

# Factors Influencing Long-term Home Care for Patients with Tracheostomy from the Perspectives of their Family Members

## Abstract

**Background:** Family caregivers are the principal caregivers of patients with tracheostomy and can reduce the risk of re-hospitalization through giving quality care to their patients. Caregiving to patients with tracheostomy is a complex process influenced by many different factors. However, there are inadequate data about these factors, and hence, this study aimed at exploring the factors influencing long-term home care for patients with tracheostomy from the perspectives of their family caregivers. **Materials and Methods:** We conducted this descriptive qualitative study in 2023–2024. Participants were nine family caregivers, one patient with a tracheostomy history of three years, a home care nurse, and an anesthesiologist purposefully selected from Mazandaran, Iran. Data were collected through 12 in-depth semi-structured interviews and were analyzed through conventional content analysis. The criteria proposed by Lincoln and Guba were used to ensure trustworthiness. **Results:** The three main categories of the factors influencing long-term home care for patients with tracheostomy were healthcare system dysfunction, challenges of tracheostomy care, and effective management of tracheostomy care. These three categories had 13 subcategories. **Conclusions:** Careful attention to the special needs of patients with tracheostomy, close collaboration among healthcare professionals and family caregivers, and development of a strong support network are essential to reduce the challenges and complications of home-based caregiving to patients with tracheostomy.

**Keywords:** Family caregivers, home care services, qualitative research, tracheostomy

## Introduction

Tracheostomy is a surgical procedure in which a long-term or temporary hole is created between the second and the third rings of the trachea.<sup>[1]</sup> The most important indications of tracheostomy include long-term endotracheal intubation, ineffective airway clearance, airway obstruction, chronic pulmonary disease, neuromuscular failure, gastrointestinal disorders, tumors, head and neck surgeries, traumas, cardiovascular diseases, infections, and neurological disorders.<sup>[2]</sup> Almost 7000 tracheostomies are performed each year in Australia and New Zealand.<sup>[3]</sup> This number is 100,000–113,000 in the United States.<sup>[4,5]</sup> The overall prevalence of tracheostomy in Iran is 40.59 cases per 100,000 people.<sup>[6,7]</sup> The probable complications of tracheostomy are bleeding, tracheostomy tube displacement, tracheal stenosis, granulation tissue formation, tracheomalacia, pneumonia, aspiration, and

tracheoesophageal fistula.<sup>[8,9]</sup> The prevalence rate of these complications is 49%, and their mortality rate is 2%.<sup>[10]</sup> Moreover, tracheostomy affects patients' breathing, communication, eating, psychosocial well-being, and quality of life and causes mental, functional, occupational, social, and financial problems for both patients and their family members.<sup>[2,6,11]</sup>

Tracheostomy may be used for long periods of time, and hence, most patients (73.4%) return home with a tracheostomy tube in place.<sup>[12]</sup> In home settings, patients with tracheostomy (PWT) are dependent on their family members' care, help, and support. Prevention of tracheostomy complications and improvement of patient survival need an interdisciplinary team for home care to effectively fulfill patients' needs. The members of this team include nurses, physicians, physiotherapists, nutrition specialists, social workers, speech therapists, and family caregivers.<sup>[13,14]</sup> A

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qualitative study showed that home caregiving to PWT had positive outcomes such as reduction of the costs and the need for hospital care and enhancement of patient satisfaction.<sup>[11]</sup> Caregiving to PWT is a specialized task, and hence, family caregivers need quality education about tracheostomy care because they have significant role in caregiving to PWT at home.<sup>[15-17]</sup> A study highlighted that most families of PWT need professional nurses to provide their patients with specialized home care services such as respiratory care and mechanical ventilation services at least for 8–10 hours per day and also to provide them with education about tracheostomy care.<sup>[18]</sup> Nonetheless, there are no outpatient tracheostomy care centers in some countries and PWT and their families receive limited, if any, emotional, informational, and financial support.<sup>[2]</sup> The gap between hospital education and real caregiving at home causes family caregivers to have limited readiness and competence for home care.<sup>[2,19,20]</sup>

The complex and specialized process of caregiving to PWT and the difficulty of diagnosing and managing tracheostomy complications cause stress, anxiety, emotional problems, fear, and insecurity for family caregivers and alter family integrity.<sup>[7]</sup> However, the lack of effective educational programs for family caregivers, their limited access to rehabilitation services, and ineffective communication between healthcare professionals and family caregivers make home-based caregiving a challenging and stressful process for family caregivers. These challenges can reduce the quality of family caregivers' care<sup>[2,21]</sup> and highlight the need for healthcare professionals' support.<sup>[12]</sup>

Different factors can influence the quality of home-based caregiving to PWT. A qualitative study found that family members' knowledge about patient care, accurate ventilator setting, and warning signs may influence care quality.<sup>[15]</sup> Another study showed that lack of knowledge about tracheostomy care and other care-related techniques may lead to care-related errors and serious complications.<sup>[22]</sup> Financial problems, limited access to healthcare services,<sup>[23]</sup> and interaction with healthcare professionals<sup>[24]</sup> can also influence families' ability to provide quality care to PWT.

A review of the studies into tracheostomy care shows that there are many knowledge gaps regarding the process of tracheostomy care.<sup>[11]</sup> Therefore, more studies in this area are essential to further explore the different aspects of this process. Qualitative studies can provide in-depth knowledge about phenomena through focusing on individuals' experiences and perspectives to explore phenomena in their natural contexts. This qualitative study aimed at exploring the factors influencing long-term home care for PWT from the perspectives of their family caregivers.

## Materials and Methods

We conducted this descriptive qualitative study from September 2023 to August 2024 using conventional

content analysis. Conventional content analysis allows the detailed description of the content and helps researchers identify and analyze patterns and trends within the data. It is a valuable method for understanding social phenomena, cultural narratives, and communication styles.<sup>[25,26]</sup> The population of the study comprised the family caregivers of PWT. Moreover, PWT who could verbally communicate, physicians, and nurses were included to further clarify the different aspects of the study phenomenon. Inclusion criteria were age above 18 years, an experience of caregiving to a family member with tracheostomy for at least one month, and consent to participate in the study. Sampling was performed purposefully and with maximum variation with respect to educational level and caregiving experience. Participants were nine family caregivers, one adult PWT with a tracheostomy history of three years, a home care nurse, and an anesthesiologist purposefully selected from Mazandaran, Iran. In qualitative studies, there is no strict criterion for sample size determination, and sampling continues until data saturation is achieved. Saturation is usually defined as a point at which no new categories or themes emerge. In addition, saturation includes the development of the attributes and dimensions of categories.

Data were collected through 12 personal semi-structured interviews conducted at participants' suggested time and location. Interviews with family caregivers and patients were conducted at their homes, while interviews with nurses and physicians were conducted in their workplace. Interview duration ranged from 30 to 50 minutes. The interviewer, i.e. the first author, had the experience of care provision to PWT and the experience of tracheostomy care education to nursing students. Participants were ensured that their data would remain confidential and that they had the right to withdraw from the study at will. Interview questions were determined based on participant type. For example, a question for family caregivers was "Based on your experiences of caregiving to a PWT, what factors can influence caregiving to these patients?" An example of the questions for the participating PWT was "Based on your experiences of your disease, what factors can influence caregiving to PWT?" Moreover, an example of the interview questions for the participating nurse was "May you please explain what factors influence your home care services for PWT?" At the end of the interviews, we asked participants, "Would you like to add any other point?" All interviews were audio-recorded and the duration of them was 45–60 minutes.

In this study, data analysis was conducted using the five-step conventional content analysis method developed by Graneheim and Lundman. The data were transcribed word by word, and the transcripts were perused several times to grasp their main ideas. Meanwhile, meaning units were identified and coded with the main context in the mind. The codes were compared and categorized into

subcategories and categories. In other words, we compared the extracted concepts with each other in terms of their attributes and dimensions and grouped similar concepts into subcategories and categories. Data collection and analysis were kept on up to obtaining no new data from the interviews and until the categories were fully developed.<sup>[27]</sup>

The criteria proposed by Lincoln and Guba (1985) were utilized to ensure trustworthiness. These criteria are credibility, dependability, transferability, and confirmability. Credibility was maintained by returning the codes of each interview to the corresponding participant to check the congruence between the codes and his/her experiences. The dependability was ensured through twice coding the excerpts of the data with a 12-week interval and comparing the results of the two analyses. Sampling with maximum variation with respect to age, educational level, and caregiving experience was also employed to ensure transferability. Besides, confirmability was ensured through confirming the accuracy of data analysis by three experienced qualitative researchers from Kashan and Babol Faculties of Nursing and Midwifery, Iran, and by providing detailed explanations about participants' characteristics, data collection, and data analysis.

### Ethical considerations

This exploration has the approval of the Ethics Committee of Kashan University of Medical Sciences, Kashan, Iran (code: IR.KAUMS.NUHEPM.REC.1401.080). We attempted to have close adherence to the ethical principles of research on humans, including confidential data management, participants' freedom to participate in or withdraw from the study, and written informed consent for participation.

### Result

Participants were three male family caregivers, six female family caregivers, one male PWT, one home care nurse, and one anesthesiologist, with an age range of 30–70 years. Their educational levels varied from junior secondary degree to doctoral degree [Table 1].

In total, 1500 primary codes were generated in the process of data analysis. Similar codes which transferred the same meaning were combined, and 320 final codes were generated. These codes were classified into three main categories, namely healthcare system dysfunction, challenges of tracheostomy care at home, and effective management of tracheostomy care at home [Table 2].

### Healthcare system dysfunction

Caregiving to PWT starts in the intensive care unit. After the stabilization of their physical conditions, these patients are transferred to general hospital wards and then, to home settings for long-term home care. Healthcare organizations can provide them with quality services in clinical settings, while their family members face many different challenges related to the healthcare system in caregiving to them in home settings. These challenges include limited access to tracheostomy care resources, inadequate professional competence of tracheostomy care team members, and inefficient hospital discharge and patient follow-up system.

### Limited access to tracheostomy care resources

Standard tracheostomy care reduces the need for tracheostomy and ensures care quality. This depends on families' easy access to tracheostomy care resources. However, participants' experiences showed that shortage of professional tracheostomy care staff, particularly for home care, and incomplete insurance coverage of home care services face the families of PWT with numerous problems and reduce their ability to give quality care to their patients. *"We decided to transfer my mother to home. Obviously, we couldn't care for her and hence, negotiated with different nurses for home care. Unfortunately, all of them offered the same cost for home care services and we had no option but to use their services (P. 3)."*

Moreover, incomplete insurance coverage of tracheostomy care services requires families to use low-quality rental equipment, non-specialty nurses, and non-professional

**Table 1: The characteristics of participants**

Participant type	Age (Years)	Gender	Education	Tracheostomy duration	Underlying disease	Caregiving duration	Kinship with patient
Family caregiver	45	Male	Master's	9 months	Cerebrovascular accident	7 months	Child
Family caregiver	32	Male	Bachelor's	7 months	Apnea	6 months	Child
Family caregiver	47	Male	Junior secondary	3 months	Asthma	2 months	Child
Family caregiver	36	Female	Diploma	3 years	Amyotrophic lateral sclerosis	3 years	Wife
Patient	30	Male	Diploma	3 years	Cervical mass	–	–
Family caregiver	56	Female	Diploma	2 years	Cerebrovascular accident	21 months	Wife
Family caregiver	51	Female	Bachelor's	5 months	Lung disease	4 months	Child
Family caregiver	30	Female	Diploma	7 months	Intracerebral hemorrhage	6 months	Child
Family caregiver	70	Female	Junior secondary	7 years	Car accident	7 years	Mother
Family caregiver	55	Female	Diploma	2 years	Lung disease	2 years	Sister
Home care nurse	32	Male	Master's	–	–	5 years	–
Doctor	56	Male	Anesthesiologist	–	–	18 years	–

**Table 2: The subcategories and categories of the factors influencing long-term home care for PWT\* from the perspectives of their family caregivers**

Categories	Subcategories
Healthcare system dysfunction	Limited access to tracheostomy care resources Inadequate professional competence of tracheostomy care team members Inefficient hospital discharge and patient follow-up system
Challenges of tracheostomy care at home	Family caregivers' lack of knowledge and skills Heavy caregiver burden Ineffective interpersonal communications Home-based tracheostomy care crises
Effective management of tracheostomy care at home	Psychosocial adaptation Observational learning Attraction of healthcare professionals' support Modification of the physical space for home care Crisis management Giving general and specialized care services

\*Patients with tracheostomy

care centers. *"We haven't received so far any help from insurance organizations or centers because they don't cover tracheostomy care services (P. 9)."*

#### *Inadequate professional competence of tracheostomy care team members*

Tracheostomy care providers need to have great knowledge, skills, experience, and mental and ethical capacities to be able to fulfill the different and complex needs of PWT and to empower their family caregivers for quality caregiving. However, the limited professional experience, ethical negligence, and low-quality educations of tracheostomy care providers lead to family caregivers' ineffective learning of tracheostomy care services and thereby, increase the risk of tracheostomy complications. *"Unfortunately, they ridiculously tell us about for example suctioning or nasogastric feeding in only thirty seconds. The whole process of such education lasts only five minutes (P. 10)."*

Some participants reported the early removal of tracheostomy without any medical order and in contrast with professional and ethical principles. *"Three or four months after discharge from hospital, I asked my family members not to touch or suction the tracheostomy tube. I wanted to check the result. Then, when my nurse came, I asked her to remove the tube and she removed it (P. 5)."*

#### *Inefficient hospital discharge and patient follow-up system*

Family members have limited readiness, if any, for tracheostomy care during the first days after hospital discharge. Therefore, healthcare professionals need to follow patients' conditions in this period. Lack of effective patient follow-up programs and interdisciplinary

collaboration among healthcare professionals and family members may lead to the omission of valuable care-related data, put patients at risk for tracheostomy complications, and increase the need for re-hospitalization. *"One night, my mother developed respiratory problem and we couldn't do anything. Her nurse also didn't answer her phone. We called another nurse to ask how to perform suctioning. But she said that your nurse is someone else and avoided helping us (P. 3)."*

#### **Challenges of tracheostomy care at home**

The increasing number of PWT has increased the need for careful attention to the challenges of effective and safe tracheostomy care at home. PWT need specialized long-term care services such as continuous monitoring of respiratory status and effective management of potential complications. During the process of caregiving to PWT, family caregivers face different challenges, chiefly lack of knowledge and skills, caregiver burden, ineffective interpersonal communications, and home-based tracheostomy care crises.

#### *Family caregivers' lack of knowledge and skills*

The adequate fulfillment of the complex needs of PWT, such as the need for tracheostomy suctioning, mechanical ventilation, and nasogastric feeding, depends on family caregivers' adequate care-related knowledge and skills. However, the family caregivers of these patients do not have adequate care-related knowledge and skills and, hence, face serious challenges during the process of caregiving to their patients. This may lead to serious complications such as respiratory distress which may need re-hospitalization. *"Like feeding a baby, they gave mixed food to their patient using a small spoon while the patient was in supine position (P. 12)."*

Family caregivers' inadequate skill for airway management causes great stress for family members and endangers patient life. *"My mother and sister rapidly came and hurriedly suctioned my tracheostomy. It took too much time and I fainted (P. 5)."*

#### *Caregiver burden*

The family caregivers of PWT have different physical, emotional, and social responsibilities, and hence, caregiving imposes heavy burden on them and negatively affects their physical and mental health and quality of life. *"Caregiving has greatly affected our social relationships. I can't further allocate adequate time to my own children and my social activities such as palling around with friends and going to gym. My life plan has completely changed (P. 7)."*

Moreover, these caregivers face the heavy costs of treatment, medical equipment, medications, and intensive care services, while their patients' long-term need for care services changes their lifestyle and reduces their income. *"The tracheostomy tube has been changed six times during*



*these three years. Families need to buy the tube and ask hospital physicians to change the tube. They need to independently pay all the costs of these services (P. 11)."*

### *Ineffective interpersonal communications*

PWT have problems in establishing interpersonal communications and expressing their needs due to the tracheostomy tube. Their family caregivers are also unable to understand their needs, experience stress and bafflement, and may be unable to appropriately communicate with or receive important information from them. Such ineffective interpersonal communications can negatively affect the quality of family relationships. *"He was completely conscious but couldn't make any sound due to the tracheostomy tube. This caused problems in establishing communication with him (P. 4)."*

### *Home-based tracheostomy care crises*

PWT may experience serious health-related crises such as infection and tracheostomy tube obstruction due to their family caregivers' inability to give appropriate care. Such crises may rapidly turn into life-threatening conditions or even lead to death. *"In the first days, we noticed tracheostomy tube obstruction and problematic breathing of our patient and there was no nurse with us at that moment (P. 1)."*

### *Effective management of tracheostomy care at home*

The management of tracheostomy care at home is a critical responsibility assigned to family members and can seriously influence patient quality of life. Patient transfer to home setting and giving home care have unique challenges, the management of which needs adequate knowledge and skills. Therefore, family caregivers attempt to develop good care plans and use effective strategies to fulfill their patients' needs. These plans and strategies include psychosocial adaptation, observational learning, attraction of healthcare professionals' support, modification of the physical space for home care, management of the crises, and giving general and specialized care services. The results of their attempt include improvement of patients' quality of life and lower rate of complications.

### *Psychosocial adaptation*

Psychological adaptation enables family caregivers to better manage caregiving-related emotions and stressors and improve their abilities to manage emotional crises. Social adaptation also includes establishment and maintenance of interpersonal relationships, receiving social support, and performance of social roles, which can in turn reduce sense of isolation and loneliness. *"We, the family members, spoke with each other and asked God to help us manage our problems and to heal our mother. Our empathy and positive thinking have had positive outcomes (P. 7)."*

### *Observational learning*

As the main supporters of PWT, family caregivers need

to rapidly learn care-related techniques and procedures. Observational learning can be a very strong and useful method for them to promote their abilities. It enables them to use the experiences of others, particularly nurses and physicians, and gradually improve their skills to perform the care-related tasks which were already frightening and critical. *"I frequently visited our patient in the hospital and frequently observed airway suctioning and nasogastric feeding. Lengthy patient visits helped me partially learn how to perform suctioning and nasogastric feeding (P. 4)."*

### *Attraction of healthcare professionals' support*

Effective and comprehensive tracheostomy care needs close collaboration and interaction among different healthcare professionals, including nurses, physicians, occupational therapists, social workers, and psychologists. Family caregivers, as the main caregivers at home, attempt to attract healthcare professionals' support, improve collaboration among them, and, thereby, give quality care to their patients. *"We make the necessary arrangements with home care nurses to provide tracheostomy-related care services. They can even change the tube if needed. We also make arrangements with physiotherapists, wound management specialists, and speech therapists (P. 7)."*

*"Some physicians assess our patient's conditions without any need to move out the patient and just based on our provided patient history and patient's medical records. We took our father's records to the physicians and talked to them or asked them to visit him at home (P. 1)."*

### *Modification of the physical space for home care*

Modification of the physical space of home for caregiving to PWT is one of the main aspects of home care management. PWT specifically need a safe home environment which supports their recovery. Their home environment should have appropriate health-related equipment and facilities, appropriate lighting, effective ventilation, and appropriate medical equipment such as tracheal filters and medications. Moreover, an appropriate place is necessary for patients to independently sit and rest. *"At the time of hospital discharge, they gave us a list of the necessary equipment such as ventilator and suction device. We referred to the medical equipment unit and they guided us. Moreover, we asked information from those relatives and friends who could help us. Finally, we bought the necessary equipment (P. 7)."*

### *Crisis management*

Management of the tracheostomy crisis is a critical challenge which needs knowledge, skills, and preparedness. Family caregivers need to develop their knowledge and skills in order to detect the warning signs of serious complications such as tracheostomy tube obstruction, sudden changes in respiratory status, and respiratory

infections. *"It seemed that his airway became dry and the secretions occluded it. They told us to use humidifier or set the ventilator to deliver humidified air. They also taught us to perform physiotherapy for our father. These helped reduce the problems (P. 1)."*

#### *Giving general and specialized care services*

PWT have complex needs and hence, need specialized home care. Family caregivers, who are their main caregivers, develop their abilities and skills to give general and specialized care services to their patients. General care services include personal hygiene, feeding, and mobility-related activities, while specialized care services include tracheostomy tube management, infection prevention, wound care, and warning sign detection. *"He previously had no movement and was almost paralyzed. But now, he is slightly better. We help him sit on the edge of the bed and walk with our help and a walker. Of course, independent walking is still too soon and needs time (P. 8)."*

*"We didn't have any nurse during the first 48 hours after hospital discharge. In that period, I dared to independently perform suctioning and nasogastric feeding (P. 7)."*

## **Discussion**

This study explored the factors influencing long-term home care for PWT from the perspectives of their family caregivers. Findings revealed that the main categories of these factors were healthcare system dysfunction, challenges of tracheostomy care at home, and effective management of tracheostomy care at home.

Limited access to tracheostomy care resources, inadequate professional competence of tracheostomy care team members, and inefficient hospital discharge and patient follow-up system were the three subcategories of the first category. Shi *et al.*<sup>[28]</sup> stated that most nurses may have not received adequate education about tracheostomy care during their university education, and hence, their inability to appropriately diagnose problems may lead to serious complications. On the other hand, Meyer-Macaulay *et al.*<sup>[29]</sup> reported (2021) that some home care nurses may provide home care without the supervision and support of healthcare authorities, and this may prevent them from developing their skills. Mungan *et al.*<sup>[30]</sup> found that limited skills for tracheostomy care may lead to complications such as respiratory infections, airway obstruction, and damage to tissues surrounding the tracheostomy tube which may in turn increase the risk of re-hospitalization, impose heavy costs on patients and their families, and cause them great stress.

Family caregivers' limited access to tracheostomy care resources was a subcategory of the first main category. In agreement with this finding, Amar-Dolan *et al.*<sup>[31]</sup> showed (2020) that the families of PWT had poor access

to the necessary instruments and stuff for caregiving and complication management, and highlighted that this may postpone recovery and increase the risk of complications. Crist *et al.*<sup>[32]</sup> also found that while easy access to medical equipment and resources in home settings is necessary for effective home care, the heavy costs or limited accessibility of equipment and resources such as airway humidifiers and filters may reduce care quality and increase the risk of infection and respiratory problems.

We also found inefficient hospital discharge and patient follow-up system as an influential factor on family caregivers' home care for PWT. Lack of comprehensive planning to transfer medical information to family caregivers is one of the main problems in the process of hospital discharge. Most patients and family members do not have adequate information about post-discharge care and tracheostomy management techniques, cannot properly supervise their patients' conditions for long period of time, and may not be able to use effective strategies when serious problems occur for their patients. Almansour *et al.*<sup>[13]</sup> indicated that families' poor access to information about patient management and their poor communication with healthcare centers reduce the possibility of diagnosing complications and changes in patients' conditions and postpone the onset of the necessary treatments. The lack of clear strategies to provide post-discharge support and counseling can negatively affect home care quality, undermine patients' health and quality of life, and face them with considerable problems. Therefore, a comprehensive and collaborative interdisciplinary approach is necessary to provide family caregivers with continuous education, support, and counseling, empower them for home-based caregiving, facilitate their access to healthcare resources, and, thereby, improve their abilities, enhance patients' quality of life, and reduce the risk of complications.

The second main category of the factors influencing long-term home care for PWT was challenges of tracheostomy care at home. Family caregivers' lack of knowledge and skills was one of its subcategories. Participants' experiences indicated that family caregivers need great knowledge and skills for quality caregiving to PWT; otherwise, they may cause serious problems and complications for their patients during the process of caregiving. Meyer-Macaulay *et al.*<sup>[29]</sup> reported that many families had inadequate knowledge about caregiving to PWT, particularly about changing and cleaning tracheostomy tube and detecting the warning signs of complications and noted that this may lead to infections and tracheostomy tube obstruction. Nakarada-Kordic *et al.*<sup>[20]</sup> also found that the family caregivers of PWT lacked the technical and practical skills for caregiving and, hence, could not manage assistive devices, assess patients' conditions, and appropriately respond to emergency situations. This lack of knowledge and skills may reduce family caregivers' ability to detect warning

signs, manage problems, take the necessary actions, and, hence, may seriously endanger patient life.<sup>[15]</sup> Contrary to our findings, Vatandoust *et al.*<sup>[33]</sup> found that some family caregivers actively engage in the process of caregiving and may participate in tracheostomy care courses to receive education about appropriate tracheostomy care, tracheostomy tube change, and complication management. This contradiction may be due to the improvement of caregivers' knowledge and experience over time and their better access to care-related data over the internet.

Caregiver burden was another challenge of tracheostomy care in the present study. In line with this finding, an investigation (2019) indicated that caregiving-related activities, such as patient positioning, tracheostomy tube change, and medication management, need great physical effort and, hence, can reduce caregivers' physical ability and cause them excessive fatigue, muscular pains, and physical problems.<sup>[34]</sup> Bonacasa *et al.*<sup>[35]</sup> reported that family caregivers have concerns over patient health, fear over complications, stress, anxiety, depression, and considerable emotional burden, which can negatively affect their family relationships and reduce their received social support. Moreover, Chandran *et al.*<sup>[36]</sup> showed that the heavy costs of medical equipment and medications and the inability of some family caregivers to perform their occupational activities can also reduce family income and put heavy financial strain on families. Although 50%–90% of home care costs in developed countries are paid by governments,<sup>[37]</sup> Navipour *et al.*<sup>[38]</sup> stated reported limited governmental support for home care services in Iran. This contradiction is due to the differences in governmental policies for home care services in different countries.

Another challenge of tracheostomy care was ineffective interpersonal communications. PWT may be unable to establish normal verbal communications, and their family members may be unable to appropriately understand their emotions, needs, or requests. These problems may cause misconceptions and tensions in relationships, and families may feel necessary to greatly attempt to facilitate communication which in turn increases their workload, causes them psychological strain, and negatively affects their mental health. Therefore, family caregivers need communication-related education and support in order to better cope with communication-related challenges and have better communication with their patients.

Effective management of tracheostomy care at home was the third main category of the factors influencing tracheostomy care. Findings showed that psychosocial adaptation, observational learning, attraction of healthcare professionals' support, modification of the physical space for home care, crisis management, and giving general and specialized care services may facilitate tracheostomy care by family caregivers. Baddour *et al.*<sup>[39]</sup> (2021) reported that family caregivers can reduce their stress and anxiety

through learning stress management techniques such as meditation and relaxation exercise and highlighted that those family caregivers who receive greater social support feel lower sense of isolation and loneliness. Respecting observational learning, Xu<sup>[40]</sup> found that family caregivers can learn different caregiving methods and emotional responses to patients through observational learning and, thereby, modify their caregiving approaches. Moreover, observational learning helps family caregivers identify and manage caregiving-related crises.<sup>[41]</sup> However, Kavanaugh *et al.*<sup>[42]</sup> showed that learning through observation may reduce caregivers' creativity in care because the conditions and the needs of each patient and each caregiver are unique.

We also found attraction of healthcare professionals' support and modification of the physical space for home care as other influential factors on tracheostomy care at home. Similarly, Cherney *et al.*<sup>[43]</sup> reported that family caregivers' attempt to arrange patient visit by different healthcare professionals, such as physicians, nurses, physiotherapists, and speech therapists, can create a strong support network and, thereby, facilitate the fulfillment of patients' different needs. The availability of the necessary medical equipment for tracheostomy care, such as respiratory devices, tracheostomy tubes, and monitoring instruments, can facilitate caregiving and reduce reaction time in emergency situations.<sup>[44]</sup> Our limited access to patients' medical records and home care agencies limited our access to potentially eligible patients. Moreover, difficulties in gaining participants' trust to enter their homes and maintaining their privacy were among the limitations of this study.

## Conclusion

This study concludes that the long-term and complex process of caregiving to PWT is influenced by many mental, educational, financial, and social barriers which may reduce care quality and lead to family caregivers' burnout. On the other hand, this process is influenced by different facilitators such as access to appropriate information, psychosocial support, and healthcare and financial resources. Improving family caregivers' access to these resources can improve their ability to give quality care to their PWT at home and thereby, improve patient health. Healthcare policy-makers need to develop and implement educational and supportive programs, establish tracheostomy-related support associations, improve the accessibility of tracheostomy equipment, strengthen relationships between healthcare providers and family members, and provide strong financial and insurance support to PWT and their family caregivers in order to reduce the challenges of caregiving to PWT and improve the quality of family caregivers' tracheostomy care at home. As tracheostomy care starts in hospital settings, exploration of healthcare providers' perspectives on the influential factors on the process of hospital-based care



provision to PWT is recommended. Moreover, development of coherent models for home-based caregiving to these patients is recommended.

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Nothing to declare.

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