

Gaining Experience Over Time: The Family Caregivers' Perception of Patients with a Tracheostomy in Home Care

Abstract

Background: The transition of tracheostomy patients to the home poses many challenges for both the patient and the family. Identifying and understanding the experiences of family caregivers pave the road for discovering and meeting care needs. This study has been aimed to explain the experiences of family caregivers of patients with a tracheostomy about patient care at home.

Materials and Methods: This qualitative study was conducted using a conventional content analysis approach from September 2018 to January 2019. Participants included nine family caregivers and one professional caregiver who were selected through purposive sampling method. The in-depth interviews were conducted at home or in health centers using field notes. Data were recorded manually and analyzed using the five-step method proposed by Graneheim and Lundman.

Results: The data led to the emergence of 1591 initial codes, 23 subcategories, and 6 categories. Categories include the need for training, the need for receiving care support, care challenges, care burden, gaining experience, hope, and inner satisfaction. **Conclusions:** In this study, the family caregivers faced with lots of challenges in caring patients with tracheostomy so that they were in needs of training and support from professionals. Although they got skillful in care and endure burden, they were so hopeful and satisfied with their attempts. Hence, there is a need for official nongovernmental organizations with the aim of maintaining care and protecting their families.

Keywords: Caregivers, family, home nursing, IRAN, nurses, tracheostomy

Introduction

In recent decades, one policy which most health systems emphasize on is reducing the stay time in hospital and transiting the continuing care at home.^[1] Patients with a tracheostomy are among those with critical conditions who require informal caregivers. Over the past two decades, the population of an adult patient in need of tracheostomy has grown and a large number of them are discharged due to limited resources.^[2,3] The conditions peculiar to tracheostomy patients during discharge are often stressful for the family.^[4] Home care for such a disease is often accompanied by severe emotional feelings and increased vulnerability.^[5] According to Callans *et al.*, the family faces multiple roles following the transition of the patient to home.^[6] It is very difficult for the family to accept that the patient should be transmitted to home under such conditions.^[7] Therefore, identifying sources of stress in care is essential and sometimes effective in meeting the needs of caregivers.^[8]

Nurses play an important role in preventing the anxiety of transmission.^[9] They are required to provide information, psychological, and social support. In countries such as the United States, England, Sweden, and Finland, the required supports are provided to the family after the patient is discharged from the Intensive Care Unit (ICU)^[10]; however, discharge planning and patient care by the family at home have not been sufficiently addressed in Iran.^[11] In addition, existing knowledge about family experiences of transitional care is insufficient.^[12] Sherlock *et al.* demonstrated that tracheostomy experience presents a set of physical and emotional issues for patients.^[13] The results of a systematic review showed that experiences of patients mainly include communication, physical and psychological problems, and chronic complications.^[14] To the best of author's knowledge, there are not many studies on the first-hand perceptions of family caregivers of adult patients with tracheostomy, and most studies have

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concentrated on the experiences of caregivers of children with a tracheostomy.^[15,16] Few studies, mainly quantitative cases, have been carried out on tracheostomy patients in Iran, and the experiences of this group have not been investigated.^[17,18] This is a significant gap because it cannot be supposed that the experiences of these family caregivers are similar to that of those in different cultural and social contexts. Hence, the extensive understanding of the care needs of tracheostomy patients under family care had to be considered in a study. Likewise, the identification of these experiences would help patients and their families go through this period of life with the least vulnerability. Moreover, it is worth noting that based on my clinical and educational experiences in working with these patients and their families in ICUs, they are in need of training and support at discharge time. However, we do not have any scheduled and defined discharge plan for them. There is no professional supportive center for them in Iran. Therefore, we know very little about these patients and their care processes at home. Hence, the present study was conducted to explain the family caregivers' experiences of tracheostomy patients about patient care at home.

Materials and Methods

The present study is categorized as a qualitative research conducted using a conventional content analysis approach from September 2018 to January 2019. Participants included nine family caregivers and one professional caregiver. Purposive sampling was performed with the maximum variation, i.e., temporary or permanent tracheostomy, the relationship between the caregiver and the patient, cause of tracheostomy, sex, and age of the caregiver. Inclusion criteria for caregivers were as follows: being the primary caregiver of the patient, accepting the responsibility of home care for at least two months, being able to communicate verbally, the stability of physical, emotional, and psychological state during the interview. Inclusion criteria for patients were being over 18 years and undergoing tracheostomy. Pediatric tracheostomy patients under mechanical ventilation and laryngectomy were not included in the study. Before starting the study, the researchers coordinated with the nursing offices of public and private hospitals and authorities of ICU and neurosurgery; Ear, Nose, and Throat (ENT), and emergency wards in Lorestan provinces to find out the eligible cases. The researcher's contact number was provided to the nursing offices to inform the researcher if the patient referred to the mentioned wards.

A set of in-depth unstructured interviews were individually conducted by one of the researchers. The time of the interviews was determined with the preference of the participants. The interviews lasted between 45 and 75 min. All the interviews were recorded on an audiotape. In interviewing the caregivers, the open-ended question asked from the participants was "Would you please explain to me your experiences with providing care for Mr/Ms ... at

home and to inform how they spend their days with their patients." As the interviews went on and as they mentioned their attempts to learn about the provision of care, the focus of the interviews shifted to this issue. Furthermore, during the interviews, some probing questions like "Is there any instance in this regard?, What did you feel when that happened?, and What do you do when you feel so?" were asked based on the participants' statements to deepen the interviews. Furthermore, field notes were used to record the behaviors of the participants during the interviews.

The simultaneous analysis was performed by data collection and using the five-step approach of Granehim and Lundman (2004). Immediately after every interview, the researchers listened to the transcripts of the interviews. They were transcribed, typed, and read several times. In the next step, significant parts or initial codes were identified. Then, using the continuous comparison technique and identifying differences and similarities, the codes were categorized and subcategories and categories were identified. Finally, the findings were compare and the categories emerged.^[19,20]

The criteria proposed by Lincoln and Guba, including credibility, transferability, dependability, and confirmability, were used to increase the rigor of the research findings. To gain credibility, we selected those individuals who had the experience of the phenomenon under study and were able to express their experiences. The long-term engagement of the researcher and his contact with the participants were also taken into consideration. More than one individual performed the task of analyzing the data with the aim of an in-depth interpretation of the data. It was attempted to increase data transferability by providing clear descriptions of the culture, context, and characteristics of the patients.^[21] To ensure dependability and confirmability, audit trail strategy was used. Auditors assessed the analytical process. They were not part of the research team.^[22]

Ethical considerations

The code of ethics was also obtained from the Research and Technology Department of Lorestan University of Medical Sciences (Code: IR. LUMS.REC.1396.346). After providing necessary explanations about the objectives of the study, written informed consent was obtained from all participants. The subjects were allowed to record audio.

Results

Tables 1 and 2 provide information on tracheostomy patients and their family caregivers. Nine family caregivers and a private nurse between the ages of 24 and 56 participated in the study. The results led to 1591 initial codes, 23 subcategories, and 6 categories [Table 3]. Categories include the need for training, the need for receiving care support, care challenges, care burden, gaining experience, hope, and inner satisfaction.

Table 1: Individual characteristics of tracheostomy patients

Patients	Age	Gender	The cause of tracheostomy
1	86	M*	Stroke
2	50	M	Accident
3	54	M	Accident
4	19	M	Cardiac arrest
5	47	M	Stroke
6	62	M	Laryngeal cancer
7	37	M	Stroke
8	22	M	Accident

*M: Male

Table 2: Individual characteristics of the participants (family caregivers)

Participants	Age	Gender	Kind of relationship with the patient
P1	56	F*	Child
P2	54	F	Sister
P3	24	M**	Child
P4	35	F	Husband
P5	36	M	Private nurse
P6	51	M	Father
P7	35	F	Husband
P8	42	M	Wife
P9	42	M	Brother
P10	24	M	Brother

*F=Female, **M=Male

Table 3: The categories and subcategories derived from interviews

Category	Subcategory
The need for training	Lack of training
	Caring fear
	Care with hesitation
	Consequences of lack of training
	Seeking help from specialized resources
	Seeking help from nonspecialized resources
The need for receiving social support	Receiving social support
	Lack of social support
	Collaborative care
Care challenges	Impossibility of effective communication
	Caregiver distress
Care burden	24-h care
	Costly care
	Physical consequences of caring
	Psychological consequences of caring
	Social consequences of caring
	The caregiver's helplessness
Gaining experiences	Ease of care
	Caregiver's awareness of symptoms
	Take actions commensurate to the symptoms
	Self-sufficiency
Hope and inner satisfaction	Striving for inner satisfaction glimmers of hope in the family
	Care with dedication

The need for training

Experiences of most caregivers indicated that they have not had adequate knowledge about the nature of the tracheostomy and the way to take care of it. A son who looks after his father remarked: *"The first day that we took him home, his tracheostomy was metallic. We did not know what to do. Also, we did not have suction equipment."*

Caregivers were unexpectedly forced to admit the patient and provide comprehensive care at home. This frustrated them at the beginning of the care. The sense of inability to control the situation that annoys the caregivers: *"Once she was very bad. It was like a nightmare. She did not open her eyelids. Her face was bruising"* (P4).

The caregivers continued the preformation of their duties without the supervision of an organization or professional caregivers. Due to the imposed pressure, they sought to confirm the accuracy of care. *"We had a nurse in our relatives. I asked him to see what I was doing for my patient is right. I looked at him and found out that I was doing it right"* (P7).

Lack of care training in the patient at home has detrimental consequences for both patients and caregivers such as the patient's loss of consciousness, frequent referrals to medical centers, infection, and protrusion of the tracheostomy tube, recurrent fever, and, in some cases, threatening the patient's life. The patient's father said: *"We had no clue at first. We took him home for 20 days and brought him back to the hospital. His tracheostomy was filled, but we did not know."*

Under such circumstances, family caregivers sought education from multiple sources to resolve their information vacuum. Based on the experiences of the participants, the training was mainly provided through specialized resources. *"My father suddenly felt choked; he got so bad that I wanted to take out the tracheostomy tube. I immediately called 115 (Emergency Center)"* (P1). In a few cases, caregivers used nonspecialized resources. A patient's brother stated: *"I almost know how to take care of my patients. I search the Internet for any information I need"* (P 10).

The need for receiving care support

Caregivers' statements indicated that families of tracheostomy patients required extensive support. Some caregivers said about the positive results of receiving social support, such as boosting morale, increased tolerance of difficulties and ups and downs of care, and generally facilitating patient care: *"Thank God we have good relatives, they have been with us since the first day. If they weren't, we would not be able to handle these conditions"* (P3).

In a few cases, the support received from governmental institutions was mainly noncash, including the provision

of some necessary care equipment, such as a bed or wavy mattresses. *"The hospital staff gave us 3,000,000 Iranian rial (IRR) (almost 20 USD) to buy a mattress. We could purchase a good mattress for our patients. The State Welfare Organization of Iran gave us a bed"* (P6).

Some stated that they received limited support and sometimes no social support. Moreover, caregivers often reported a lack of appropriate social support or insignificant support from relatives and social institutions. *"The State Welfare Organization did not assist us"* (P9).

Moreover, for taking care of a tracheostomy patient at home, one person was often responsible for most of the care as the primary caregiver. However, one or more other members accepted part of the care and helped the primary caregiver in providing the care. This indicates the distribution of care burden among caregivers and their support for each other in the patient care. In this regard, the patient's son said: *"To take care of my son, my wife and I shared tasks; we did shift work every 2 hours, like guarding in the military service."*

Care challenges

Through the care process, caregivers faced many challenges and opportunities. One of the problems of caregivers and patients was the lack of effective communication due to tracheostomy. *"It was difficult for us to communicate with the patient. When we talked to him, he had nothing to say"* (P3).

Tracheostomy care was one of the issues that most family caregivers provided for their patients. These care services included tracheostomy-dressing replacement, preventing the tracheostomy internal tube removal, dressing replacement, and washing the tube. Factors imposing high stress on caregivers included complications such as pressure on the neck, impaired mobility, coughing and infection, unpleasant odor of tracheostomy, prolonged and frequent hospitalization, eating disorders, and bleeding. Accordingly, some caregivers described tracheostomy as unsuccessful for their patients. *"Tracheostomy is the cause of side problems. It is the cause of infection and hospitalization in the ICU. The tracheostomy tube has been useless recently"* (P4).

Care burden

The expression of care burden was evident according to the experiences of caregivers. For many reasons, patient care imposed a heavy burden on caregivers. Providing overwhelming care required time, enormous costs, and, as a result, physical, psychological, and social consequences for caregivers. Hence, they gradually were under care burden as a result of enduring these harsh care conditions. *"We take care of my father (patient) day and night"* (P1).

One of the requirements of the home care process was the purchase of numerous consumables and nonconsumables that were costly. *"Before discharge, we provided a suction*

brush, bed, and wavy mattress. We transferred our patient from the hospital to the house by a private ambulance that was expensive" (P1). The overwhelming amount of patient care made family members always involved in caring for the patient, which in turn caused disruption in jobs and educational, economic, cultural, and social conditions. *"Since my brother's illness, my mom lost all her hair; my father is depressed; I had a shop, but I closed it"* (P10). Even in the case of one participant, the caregiver's descriptions indicated that the primary caregiver had an irreversible stroke. *"It is difficult for us to take care of the patient. I have hypertension. One night, my wife was awake taking care of our son, but she suddenly fell down. We took her to the hospital. They said too much pressure on your wife made her stroke"* (P6).

Gaining experience

Due to the lack of adequate knowledge and skills with regard to the provision of care, by gaining experience, caregivers tried to gain acceptable care knowledge over time. Over time, caregivers reasoned that with the onset of early symptoms, the tracheostomy infection or respiratory and other complications could be detected, and they could manage the patient's symptoms using preventive measures. *"At the time of infection, the sputum was ejected from the tracheostomy; it was green; when it smells a bit, we find out there is an infection"* (P2).

In particular, tracheostomy infection was one of the problems that frequently frightened family caregivers concerning the provision of care. *"All the equipment tools I used for the patient were disposable. Even when my patient was admitted to the hospital, we took our own suction from home"* (P4).

Another common complication was the risk of aspiration. Caregivers took preventive measures during feeding and after that. *"During the gavage, we made sure that his head was 30° upward that nothing would enter his lungs"* (P1).

Hope and inner satisfaction

Despite the difficult circumstances, they hoped for the recovery of patients and always strived for inner satisfaction. They enjoyed providing care and did not feel tired. *"When we take care of our father, we do it with love. We provided him with the material, spiritual, and psychological supports. We feel satisfied"* (P3).

They endured all the difficulties of this path and eventually declared that they are submissive to God's will. *"Despite all these difficulties, thank God that my dad is still alive; many people do not have a father. I thank God again"* (P3).

The participants' descriptions showed that there were glimmers of hope in their families. Not only such hope did not diminish over time, but also it provided a strong impetus for continuing the care path. Consequently, they were trying to take care of the patient under any

circumstances. One of the participants said: “*The kids love their father; every moment they hoped their father get well; they were constantly around him; when their father laughed, their hope raised*” (P7).

Discussion

In this study, the need for training, social support, care burden, care challenges, gaining experiences, and hope and inner satisfaction were main categories. The need for training was the first category. Caregivers' reluctance to accept the caring role and lack of knowledge as well as skills needed to provide care was a source of stress, particularly in the early days of care. Similarly, in the study conducted by Choie *et al.*, the acceptance of critical patients at home was considered as a new challenge.^[23] According to Ravery *et al.*, patient care is stressful for informal caregivers, because their responsibilities increase over time.^[24] Family caregivers obtained the necessary information for patient care through various sources. In one study, patients reported providing general and specialized information by professional staff as a dimension of care.^[25] Azhar *et al.* emphasized the role of providing necessary information to caregivers by health professionals.^[26] In accordance with the present results, previous studies have demonstrated that in today's society, the Internet as a high-capacity tool enables people to access health information;^[27] however, this information probably does not satisfy them.^[28]

The experiences of the caregivers were indicative of the need for social support as the second category. Some caregivers mentioned they received support from relatives, friends, and organizations, while others did not receive any support. These results are consistent with the study of Bamari *et al.* on the importance of patient and family support for appropriate home health care.^[29]

Caregivers also complained about the burden of care and had many challenges. In one study, family caregivers are described as people with unforeseen needs.^[30] In addition, patients' inability to meet their needs, on one hand, and patient discharge and delegating the responsibility for caring to the family, on the other hand, placed the care burden on the caregivers. Twenty-four-hour care, and the physical, psychological as well as social consequences of caring, were the experiences frequently mentioned by the caregivers. As it was indicated in a study, caregivers experience severe stress, depression, and anxiety due to the lack of appropriate emotional, financial, and personal support.^[31] In another study, changes in daily activities, decreased social interactions, and physical symptoms were mentioned as consequences of care.^[30] In the study of Salehi Nejad *et al.*, caregivers are referred to as “hidden patients.”^[27] Some family caregivers cannot successfully handle these changes. Such changes make caregivers increasingly socially isolated.^[5]

One of the important issues for caregivers was the cost of care. In the study of Crist *et al.* (2018), the issue of costly care was emphasized. In Mexico, families were unable to hire private professional caregivers.^[32] In developed countries, between 50% and 90% of home care, costs are provided by the government; however, the cost of home care in Iran is covered very little or not at all by the government.^[33]

The caregivers endured several kinds of difficulties during the tracheostomy care. Despite the use of multiple approaches, the inevitable complications were sometimes so severe that some caregivers described them as distressing. Cohen *et al.* described obstruction and bleeding as the two most life-threatening complications and reported tracheostomy tube obstruction as the most common cause of death in these patients.^[34] In a study conducted by Stanley *et al.*, provision of home care to tracheostomy patients was referred to as a challenge.^[35] As difficult communication can prevent patients from expressing their needs, feelings, and participation in treatment decisions, some caregivers reported tracheostomy as preventing effective communication. It is also emphasized by Tolotti *et al.* The authors believe that this factor causes fear and frustration in patients.^[35,36]

One of the main categories of study was gaining experience. An interesting finding in this regard is that caregivers went through a dynamic process in caring over time. This finding is consistent with the results of the study conducted by Farhadi *et al.* who stated that caring increases caregivers' awareness and maturity.^[37] Labbé *et al.* also pointed to the reduction of burden care and the unveiling of its positive dimensions over time.^[38]

Hope and inner satisfaction were the last category. Despite the imposed care burden, some caregivers felt satisfied with the care provided. In the study of Bastani *et al.*, caregivers had to dedicate and ignore their well-being to play their caring role.^[39] According to Nemati *et al.*, spirituality is necessary to overcome this crisis and to achieve inner peace.^[40]

One of the limitations of the present study was that due to cultural problems and lack of cooperation of female patient caregivers, all the patients had to be selected among male patients. Female tracheostomy patients may have other needs that are suggested to be considered in future studies.

Conclusion

In this study, early on, the family caregivers faced with lots of challenges in caring patients with tracheostomy and they are reluctant to accept new and overwhelming roles and costly care and caregivers lack skills and expertise. Therefore, they were in need of training and support from professionals. Although they were skillful in care and enduring the burden, they were quite hopeful and satisfied with their attempts. Hence, there is a need for official

nongovernmental organizations with the aim of maintaining care and protecting their families.

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Conflicts of interest

Nothing to declare.

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