaire and a semi-structured interview questionnaire. All interviews were recorded and transcribed.

Results. Children (12 girls and 11 boys) had a mean age of 3.43 ± 3.326 years. The mean age of tracheostomy insertion was 2.8 ± 2.508 years. Seventeen children were on ventilator support. All participants were mothers with a mean age of 32.34 ± 6.00 years. Half the mothers had primary school degrees (52.2%). The interviews revealed one main theme (burnout), three sub-themes (social isolation, perception of competence, and regrets), and five categories (burden of care, fear, awareness, decisions, and role confusion).

Conclusion. Mothers of children with tracheostomies experience numerous problems when they provide home care. They mostly have difficulty improving themselves and enduring role confusion. We must address the issues mothers of children with tracheostomies face during home care to reduce the prevalence of potential complications and improve the quality of care for both them and their children.

Keywords. care, child, experience, mother, nurse, phenomenology, tracheostomy

Introduction

The latest developments in the healthcare system and the integration of technology into care allow parents to care for their children with complex health needs at home. A tracheostomy is a surgical procedure to create an opening through the neck into the trachea to help a person breathe. In the United States, 5000 pediatric tracheostomies are performed annually.^{1,2} Parents providing home care in the post-tracheostomy period are likely to experience many life-threatening problems, leading to an increased burden of care.^{3,4}

Parents of children with tracheostomies experience physiological, mental, and social problems such as anxiety, depression, and social isolation.^{5,6} Caring for tracheostomized and ventilator-dependent children at home affects parents' work and social lives.⁴ In Türkiye, it is mostly mothers who take care of children with complex care needs.⁷ Mothers do not consider themselves competent despite receiving training in caregiving and medical devices.⁸ Parents are reluctant to accept their children with tracheostomies and have difficulty communicating and integrating socially.⁹ Parents spend too

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much time caring for their children and endure a heavy burden related to changes in parental roles, helplessness, and lack of professional support.¹⁰ The main challenges faced by family members of children with tracheostomies are coping with the new situation, new care demands, difficulty acquiring material, and limitations on social life.¹¹ Both children with tracheostomies and their caregivers (mostly parents) experience psychosocial problems. Therefore, we need to find solutions to those problems to support parents psychologically and help them experience less burden of care.¹² There is a large body of research on the care-related experiences of parents of children with tracheostomies. However, there is limited data on how providing care at home affects mothers of children with tracheostomies.^{3,11,13,14}

Aim

In Turkey, mothers are regarded as the primary caregivers, meaning they experience the homecare process much more differently than fathers. Therefore, this study focused on the home care experiences of mothers of children with tracheostomies.

Research question

What are the experiences of mothers caring for their children with tracheostomies at home?

Material and methods

Ethical approval

Ethics approval for the conduction of study was obtained from the Research Ethics Committee of the local state university (Ref No: 2021/8/11) before data collection.

Study design

This study adopted a phenomenological approach, which is a qualitative research method. Phenomenology is an appropriate method for determining lived experiences and problems.¹⁵ The study was reported using the 21-item Standards for Reporting Qualitative Research (SRQR) developed by O'Brien et al.¹⁶

Setting and participants

The data were collected between March and April 2021. The study population consisted of all parents of children with tracheostomies followed up at the pediatric pulmonary polyclinic of a university hospital. The sample consisted of 23 parents who agreed to participate in the study. The inclusion criteria were (1) having a child with tracheostomy under 18 years of age, (2) having provided home care for at least six months, (3) being able to use computers or smartphones to approve the consent form and to be interviewed, and (4) having Internet access. The exclusion criteria were (1) having lost a child with tracheostomy before and (2) having difficulty accessing/using technology.

Data collection

The data were collected using a sociodemographic questionnaire and a semi-structured interview questionnaire developed by the researchers. Interviews were conducted using the semi-structured interview questionnaire developed based on SPIDER.¹⁷ The semi-structured interview questionnaire consisted of six items on parents' earliest experiences after tracheostomy, the home care process, challenges, and the need for training (Table 1). Two clinical nurses and two nursing academics were consulted for the intelligibility and relevance of the interview questions, which were revised based on their feedback.

Table 1. Interview questions

Topics	Questions
Changes in parents' lives after tracheostomy	1. How has your life changed since your child underwent a tracheostomy? 2. In what way do you help your children with tracheostomy care? 3. When do you think your child needs you the most throughout the day?
The challenges of home care after tracheostomy	4. Have you had any problems with the home care you are providing for your child with a tracheostomy? Can you tell us about those problems?
Social life after tracheostomy	5. Has caring for your child with a tracheostomy limited your social life? In what way? Can you explain, please?
The need for training in tracheostomy care	6. In what areas do you need support regarding your child's tracheostomy care?

Interview

The parents were interviewed online at their convenience. The researchers contacted the parents on WhatsApp and sent a Google Meet link. The parents were alone during the interviews. During the interviews, their children were cared for by other caregivers (father, grandmother, grandfather, etc.). The researchers received verbal consent to record the interviews and took notes during the interviews. There were at least two researchers during each interview. One of the researchers led the interview, while the other asked follow-up questions and took notes about the interviewee's facial expressions and gestures. One of the researchers was a nursing academic, while the other was a pediatric nurse. Each interview lasted 30-45 minutes.

Methodological rigor

The scientific rigor criteria of credibility and transferability (validity) and consistency and confirmability (reliability) were checked. Audit trail and expert feedback were used for confirmability. Two academics and a clinical nurse checked the semi-structured interview questionnaire for consistency. The moderator summarized the participants' responses and read them to them. In this way, repetitive questioning and participant control were achieved for credibility. A purposive sampling method was used for transferability. The sample consisted of 23 mothers. Data saturation was reached after fifteen interviews. However, eight more interviews were conducted. Those participants gave similar answers.

Therefore, the interviews were terminated afterward. Findings cannot be generalized to all patients with tracheostomies due to the medical reasons for tracheostomy and the fact that the age groups are different.¹⁸

Data analysis

The study adhered to the seven steps of Colaizzi's phenomenological data analysis.¹⁹ The researchers listened to the interviews repeatedly and then transcribed them. They followed Colaizzi's steps to evaluate phenomenological data and group common themes. Afterward, each researcher consolidated the results and developed subthemes. The data were analyzed using the interactive analysis technique developed by Miles and Huberman.²⁰ The interrater agreement was calculated as 0.890. The researchers agreed on one main theme, three subthemes, and five categories.

Table 2. The steps of Colaizzi's phenomenological data analysis^a

1.	Description of all participants' answers by careful reading*
2.	Defining the expressions directly related to the researched phenomenon**
3.	Formulation of key expressions identified**
4.	Creating theme sets from formulated expressions**
5.	Making a broad definition of the researched phenomenon**
6.	Determining the basic structure of the researched phenomenon
7.	The researcher giving feedback to the participants regarding the phenomenon determined***

^a * the texts recorded by the reporter were read and combined by both researchers within the first 72 hours of the interviews to avoid data loss; ** Miles and Huberman's formula was used to provide a consensus on statements and to understand and group them; *** the researchers had the participants confirm the statements they were unsure about without adding their comments

Results

Children (12 girls and 11 boys) had a mean age of 3.43 ± 3.326 years. The mean age of tracheostomy insertion was 2.8 ± 2.508 years. Seventeen children were on ventilator support. All participant parents were mothers with a mean age of 32.34 ± 6 years. Half the mothers had primary school degrees (Table 3).

The data were coded, yielding one main theme (burnout), three subthemes (social isolation, challenging self-improvement, and regrets), and five categories (burden of care, fear, awareness, decisions, and role confusion). The greatest challenge for parents was burnout. However, they also suffered from social isolation, had difficulty improving themselves, and had regrets. Table 4 explains the themes.

Theme

Burnout

The main theme was "burnout." Participants reported social isolation while caring for their tech-dependent

children at home due to the limitations of tech-dependent life. They stated that social isolation made it difficult for them to share the burden of care and caused them to see their own self-efficacy as inadequate. They reported being caught between their roles as parents and caregivers. They noted that they regretted some of their decisions, which resulted in burnout. They remarked that they continued to take care of their children at home but drifted into a deep burnout over time. The main theme of "burnout" consisted of the sub-themes of social isolation, perception of competence, and regrets.

Table 3. Demographic characteristics

Participant	Child Age (years)	Child Gender	Age of tracheostomy	Mechanical Ventilation Support	Parent Age (year)	Parent Education (degree)
P1	1.5	Boy	4 years	Yes	42	Primary school
P2	2	Girl	1.5 years	Yes	26	High school
P3	1	Boy	1 year	Yes	38	Primary school
P4	2.5	Girl	2 years	Yes	29	Middle school
P5	2	Boy	1 year	Yes	28	High school
P6	1	Girl	8 months	No	33	High school
P7	1	Girl	6 years	Yes	44	Primary school
P8	6	Boy	5 years	No	26	Middle school
P9	6	Girl	5 years	Yes	30	Bachelor's
P10	4	Girl	4 years	Yes	25	Primary school
P11	3	Girl	3 years	No	33	Bachelor's
P12	1.5	Boy	1.5 years	Yes	23	High school
P13	1	Boy	1 year	Yes	35	Primary school
P14	18	Boy	12 years	Yes	43	Primary school
P15	11	Girl	1 year	Yes	32	Primary school
P16	1	Boy	1 year	No	25	High school
P17	3	Boy	3 years	Yes	30	Primary school
P18	1.5	Girl	1.5 years	No	30	Primary school
P19	1.5	Boy	7 months	Yes	38	Literate
P20	1.5	Girl	1.5 years	Yes	28	Middle school
P21	3	Boy	2.5 years	Yes	39	Primary school
P22	2	Boy	2 years	Yes	33	Primary school
P23	4	Girl	3 years	No	34	Primary school

Table 4. Theme and subthemes

Main Theme/Subtheme	Category	Subcategory
*Burnout		
Social isolation	(1) Burden of care	(1) Limited social acceptance (2) Tech-dependent life
Perception of competence	(1) Fear	(1) Losing the child (2) Cannula blockage and dislodgement
	(2) Awareness	(1) The need for structured training (2) Learning by living
Regrets	(1) Decisions	(1) Decision For Tracheostomy Formation (2) Switching to ventilator support (3) Home care
	(2) Role confusion	(1) Acceptance by siblings (2) Feeling incompetent as a mother

Subthemes

Social isolation

Participants were socially isolated mainly due to the burden of care, resulting in burnout. This was because being socially isolated prevented participants from using the social support systems that could help them feel less burden of care.

Burden of care

The first category was “burden of care,” consisting of the subcategories “limited social acceptance” and “tech-dependent life”. The first subcategory is limited social acceptance. Participants were uncomfortable about how other parents treated them and could not participate in social life due to their children’s health conditions. The second subcategory is Tech-dependent life. Participants stated that they had almost no social life because they could not leave home as their children had to lead tech-dependent lives (aspirator, ventilator, monitor, etc.). The following are some quotations:

“I don’t want them looking at my kid like he is any different from them. That’s why I don’t have much social life.” P16

“I can’t leave home. I keep thinking about my kid even when I go to the supermarket for shopping.” P1

Perception of competence

The second theme was “perception of competence.” Participants stated that they had a tough time getting used to caring for their children in the hospital and at home. The theme consisted of two subcategories: “fear” and “awareness.”

Fear

Participants had concerns about taking responsibility for the care of their children as they were afraid of making mistakes or losing their children. The category “fear” consisted of two subcategories: “losing the child” and “cannula blockage and dislodgement.” The first subcategory is “*Losing the child*”. Participants noted that they were terrified of losing their children because of a mistake they might end up making during the care. The second subcategory is “*Cannula blockage and dislodgement*”. Participants remarked that one of the greatest challenges of homecare was the blockage and dislodgement of the cannula. The following are some quotations:

“I’m afraid of losing my child, like, what if an earthquake hits? I can’t leave her behind; I can’t have that on my conscience.” P21

“I’m terrified that the cannula might come off. If it’s gonna happen, I hope it’s gonna happen when we’re in the hospital. The training was very nice, but I don’t dare to fix it; I’m afraid of hurting my kid.” P9

“I’m scared that the cannula might get clogged. Once his saturation was almost below 40, I didn’t know what to do. I was afraid of losing him.” P5

Awareness

The category “awareness” was about the fact that participants realized they needed the training to care for their tech-dependent children at home. They stated that they even had difficulty getting their tech-dependent children to care for themselves. They said that they did not know

the principles of care. The category “awareness” consisted of two subcategories: “the need for structured training” and “learning by living.”. The first subcategory was “*The need for structured training*”. Participants received training before discharge. However, they were too stressed out to understand the training because their children were in the intensive care unit. They noted that the home setting was completely different from the hospital and that they did not dare to put what they learned into practice.

The second subcategory was “*Learning by living*”. Participants stated that they experienced burnout mostly because they had to learn some things by trial and error. They felt incompetent, although they received training. However, they added that their home care experiences raised their awareness. The following are some quotes: For example,

“I got trained but I just couldn’t understand anything because I was stressed and freaked out back then. So I think they should give us training again.” P19

“I learned everything from the problems I had about tracheostomy care. But there must be another way. We should get more support. It was pretty hard for me to take over care at home. One shouldn’t have to learn tracheostomy care from mistakes and problems.” P18

Regrets

“Regrets” was the third theme. Participants believed they were responsible for the decisions they made about caring for their tech-dependent children. They noted that they had difficulty taking care of their non-tech-dependent children because they had to devote most of their time to caring for their tech-dependent children. The theme “regrets” consisted of two categories: “decisions” and “role confusion.”

Decisions

The category “decisions” was about the decisions made by participants about caring for their tech-dependent children. The category consisted of three subcategories: “*decision for tracheostomy formation*” “switching to ventilator support,” and “home care”. The first subcategories is “*Decision For Tracheostomy Formation*”. Participants stated that they regretted their decision about the tracheostomy procedure. They believed it was a premature decision as they did not consider the possibility that their children might get better without a tracheostomy. The second subcategories is “*Switching to ventilator support*”. Ventilator support was another challenge for participants because being tech-dependent made things much more difficult. Third subcategory is “*Home care*”. For participants, home care itself was a challenge. Participants who needed training and had difficulty maintaining self-care had doubts about their decisions about providing home care as they believed that it was a mistake. The following are some quotes:

“My kid had osteogenesis imperfecta, so it was pretty hard for us to decide the right time for the tracheostomy procedure. On the one hand, he couldn’t breathe, and on the other hand, his neck might have been broken.” P8

“I freaked out the first time I saw my kid. I just lost my head. I had training, but home care was pretty hard. I sometimes have doubts about the tracheostomy procedure. I wish my kid didn’t need to get ventilator support.” P17

“I said ‘No’ when they wanted to discharge my kid because I was afraid that I wasn’t gonna be able to care for her at home. But they discharged us anyway.” P13

Role confusion

The category “role confusion” referred to the changes in family processes that participants experienced after their children underwent tracheostomies. The category consisted of two subcategories: “acceptance by siblings” and “feeling incompetent as a mother.” The first subcategory was “*Acceptance by siblings*”. Participants stated that caring for their children with tracheostomies at home also affected their siblings. Participants noted that tech-dependent life and long hospital stays impacted every aspect of life at home. They added that their non-tech-dependent children were unsure about what they were supposed to feel for their siblings with tracheostomies. The second subcategory was “*Feeling incompetent as a mother*”. Participants stated that they felt incompetent when it came to taking care of their tech-dependent children. They believed they encountered problems with caring for their tech-dependent children because of their own incompetence. The following are some quotes:

“My non-tech-dependent children want to go out and play in the park, but I can’t take them there because I’m afraid that my tech-dependent children might get an infection.” P3

“My non-tech-dependent children keep asking me when we’ll have friends over or when we’ll go and visit them.” P4

“I still can’t do some things, like aspiration or dressing. My husband does those things. I feel bad, and I want to do them, but I just can’t look at the hole” P10

“I have an 11-year-old daughter, too. Our life has changed completely. I couldn’t take care of her. We were completely isolated at home. I found myself in a situation where I couldn’t even notice that she needed me.” P6

Discussion

This study focused on the home care experiences of mothers of children with tracheostomies. The findings yielded one main theme (burnout) and three subthemes (social isolation, challenging self-improvement, and regrets).

Participants stated that society should recognize the increasing burden of care associated with chronic diseases and help them cope with their problems. Caring

for children with complex health needs at home places a heavy burden on parents. Because of this burden, they are socially isolated and suffer from sleep disturbances and temporal limitations. Parents of children with tracheostomies are physically and psychologically overwhelmed at home after discharge.²¹ They have difficulty managing their time because they have other responsibilities. In other words, they have little time and energy left to care for their non-tech-dependent children because they spend most of their time caring for their tech-dependent children. This causes social isolation, anxiety, and communication problems. They also have a low quality of time because they have difficulty understanding their children’s health conditions.³

Swain and Acharya reported that the tracheostomy tube created social stigma and caused anxiety in social interactions.⁹ More and more children with complex health needs are dependent on technological devices.²² Therefore, we should support home care to improve parents’ and their children’s physical, emotional, and mental health.²³ Our participants reported that they struggled with the increased burden of care after their children were discharged. They added that they were socially isolated because they could not share their burden with other family members and feared that they would not be accepted by society.

The number of children with tracheostomies is increasing day by day. However, home care technologies are advancing, allowing parents of children with tracheostomies to execute numerous complex skills at home. In other words, parents of children with tracheostomies assume the responsibilities of healthcare professionals over time.²⁴ Therefore, nurses should help children with tracheostomies develop those skills. They should also provide them with training programs and assess how much they can adapt to the new situation. Thus, they can resolve many complex and complicated variables during home care. In other words, they can minimize the problems parents of children with tracheostomies experience during home care.” On the other hand, those parents should design their homes to provide care more easily and encounter fewer complications.²⁵ After discharge, they need to learn several challenging skills related to home care at the same time because they face numerous complicated problems during the process.²⁶ They have difficulty caring for their children with tracheostomies at home, although they receive training from healthcare professionals.²⁷ When faced with challenges, they often turn to unreliable websites to meet their information needs.^{26,28} Inaccurate sources of information and poor information management reduce the quality of home care.²⁷ The more training the parents receive, the fewer complications their children develop and the less often they are hospitalized.²⁹ However, parents do not feel ready for home care.³⁰ Changing the tube, bleed-

ing, infections, and tube blockage are the most common problems experienced by parents during home care.^{31,32} Breathing problems children with tracheostomies experience are a cause for concern for parents.³³ Therefore, parents should be provided with post-discharge training to help them manage life-threatening situations during home care.¹³ Our participants also stated that the training they received in the hospital was not long-lasting. They noted that they went through a tough self-developmental process after they began caring for their tech-dependent child at home. In other words, they learned by trial and error, which was painful for them. They also remarked that the fear of losing their children was the greatest force that pushed them to improve themselves. Research also shows that parents fear life-threatening complications (i.e., tube blockage and dislodgement). Our participants recommended that healthcare professionals regularly provide structured training during the home care process instead of one-time training in the hospital.

Medical technologies have extended the life expectancy of children with complex health needs. Parents have to make numerous medical decisions, including tracheostomy.³⁴ According to Nageswaran et al., parents turn to different support systems (clergy, medical staff, etc.) before making medical decisions for their children. They receive adequate support but have gaps in their knowledge.¹⁴ Parents prioritize the interests of their children when making medical decisions. However, they have difficulty making medical decisions when they do not fully understand the objectives of complex treatments (tracheostomy or respiratory support).³⁵ The more health professionals respect parents' self-efficacy and decisions about pain and symptom control, the more accurate their decisions will be.³⁶ Our participants noted that they regretted their past decisions, such as giving the O.K. to the tracheostomy procedure, ventilator support, or home care. They also remarked that life-threatening complications their children experienced made them regret their decisions.

Our participants also noted that the whole process of home care affected their families. Siblings of tech-dependent children grow up experiencing many emotions (pain, grief, anxiety, loss, etc.).³⁷ Effective communication helps strengthen family bonds and protect mental health.³⁸ Siblings of children with life-threatening diseases have more emotional and behavioral problems and lower quality of life.² Children with complex health needs have a greater impact on family members. This impact is associated with socioeconomic status, support systems, year of diagnosis, and home care support.³⁹ Family members communicate less often, and siblings have more unmet needs when tech-dependent children are at home.⁴⁰ Parents experience pain as they care for their tech-dependent children because they have gaps

in their knowledge and have difficulty meeting their non-tech-dependent children's needs.⁴¹ Our participants also had difficulty meeting their non-tech-dependent children's needs, which was a great problem. They found it difficult to manage family processes because their Our participants also had difficulty meeting their non-tech-dependent children's needs, which was a great problem had difficulty communicating with their tech-dependent siblings and accepting their health conditions. They noted that this caused them to feel more and more incompetent.

Mothers who actively care for children with tracheostomies at home experience numerous spiritual and tracheostomy care issues. Training programs for healthcare professionals reduce unplanned hospitalizations and emergencies during home care regarding children with tracheostomies.⁴² Home care and repeated hospitalizations cause job losses and financial problems for parents. Financial problems result in an increased burden of care and mortality and morbidity rates and poor quality of life.⁴³ Mothers believe that their children with tracheostomies have difficulty socializing and meeting their educational needs.⁴⁴ We should take into account the cultural structure and education level in Turkey and develop standardized training programs and determine their impact. Nurses should support mothers for post-discharge home care and follow up on them regularly to help them overcome their problems.

Conclusion

This study focused on the experiences of mothers of children with tracheostomies. Mothers caring for their children with tracheostomies at home are socially isolated. Moreover, they have difficulty improving their care because they have gaps in their knowledge. They also regret some of their decisions and find it difficult to navigate family relationships. Therefore, we need healthcare policies to improve home care services to help them overcome these challenges. We need to set criteria and timelines for the discharge of children with complex care needs and their parents. Healthcare professionals should provide family-centered care to support discharge processes and protect family processes. We should ensure that they receive community-based specialized healthcare services. In this respect, pediatric nurses should take an active role in home care services. We need to set up short-term care clinics for parents and improve home health care. If we set up social networking sites led by pediatric nurses, we can help mothers experience less social isolation. Our results will guide pediatric nurses in the way they train mothers of children with tracheostomies. In other words, they will raise pediatric nurses' awareness of family-centered care and adaptation to social life rather than focusing only on life-threatening complications related to home care.

Declarations

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Author contributions

Conceptualization, H.D. and E.G.; Methodology, H.D. and E.G.; Software, H.D. and E.G.; Validation, H.D. and E.G.; Formal Analysis, H.D. and E.G.; Investigation, H.D. and E.G.; Resources, H.D. and E.G.; Data Curation, H.D. and E.G.; Writing – Original Draft Preparation, H.D. and E.G.; Writing – Review & Editing, H.D.; Visualization, H.D. and E.G.; Supervision, H.D.; Project Administration, H.D.

Conflicts of interest

No potential conflict of interest was reported by the authors.

Data availability

The statistical analysis plan will be made available for research purposes upon request to the corresponding author.

Ethics approval

Ethics approval for the conduction of study was obtained from the Research Ethics Committee of the local state university (Ref No: 2021/8/11) before data collection.

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