



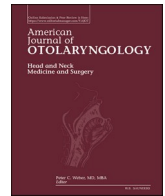
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Amplifying patient voices amid pandemic: Perspectives on tracheostomy care, communication, and connection

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ABSTRACT

Objective: To investigate perspectives of patients, family members, caregivers (PFC), and healthcare professionals (HCP) on tracheostomy care during the COVID-19 pandemic.

Methods: The cross-sectional survey investigating barriers and facilitators to tracheostomy care was collaboratively developed by patients, family members, nurses, speech-language pathologists, respiratory care practitioners, physicians, and surgeons. The survey was distributed to the Global Tracheostomy Collaborative's learning community, and responses were analyzed.

Results: Survey respondents ($n = 191$) from 17 countries included individuals with a tracheostomy (85 [45 %]), families/caregivers (43 [22 %]), and diverse HCP (63 [33.0 %]). Overall, 94 % of respondents reported concern that patients with tracheostomy were at increased risk of critical illness from SARS-CoV-2 infection and COVID-19; 93 % reported fear or anxiety. With respect to prioritization of care, 38 % of PFC versus 16 % of HCP reported

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Crisis Standards of Care
 Patient experience
 Anxiety
 Depression
 Health care professionals
 Speech-language pathology
 Respiratory therapy
 Respiratory care practitioner
 Nursing
 Safety
 Healthcare access
 Quality improvement
 Resource scarcity
 Rationing
 Comorbidities
 Advocacy

concern that patients with tracheostomies might not be valued or prioritized ($p = 0.002$). Respondents also differed in fear of contracting COVID-19 (69 % PFC vs. 49 % HCP group, $p = 0.009$); concern for hospitalization (55.5 % PFC vs. 27 % HCP, $p < 0.001$); access to medical personnel (34 % PFC vs. 14 % HCP, $p = 0.005$); and concern about canceled appointments (62 % PFC vs. 41 % HCP, $p = 0.01$). Respondents from both groups reported severe stress and fatigue, sleep deprivation, lack of breaks, and lack of support (70 % PFC vs. 65 % HCP, $p = 0.54$). Virtual telecare seldom met perceived needs.

Conclusion: PFC with a tracheostomy perceived most risks more acutely than HCP in this global sample. Broad stakeholder engagement is necessary to achieve creative, patient-driven solutions to maintain connection, communication, and access for patients with a tracheostomy.

1. Introduction

As the COVID-19 pandemic has unfolded in successive waves, public health crises have palpably demonstrated disparate harm to marginalized communities [1–8]. Many communities are defined by physical proximity, but others are connected by shared experiences that transcend geography. Such is the case with the learning community of patients with a tracheostomy. Few populations are more susceptible to harm than individuals with a tracheostomy, whose risk of severe course of illness and complications during the pandemic has been magnified by impaired communication, limited access to care, and comorbidities [9–15]. Tracheostomy is most often construed as a procedure, a medical device, or an artificial airway with a defined function [16]. However, the framing for a patient or family is very different, often construed as part of identity, communication, and survival [17]. A tracheostomy might also represent a liability during the pandemic, if it is considered an impediment when rationing scarce resources such as ventilators under Crisis Standards of Care [18,19]. Few data are available on how individuals with a tracheostomy and their families have been affected; nor has there been a purposeful effort to capture the perspective of the healthcare professionals (HCP) caring for these patients. Addressing these gaps is necessary for designing, delivering, and personalizing high-quality healthcare.

The medical conceptualization of a tracheostomy—as an intervention or device providing pulmonary clearance, bypassing an obstructed upper airway, facilitating ventilation, or accelerating liberation from a ventilator—is incomplete [20,21]. The International Classification of Functioning, Disability, and Health conceptualizes health beyond impairment, considering activities and participation across contexts [22–24]. A tracheostomy affects independence, prospects for employment, and ability to communicate [25]. Furthermore, tracheostomy care consumes copious time and energy in procuring supplies, cleaning, suctioning, and addressing emergent needs, including bleeding, infection, occlusion, or dislodgement [26]. Tracheostomy is thus an aspect of personhood and lifeline, albeit sometimes a tenuous one [15]. Fear and anxiety were commonly reported by individuals with a tracheostomy even before COVID-19 pandemic [27–39], and studies suggest that prevalence of anxiety disorders may have increased by more than threefold from a pre-pandemic baseline estimate of 7.3 % in this population [30,31].

The COVID-19 pandemic created the perfect storm of uncertainty, supply chain disruption, and healthcare workforce shortages [32,33]. Individuals with tracheostomy exhibit elevated risk for severe COVID-19 from both underlying comorbidities [34] and reduced access to care or supplies necessary to maintain safe oxygenation. Before the pandemic, approximately 100,000 tracheotomies were performed annually in the United States [35], but this number has surged with the spike in critically ill patients worldwide. Few studies have investigated the challenges faced by these patients, either in the hospital or community

[35,36]. This study explores how the COVID-19 pandemic affected resources, access to care, and well-being for patients with tracheostomy, their families and caregivers, and healthcare professionals (HCP). Comparisons of patient and family/caregiver responses to those of HCPs can afford insights into lived experiences and help to identify potential opportunities for partnership in providing safe, patient-centered care.

2. Materials and methods

2.1. Overview and approvals

This prospective cross-sectional survey explored how the altered healthcare delivery landscape during COVID-19 pandemic affected individuals with a tracheostomy, their families, and HCP. A secondary objective was to make comparisons between perspectives of patients & families, and HCP. The protocol was registered with the Institutional Review Board in accordance with the Code of Federal Regulation in compliance with University of Michigan institutional policy (IRB# HUM00208783). Participation was voluntary. The Checklist for Reporting Results of Internet *E*-Surveys (CHERRIES) was used to report findings [37,38].

2.2. Participants

All participants from the Global Tracheostomy Collaborative (GTC) Patient & Family Learning Community were invited to participate in the survey via email. Since its inception in 2012, GTC has maintained a secure registry of patients & families and HCP engaged with the quality improvement collaborative's educational and implementation efforts. Participants in this learning community may join in connection with interest group forums, global webinars, international tracheostomy symposia, or referrals from patient-facing networks. Registrants can opt into receiving newsletters, information, and survey invitations. Patients under the age of 18 years require an adult to register. This learning community is patient-centric and includes patients, family, other caregivers, and HCP; therefore, survey participants were asked whether they were primarily identified as patients, family members and caregivers, or HCP.

2.3. Survey instrument development

The 25-item survey was developed by an interdisciplinary team of healthcare professionals, patients, and family members and underwent iterative cycles of review with feedback from the larger GTC community (Fig. 1) [39–41]. The initial, larger pool of potential questions addressed quality-of-life, emotional well-being, availability of supplies, medical access, and facilitators or barriers to access to care.

Questions identified as highest priority by the development group were revised over serial rounds of edits until consensus was achieved.

The survey instrument was built using Qualtrics software, version 2020 (Qualtrics, Provo, UT) and was then vetted against a quality checklist to eliminate design flaws, such as leading questions, double-barrel questions, inadequate response options, and other sources of bias. Six questions captured demographic data, fourteen questions were multiple-

choice questions, and two questions used a sliding scale (0–10 or 0–100), for rating anxiety during the COVID-19 pandemic.

Default Question Block

Thank you so much for lending your voice during one of the defining moments of our lives! Your valuable perspectives on tracheostomy care in the COVID-19 era will improve care as we navigate this public health crisis together. This survey takes about 5 minutes to complete. All responses are confidential.

We are so grateful for the gift of your time and experiences!!

How are you related to the tracheostomy community?

- ☐ I have a tracheostomy
- ☐ I am a family member who takes care of a loved one with a tracheostomy
- ☐ I am a caregiver/carer who takes care of someone with a tracheostomy
- ☐ I am a healthcare professional with a tracheostomy
- ☐ I am a healthcare professional

Age (number in years)

Which country do you live in?

Which State or Province do you live in?

What type of area do you live in?

- ☐ Urban (City)
- ☐ Suburban (Outside the city)
- ☐ Rural

What are the challenges that you are facing related to tracheostomy during this COVID-19 pandemic?

Fig. 1. Survey instrument distributed to study participants.

How do you feel getting sick with COVID-19 affects an individual with a tracheostomy compared to the general population?

- ☐ **It is very scary.** It sometimes feels like we might not be prioritized, and that we might not be offered the same treatment options
- ☐ **It is concerning.** Individuals with tracheostomy have more complex needs, and this can add some risk. It's also concerning that caregivers may not be allowed to come into the hospital and help advocate for care needs
- ☐ **Same as everyone else.** Individuals with tracheostomy are at no more risk than anyone else

Have you experienced anxiety or fear at any time during COVID-19 pandemic?

- ☐ Yes
- ☐ No

What has caused fear during this COVID-19 era?
(Select all that apply)

- ☐ Uncertainty, Fear of the unknown
- ☐ Fear of getting COVID-19
- ☐ Fear of needing to be hospitalized
- ☐ Fear that necessary caregivers might not be available
- ☐ Fear of not getting necessary supplies
- ☐ Fear of not getting access to care
- ☐ Fear of financial loss
- ☐ Fear that I or my loved one's life may not be valued if critically ill
- ☐ Other (Enter NA if not applicable)

Rate your level of anxiety about general tracheostomy care during the COVID-19 pandemic.

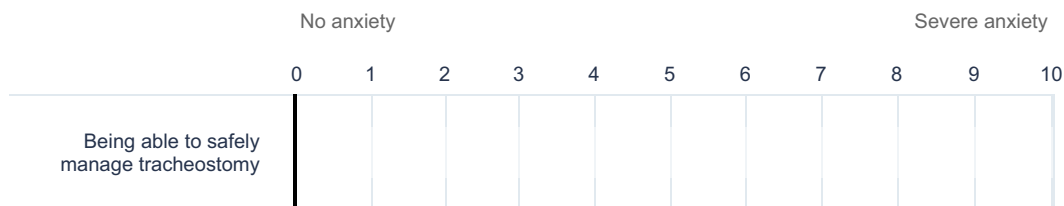


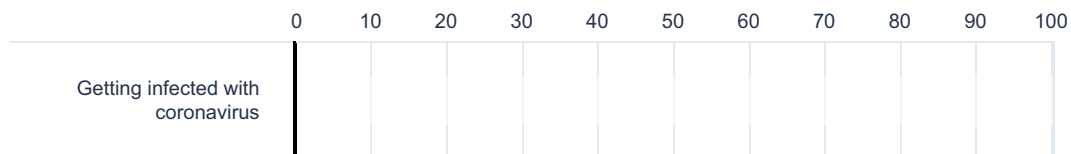
Fig. 1. (continued).

2.4. Data collection

This survey was sent out to members of the Global Tracheostomy Learning Community including patients, families, and caregivers, as well as HCP (268 individuals total). Two follow-up invitations were sent at two-week intervals, with the survey closing after four weeks.

Aggregate, de-identified survey responses were maintained on a password-protected, study-team-access-only folder behind the institutional firewall.

Rate your level of anxiety about the risk of infection during the COVID-19 pandemic.



Have you experienced severe fatigue anytime during COVID-19 pandemic?

- ☐ Yes
- ☐ No

What has caused fatigue during this COVID-19 era?
(Select all that apply)

- ☐ Stress
- ☐ Lack of sleep
- ☐ Lack of breaks
- ☐ Lack of support
- ☐ Concerns over COVID issues
- ☐ Other
-

Have you experienced feeling down, sadness, or depressed mood during COVID-19 pandemic?

- ☐ Yes
- ☐ No

Have you experienced a sense of isolation (or loneliness) during the COVID-19 pandemic?

- ☐ Yes
- ☐ No

What is your willingness for the following activities during COVID-19?

	Very Unwilling	Unwilling	Uncertain	Willing	Very Willing
Willingness to go to doctor's appointment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Fig. 1. (continued).

	Very Unwilling	Unwilling	Uncertain	Willing	Very Willing
Willingness to skip a tracheostomy tube change	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Willingness to reuse supplies due to lack of availability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How has your healthcare provider offered additional services to reduce in-person appointments for tracheostomy care?

- ☐ Virtual appointments
- ☐ Telephone conferences
- ☐ Email
- ☐ Other
- ☐ No extra services

Are you suctioning the tracheostomy tube less or more during COVID-19 pandemic (versus your usual)?

- ☐ Less
- ☐ No change
- ☐ More

What are top concerns around nursing care during COVID-19 era?

What are the shortages you are experiencing during COVID-19 era?
(Select all that apply)

- ☐ Ventilator
- ☐ Mask, gloves
- ☐ Suctioning supplies
- ☐ Tracheostomy care supplies
- ☐ Humidification supplies
- ☐ Speech devices
- ☐ Other

Have any of the following items been cancelled during the COVID-19 pandemic?
(Select all that apply)

Fig. 1. (continued).

- ☐ Doctor's appointment
- ☐ Visit by a nurse
- ☐ Tracheostomy tube change procedure
- ☐ Tracheostomy decannulation
- ☐ Sleep study
- ☐ Surgery
- ☐ Wound care appointment
- ☐ Blood draws at labs
- ☐ Others

If your hospital has reopened, what is the delay in obtaining tracheostomy-related appointments?

- ☐ 1 - 2 Weeks
- ☐ 2 - 4 weeks
- ☐ 1 - 3 Months
- ☐ 4 - 6 Months
- ☐ 7 - 9 Months
- ☐ Don't know

What kind of tracheostomy supports or resources do you need during this pandemic?
(Select all that apply)

- ☐ Virtual support groups
- ☐ Virtual wellness measures (Yoga, meditation, etc)
- ☐ Virtual education meetings
- ☐ Phone check in
- ☐ Virtual Town Hall Meeting with Healthcare Professionals
- ☐ Open forum for communication (Discussion board)
- ☐ Other

If you would like to hear from us about the results of this survey or find out more about patient and family support groups, please fill out the following questions:

Last Name (Optional)

Fig. 1. (continued).

First Name (Optional)

Email Address (Optional)

Fig. 1. (continued).

2.5. Statistical analysis and qualitative synthesis

Descriptive analyses summarized variables and distributions using mean (standard deviations), median (interquartile range), counts, and percentages where appropriate. Respondents were identified in the following groups: (1) patient, (2) family/caregiver, (3) HCP, with a fourth group pooling (1) and (2). Differences between two groups were evaluated with *t*-tests or Wilcoxon Rank-Sum tests. Differences between three groups were evaluated with ANOVA and Kruskal-Wallis one-way ANOVA, as appropriate. *Chi-square* tests were used to compare categorical variables, and Fisher Exact tests were used if the counts within cells were less than five. Stata SE 16.0 was used to analyze the quantitative data. Primary analyses compared a pooled patient/family/caregiver group vs. HCP; supplemental analyses comparing all three of the above groups were performed to identify differences in patient versus family/caregiver differences.

3. Results

One hundred and ninety-one out of 268 individuals (71.3 %) responded to the survey, including 85 (44.5 %) individuals currently with a tracheostomy in-situ. Four HCP identified as patients with tracheostomy, leaving 63 (33 %) HCP, 34 (17.8 %) family caregivers, and 9 (4.7 %) non-family caregivers of individuals with a tracheostomy (Fig. 2). Respondents were from 17 countries, with the largest proportion from United States (101 [52.9 %]), United Kingdom (33 [17.2 %]),

Finland (14 [7.3 %]), and Australia (14 [7.3 %]) (Table 1). The mean age of respondents was 48.6(13.2) years. The mean age of family member respondents was younger (43.3 ± 15.9 years) than patient respondents (51.3 ± 12.2 years), and HCP subgroups were intermediate between the two (48.3 ± 11.4 years) (Table 1; Supplemental Table 1).

3.1. Psychological aspects of tracheostomy during COVID-19 pandemic

3.1.1. Perceived risk of critical illness from COVID-19

Most respondents (121 [63.4 %]) reported the risk of critical illness from COVID-19 as “concerning,” citing the complex needs of individuals with tracheostomy and COVID-related modifications to visiting practices that prevented caregivers from entering the hospital and advocating for care needs. Fifty-eight (30.4 %) of the 191 respondents described the situation of having a tracheostomy during COVID-19 as “very scary,” with free-response comments noting that patients with a tracheostomy might not be prioritized for care or might not be offered the same treatment options as individuals without a tracheostomy or other comorbidity. The remaining 12 (6.3 %) respondents perceived that individuals with a tracheostomy were not at more risk than others, although individual responses suggested that this assessment related more to risk of transmission with tracheal breathing rather than a prediction regarding course of illness. Compared to the patient/family/caregiver group, HCP were more likely to rank the risk of critical illness in individuals with a tracheostomy as concerning rather than scary ($p = 0.006$), corresponding to a lower level of apprehension (Table 2).

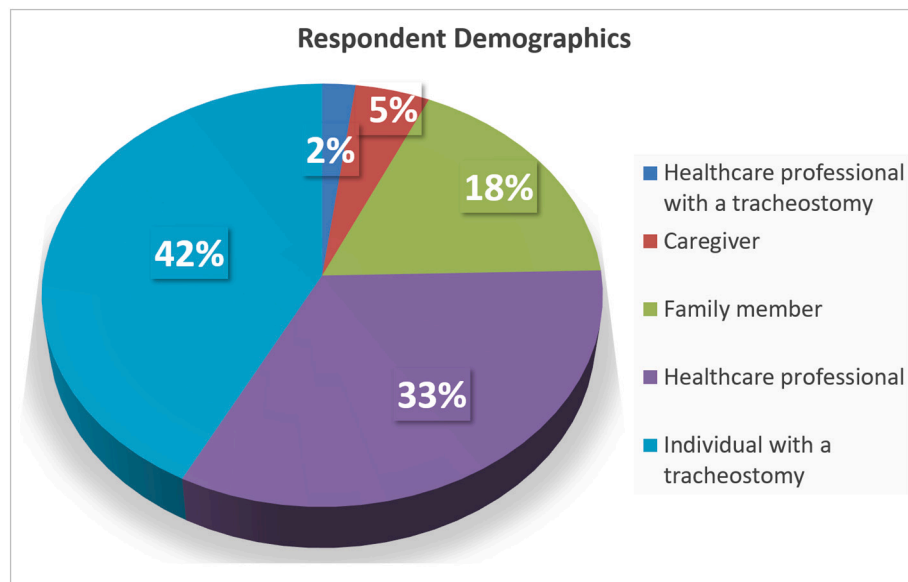


Fig. 2. Survey respondent demographics by role.

Table 1
Participant characteristics.

Characteristics		Overall	Patient/family/ caregiver	Healthcare professional
		Frequency (%) N = 191	Frequency (%) n = 128	Frequency (%) n = 63
Age in years (mean ± SD)		48.6 ± 13.2	48.6 ± 14.0	48.4 ± 11.4
Country	Argentina	1 (0.5)	0 (0)	1 (1.6)
	Australia	14 (7.3)	7 (5.5)	7 (11.1)
	Brazil	3 (1.6)	1 (0.8)	2 (3.2)
	Canada	7 (3.7)	3 (2.3)	4 (6.4)
	Finland	14 (7.3)	14 (10.9)	0 (0.0)
	India	1 (0.5)	1 (0.8)	0 (0.0)
	Ireland	5 (2.6)	4 (3.1)	1 (1.6)
	Israel	1 (0.5)	1 (0.8)	0 (0.0)
	New Zealand	1 (0.5)	1 (0.8)	0 (0.0)
	Qatar	1 (0.5)	0 (0.0)	1 (1.6)
	Romania	1 (0.5)	0 (0.0)	1 (1.6)
	Saudi Arabia	3 (1.6)	0 (0.0)	3 (4.8)
	Spain	2 (1.1)	1 (0.8)	1 (1.59)
	Sweden	2 (1.1)	0 (0.0)	2 (3.2)
	United Kingdom	33 (17.3)	23 (18.0)	10 (15.9)
	United States	101 (52.9)	72 (56.3)	29 (46.0)
	Wales	1 (0.5)	0 (0.0)	1 (1.6)
Setting	Rural	34 (17.8)	31 (24.2)	3 (4.8)
	Suburban	67 (35.1)	54 (42.2)	13 (20.6)
	Urban	90 (47.1)	43 (33.6)	47 (74.6)

3.1.2. Anxiety

One hundred and seventy-eight (93.2 %) respondents reported experiencing fear/anxiety during the pandemic, with no difference noted between patients, families, and caregivers versus HCP. However, a higher number of patients/families/caregivers than HCP reported of specific fears including: becoming unwell with COVID-19 (88 [68.8 %]

vs. 31 [49.2 %] [$p = 0.009$]), of needing to be hospitalized (71 [55.5 %] vs. 17 [27.0 %] [$p < 0.001$]), of unavailability of necessary caregivers (43 [33.6 %] vs. 12 [19.0 %] [$p = 0.04$]), of not getting access to care (43 [33.6 %] vs. 9 [14.3 %] [$p = 0.005$]), and that individuals with a tracheostomy might not be valued if critically ill (49 [38.3 %] vs. 10 [15.9 %] [$p = 0.002$]). Family members and caregivers were more fearful of uncertainty during pandemic than the patients (23 [67.4 %] vs. 40 [47.1 %] [$p = 0.03$]); family members and caregivers were also more worried than patients that their loved ones might not be valued as much if critically ill (24 [55.8 %] vs. 25 [29.4 %] [$p = 0.04$]) (Supplemental Table 2). The median level of anxiety about general tracheostomy care during the pandemic among all participants was 5 (IQR: 3–7) on a 10-point case ranging from 0 (no anxiety) to 10 (severe anxiety). Anxiety was higher in patients, families and caregivers (6 [3–7.5]) vs. HCP (4 [3–6]) ($p = 0.03$). Similarly, anxiety about coronavirus infection was higher among the patients/families/caregivers (75 [50–91]) compared to HCP (50 [30, 71]) ($p < 0.001$) (Table 2).

3.1.3. Fatigue

Overall, 130 (68.1 %) of all survey participants responded that they experienced severe fatigue during COVID-19 pandemic, with stress (79 [60.8 %]) and lack of sleep (79 [60.8 %]) being the most common causes, followed by concerns around COVID-19 (68 [52.3 %]), lack of support (29 [22.3 %]), and breaks among caregivers (24 [18.5 %]). The HCP (31 [75.6 %]) more often reported stress to be a source of fatigue than patients, family/caregivers (48 [53.9 %]) ($p = 0.02$). Patients, family, and caregivers were more likely than HCP to report lack of breaks (16 [50.0 %] vs. 3 [5.3 %] [$p < 0.001$]) and lack of support (16 [50.0 %] vs. 8 [14.0 %] [$p < 0.001$]) as sources of fatigue.

3.1.4. Mood and loneliness

One hundred and twenty (62.8 %) respondents reported feeling down, sad, or depressed during the COVID-19 pandemic, and 111 (58.1 %) experienced a sense of isolation or loneliness during the COVID-19

Table 2
Psychological aspects of tracheostomy during COVID-19 pandemic.

Psychological components		Overall	Patient/family/ caregiver	Healthcare provider	p- Value
		Frequency (%) N = 191	Frequency (%) n = 128	Frequency (%) n = 63	
Risk of critical illness from COVID-19	It is very scary	58 (30.4)	48 (37.5)	10 (15.9)	0.006
	It is concerning	121 (63.3)	73 (57.0)	48 (76.2)	
	Same as everyone else	12 (6.3)	7 (5.5)	5 (7.9)	
Experienced fear or anxiety during COVID-19 pandemic		178 (93.2)	122 (95.3)	56 (88.9)	0.09
Source of fear or anxiety	Uncertainty, Fear of the unknown	109 (57.1)	69 (53.9)	40 (63.5)	0.21
	Fear of getting COVID-19	119 (62.3)	88 (68.8)	31 (49.2)	0.009
	Fear of needing to be hospitalized	88 (46.1)	71 (55.5)	17 (27.0)	<0.001
	Fear that necessary caregivers might not be available	55 (28.8)	43 (33.6)	12 (19.1)	0.04
	Fear of not getting necessary supplies	95 (49.7)	64 (50.0)	31 (49.2)	0.92
	Fear of not getting access to care	52 (27.2)	43 (33.6)	9 (14.3)	0.005
	Fear of financial loss	37 (19.4)	25 (19.5)	12 (19.1)	0.94
	Fear that I or my loved one's life may not be valued if critically ill	59 (30.9)	49 (38.3)	10 (15.9)	0.002
	Other	19 (10.0)	10 (7.8)	9 (14.3)	0.16
Level of anxiety about general tracheostomy care during COVID-19 pandemic ^a (median (IQR))		5 (3, 7)	6 (3, 7.5)	4 (3, 6)	0.03
Level of anxiety about the risk of infection during COVID-19 pandemic ^b (median (IQR))		70 (40, 81)	75 (50, 91)	50 (30, 71)	<0.001
Experienced severe fatigue anytime during COVID-19 pandemic		130 (68.1)	89 (69.5)	41 (65.1)	0.54
Source of fatigue (n = 130)	Stress	79 (60.8)	48 (53.9)	31 (75.6)	0.02
	Lack of sleep	79 (60.8)	61 (68.5)	18 (43.9)	0.008
	Lack of breaks	24 (18.5)	19 (21.4)	5 (12.2)	0.12
	Lack of support	29 (22.3)	24 (27.0)	5 (12.2)	0.05
	Concerns over COVID-issues	68 (52.3)	47 (52.8)	21 (51.2)	0.90
	Other	18 (13.8)	10 (11.2)	8 (19.5)	0.20
Experienced feeling down, sadness, or depressed mood during COVID-19 pandemic		120 (62.8)	84 (65.6)	36 (57.1)	0.26
Experienced a sense of isolation (or loneliness) during the COVID-19 pandemic		111 (58.1)	79 (61.7)	32 (50.8)	0.15

^a Scale: 0 no anxiety – 10 severe anxiety.^b Scale: 0 no risk – 100 high risk.

pandemic. There was no statistically significant difference between patient, family/caregiver, or HCP responses (Supplemental Table 2).

3.2. Healthcare Services and Needs During the COVID-19 Pandemic

3.2.1. Shortages during COVID-19 pandemic

The most frequently reported supply shortages were masks and gloves (83 [43.5 %]), followed by tracheostomy stoma supplies (40 [20.9 %]) and humidification supplies (22 [11.5 %]). Suctioning (21 [11.0 %]) and ventilator supplies (19 [10 %]) were also of concern. Of note, HCP reported a shortage of suctioning supplies more frequently than patients, families, and other caregivers ($p = 0.01$) (Fig. 3). Family members and caregivers cited shortage of humidification as a problem more often than patients ($p = 0.03$).

3.2.2. Attitudes toward healthcare visits, tracheostomy changes, and supply shortages

Many respondents, 74 (38.74 %), reported ambivalence about going to a doctor's appointment or taking individuals they were caring for to a doctor's appointment, while 43 (22.5 %) reported they would be willing to go to their doctor's appointment during the COVID-19 pandemic (Table 3). Sixty-seven (35.1 %) respondents reported uncertainty about their willingness to skip a tracheostomy tube change, while 44 (23 %) reported unwillingness to skip a tracheostomy tube change. Sixty-five (34 %) respondents reported uncertainty about their willingness to reuse supplies, while 51 (26.7 %) were willing to reuse supplies due to lack of supplies during the COVID-19 pandemic. Among the patients/families/caregivers group, patients were more willing to skip a tracheostomy tube change than their family members or caregivers ($p = 0.02$) (Supplemental Table 3).

3.2.3. Tracheostomy-related appointments, delays, and cancellations

When queried about additional services provided to reduce in-person appointments, responses included virtual appointments 87 (45.6 %), telephone conferences 73 (38.2 %), and emails 82 (42.9 %). No differences were noted between patient/family/caregiver and HCP groups. However, among the patient/family/caregiver group, family members and caregivers wanted virtual appointments (30 (69.8 %) vs. 29 (34.1 %) [$p < 0.001$]) and telephone conferences (26 (60.5 %) vs. 26 (30.6 %) [$p < 0.001$]) more than patients did, whereas patients (44 (51.8 %)) were more likely to favor emails than family members and caregivers (8

(18.6 %)) ($p < 0.001$) (Supplemental Table 3). Many respondents reported delays in care spanning weeks to months. Services that were most often canceled included clinic-based doctor's appointments 105 (55 %), followed by surgical procedures 53 (27.8 %), and tracheostomy tube changes 45 (23.6 %) (Fig. 4). A higher number of patient/family/caregiver respondents reported canceled doctor's appointments than did HCP ($p = 0.008$), whereas HCP were more likely to report cancellation of surgeries ($p = 0.002$), sleep studies ($p < 0.001$) and tracheostomy decannulations ($p < 0.001$) (Table 3).

3.2.4. Tracheostomy informational resources

Respondents reported that they accessed a variety of tracheostomy resources during the COVID-19 pandemic, including phone support 44 (23.0 %), online discussion boards 44 (23.0 %), tracheostomy support groups 43 (22.5 %), virtual clinic visits 39 (20.4 %), and virtual forums for discussion 30 (15.7 %) (Fig. 5). Family members and caregivers reported greater interest in online discussion boards than patients (Table 3).

4. Discussion

Patients with a tracheostomy are inherently vulnerable due to medical complexity and comorbidities. One of the unanswered questions is whether SARS-CoV-2 is more transmissible via a tracheostomy tube that provides direct access to the airway and lungs. A tracheostomy tube bypasses the nasopharynx, the usual port of receptor-mediated viral entry to the respiratory tract. The survey illuminates several points regarding well-being, access to care, availability of supplies, and resource utilization relating to tracheostomy. Data from our study suggest that during COVID-19 pandemic, patients and their families and caregivers may experience certain fears and barriers more acutely than the healthcare professionals engaged in their care may recognize. These include fear of developing COVID-19, fear of being hospitalized, and fear of being denied care during the pandemic. Interestingly, while HCP do have heightened concern relating to risk of infection from aerosol-generating procedures or risk of complications from infection, their concern for individuals with tracheostomies regarding these issues remains significantly lower than the patients, families, and other caregivers [42].

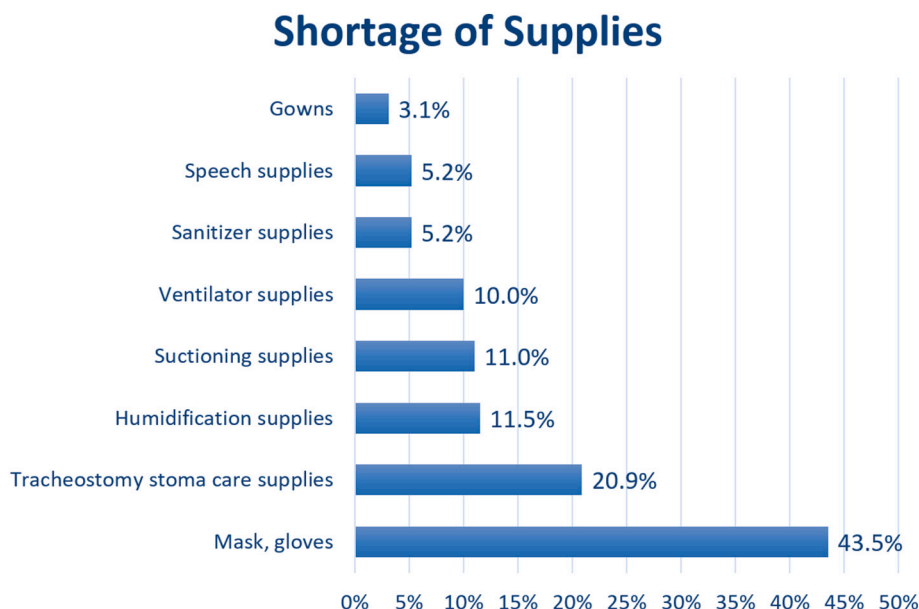


Fig. 3. Tracheostomy supply shortages during pandemic experienced by survey respondents.

Table 3

Tracheostomy healthcare services and needs during COVID-19 pandemic.

Healthcare services or need		Overall	Patient/family/ caregiver	Healthcare professional	p- Value
		Frequency (%) N = 191	Frequency (%) n = 128	Frequency (%) n = 63	
Supply shortages	Mask, gloves	83 (43.5)	52 (40.6)	31 (49.2)	0.26
	Tracheostomy care supplies	40 (20.9)	26 (20.3)	14 (22.2)	0.76
	Humidification supplies	22 (11.5)	11 (8.6)	11 (17.5)	0.07
	Suctioning supplies	21 (11.0)	9 (7.0)	12 (19.1)	0.01
	Ventilator supplies	19 (10.0)	9 (7.0)	10 (15.9)	0.06
	Sanitizer supplies	10 (5.2)	8 (6.3)	2 (3.2)	0.37
	Speech supplies	10 (5.2)	5 (3.9)	5 (7.9)	0.24
	Gowns	6 (3.1)	2 (1.6)	4 (6.4)	0.09
Suctioning needs compared to pre-pandemic	No change	165 (86.4)	108 (84.4)	57 (90.5)	0.01
	Less than usual	13 (6.8)	7 (5.5)	6 (9.5)	
	More than usual	13 (6.8)	13 (10.2)	0 (0.0)	
Attitudes toward healthcare visits and supply shortages	Willingness to go to doctor's appointment				
	Very unwilling	20 (10.5)	17 (13.3)	3 (4.8)	0.06
	Unwilling	31 (16.2)	24 (18.8)	7 (11.1)	
	Uncertain	74 (38.7)	51 (39.8)	23 (36.5)	
	Willing	43 (22.5)	23 (18.0)	20 (31.8)	
	Very willing	23 (12.0)	13 (10.2)	10 (15.9)	
	Willingness to skip a tracheostomy tube change				
	Very unwilling	37 (19.4)	28 (21.9)	9 (14.3)	0.07
	Unwilling	44 (23.0)	34 (26.6)	10 (15.9)	
	Uncertain	67 (35.1)	38 (29.7)	29 (46.0)	
	Willing	26 (13.6)	19 (14.8)	7 (11.1)	
	Very willing	17 (8.9)	9 (7.0)	8 (12.7)	
	Willingness to reuse supplies due to lack of availability				
	Very unwilling	20 (10.5)	14 (10.9)	6 (9.5)	0.10
	Unwilling	37 (19.4)	29 (22.7)	8 (12.7)	
	Uncertain	65 (34.0)	36 (28.1)	29 (46.0)	
	Willing	51 (26.7)	38 (29.7)	13 (20.6)	
	Very willing	18 (9.4)	11 (8.6)	7 (11.1)	
Additional services provided to reduce in-person appointments	Virtual appointments	87 (45.6)	59 (46.1)	28 (44.4)	0.83
	Telephone conferences	73 (38.2)	52 (40.6)	21 (33.3)	0.33
	Email	82 (42.9)	52 (40.6)	30 (47.6)	0.36
Delay in obtaining tracheostomy-related appointments	1–2 weeks	15 (7.9)	5 (3.9)	10 (15.9)	0.03
	2–4 weeks	6 (3.1)	3 (2.3)	3 (4.8)	
	1–3 months	17 (8.9)	11 (8.6)	6 (9.5)	
	4–6 months	2 (1.1)	1 (0.8)	1 (1.6)	
	7–9 months	3 (1.6)	3 (2.3)	0 (0.0)	
	Don't know	148 (77.5)	105 (82.0)	43 (68.3)	
	Services canceled				
Services canceled	Doctor's appointment	105 (55.0)	79 (61.7)	26 (41.3)	0.008
	Surgery	53 (27.8)	25 (19.5)	28 (44.4)	<0.001
	Tracheostomy tube changes	45 (23.6)	30 (23.4)	15 (23.8)	0.96
	Visit by a home nurse or RT	28 (14.7)	15 (11.7)	13 (20.6)	0.10
	Sleep study	27 (14.1)	11 (8.6)	16 (25.4)	0.002
	Blood draws at labs	20 (10.5)	15 (11.7)	5 (7.9)	0.42
	Tracheostomy decannulation	16 (8.4)	2 (1.6)	14 (22.2)	<0.001
	Wound care appointment	5 (2.6)	2 (1.6)	3 (4.8)	0.20
	Physical therapy	3 (1.6)	3 (2.3)	0 (0.0)	0.30
	Speech and/or swallow study	1 (0.5)	0 (0.0)	1 (1.6)	0.33
	Support group	43 (22.5)	32 (25.0)	11 (17.5)	0.24
	Wellness	27 (14.1)	21 (16.4)	6 (9.5)	0.20
Resources needed during the COVID pandemic	Virtual	39 (20.4)	21 (16.4)	18 (28.6)	0.05
	Phone support	44 (23.0)	30 (23.4)	14 (22.2)	0.85
	Town hall	30 (15.7)	15 (11.7)	15 (23.8)	0.03
	Discussion board	44 (23.0)	26 (20.3)	18 (28.6)	0.20

4.1. Anxiety

Even before COVID-19, patients with tracheostomy reported fear, social withdrawal, and stigma, with unease around others' reactions to presence of a tracheostomy [29]. Widespread fears relating to SARS-CoV-2 transmission by the public likely intensified feelings of powerlessness and discomfort among individuals with a tracheostomy, evident in the 93 % of respondents who reported fear or anxiety. Restoring speech has long been a priority for patients with tracheostomy [43,44], but placement of one-way valves and decannulation were often delayed during the pandemic. The vulnerability inherent in relying on others for care also may have increased anxiety, as impaired communication in this population increases anxiety, depression, and stress for both HCP

and patients [45]. Few studies have specifically explored patients and families' survivorship challenges [46] which can affect mental health, physical impairments, and cognitive impairments. Post-traumatic stress disorder is common after COVID-19 critical illness [47].

Our findings are in keeping with the literature on families and caregivers of children with a tracheostomy and home ventilation during COVID-19 pandemic [48,49]. Sources of anxiety included concern for contracting COVID and impaired communication, difficulty accessing medical care, limited nursing support, lack of supplies, and fewer opportunities for social activities and engagement. Living with a tracheostomy has always been fraught with challenges, and many stressors increased during COVID-19 pandemic. The average QOL scores for pediatric tracheostomy patients are lower than for patients with many

Healthcare Services Canceled

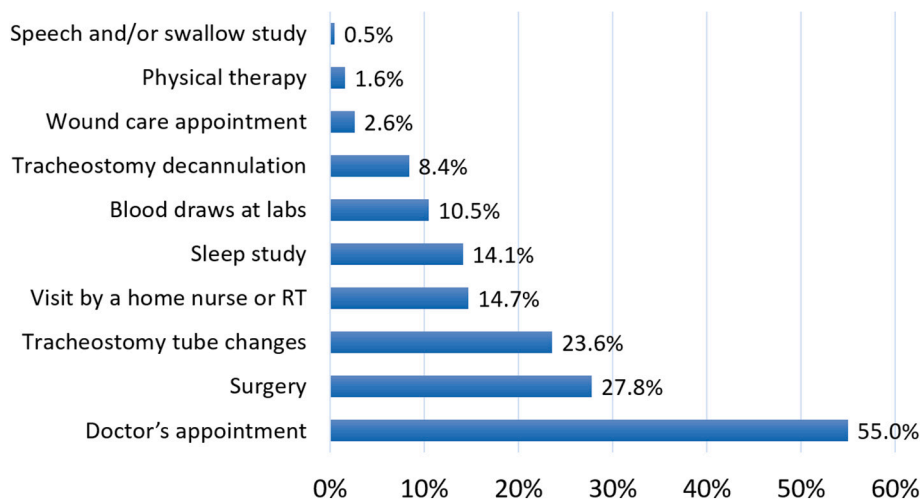


Fig. 4. Enumeration of healthcare services interrupted for study participants.

Resources Sought During COVID-19 Pandemic

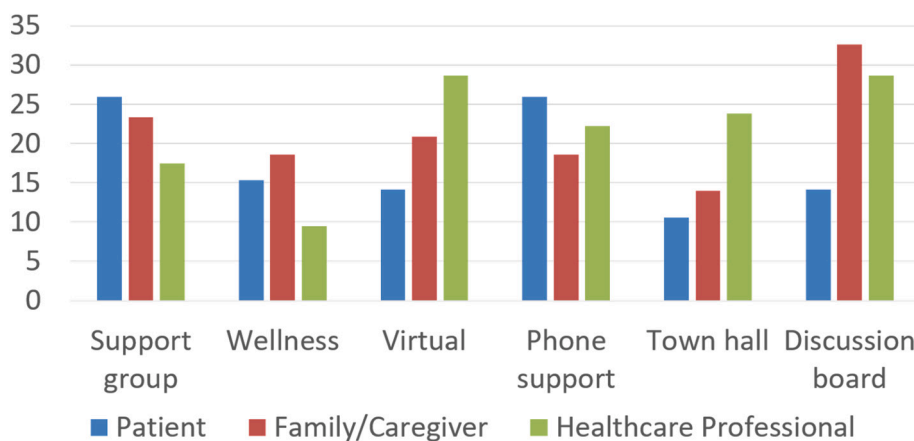


Fig. 5. Resources sought during COVID-19 pandemic by role.

other chronic illnesses [50]. QOL surveys of parents caring for children with tracheostomy find moderate distress and significant negative effects on mental health, [31] similar to caregivers of adults living with tracheostomy [29].

4.2. Communication

Speech and ability to communicate affect self-esteem [29,51], sense of control, and independence [54] for patients with a tracheostomy. During the pandemic, patients with tracheostomy reported significant communication difficulties and these previously reported results were reflected in our survey where most respondents exhibited concern about the isolation of patients with tracheostomies [53]. Wearing mask disrupts facial cues, impeding perceptions of empathy [54] and patient-caregiver communication [43,44]. Social distancing and fear of contracting COVID-19 may also interfere with communication and contribute to feelings of isolation. Physical distancing in hospitals further increases emotional isolation for patients with tracheostomy [55]. Patients with tracheostomy may also experience prejudice or be eschewed by the public due to perceived risk of SARS-CoV-2 spread via

tracheostomy. Overall, during the pandemic there were significant constraints on patient visits due to infection control protocols; additional study of how these factors affected patients and families is needed.

4.3. Access to care and supplies

Patients with tracheostomy have highly specialized needs for medical care and medical supplies and are therefore acutely aware of resource scarcity. The pandemic shortages in personal protective equipment (PPE) have been widely publicized [36,56,57], but there has been far less attention to the added complexity for patients and their families trying to procure such equipment. A prior survey of HCP, patients, and caregivers reported tracheostomy-related challenges in accessing PPE and durable medical equipment [53]. Increased supply shortages observed in our study corroborate these findings, with 50 % of respondents reporting concerns about not receiving necessary supplies. Concerningly, our data highlight that patients and families/caregivers perceive some supply needs, most significantly suctioning requirements, more acutely than HCPs. This discordance has the potential to contribute to additional administrative challenges for patients as they

advocate for supply allocations during times of scarcity.

4.4. Medical appointments and home care visits

Our survey results also highlight that most patients, families, and caregivers are reluctant to seek out in-person medical care, including necessary tracheostomy tube changes, owing to concerns about COVID-19 protocols in healthcare facilities. The care needs of this population are significant; up to 11 % of children require four or more hospitalizations in the six months after tracheostomy placement [58].

Tracheostomy-related outpatient appointments were often disrupted during the pandemic, with many respondents reporting cancellations, rescheduling, or other delays. Thus, reduced tracheostomy care during the pandemic arose from limited resources, restrictive policies, and hesitancy on the part of patients and families. Delays in care can adversely affect a patient's ability to phonate, achieve decannulation, and progress to independence. In the pandemic era, in-person, team-based care has proven less practicable; however, accelerated adoption of telehealth has enhanced opportunities for multiple providers to meet with patients.

These findings extend into the home nursing arena; previous studies have also shown that most families caring for children with tracheostomy were not satisfied with availability of nursing coverage [32]. Many patient and family respondents to our survey chose to opt-out of such care and “go it alone” without professional help to minimize risk of infection. Still, many respondents noted that home care nursing visits were canceled with frequency during the pandemic, likely secondary to staffing concerns. This shortfall has become more pressing amid burnout among HCP and shifts in staffing to accommodate services such as COVID-19 testing and vaccine administration needs. These trends will continue to impede access to care and home health resources for these patients with tracheostomy [53].

4.5. Study limitations

Our study has several limitations relating to sampling and survey methods. Although we were able to reach a global audience, we had a limited sample size, with only limited respondents from several of the 17 countries represented, with potential bias in sampling, responses, recall, or self-reporting status. Highly engaged individuals comprise the patient, family, and caregiver learning community, and their attitudes and experiences may differ the overall global community at large. In addition, the wide range of medical fields represented precludes making conclusions specific to these subcategories. To perform comparisons between HCP and the patient/family/caregiver respondent groups, we combined input from individuals with tracheostomy and both family and non-family caregivers, although our supplemental analysis splitting these groups yielded similar results. We did not stratify responses by age, chronicity, or indication for tracheostomy. Additionally, although we reviewed validated mental health and global quality of life instruments when designing this survey, we opted to maximize the breadth of insights while minimizing user fatigue. Thus, our survey instrument remains an as-yet unvalidated tool. Lastly, some HCP had a tracheostomy themselves, but numbers were too small for analysis beyond anecdotal observations. Last, the HCP who participated in this learning community and opted to take the time to complete our survey may differ in important ways from counterparts less familiar with a tracheostomy, including a commitment to tracheostomy care as evidenced by their membership in the Global Tracheostomy Collaborative (the organization through which the survey was disseminated).

4.6. Opportunities for improvement

The challenges in tracheostomy care are legion, but many opportunities exist to improve patient-centered care, including empowering patients, ensuring necessary caregiver support, addressing social factors,

and systems-based approaches (Fig. 6). Caregivers are steadfast in their commitment, averring that meeting needs of their loved ones is a moral imperative, no matter the sacrifice [59]. Evidence-based techniques that mitigate caregiver burden include providing access to relevant information; providing education that ensures mastery of equipment; cultivating a positive attitude; sharing responsibilities; and ensuring available assistance is commensurate with needs [59]. These measures collectively serve as bulwarks against the upheaval associated with the pandemic. Purposeful efforts are necessary to foster a global learning community [30], promote collaborative best practices [60], and align patient-centered care with safety across stakeholders [61].

Our study affords insights into several priority areas that can be targeted to reduce vulnerability of individuals with a tracheostomy and improve self-sufficiency in times of crisis. Ensuring adequate education on tracheostomy care, including simulation prior to hospital discharge, can improve comfort and competence. In addition, provisions for limited medical literacy should include screening and supplemental educational resources. Social determinants of health are strongly associated with health outcomes and mediate many barriers to healthcare access. Standardized collections of such data in electronic health records can facilitate assistance identification. Last, untreated anxiety degrades post-procedure quality of life [29], and proactive measures can improve well-being. Patients need ongoing support from their healthcare team to fill knowledge gaps, address new concerns, and provide specialized care. The International Classification of Functioning, Disability and Health provides a framework to evaluate person-centered care and health across the domains holistically. Finally, emerging technologies should be more fully incorporated into the lives of individuals with tracheostomies to mitigate social isolation and expand access to care and community.

Future studies are needed to understand how technology can be leveraged to improve care coordination, including virtual follow-up appointments when feasible. Proactive approaches to address supply and personnel shortages can also attenuate the effects of pandemic surges on health systems [62]. Fostering virtual networks can foster a sense of community, allowing shared learning and coping among patients and families [31]. Families of pediatric patients with tracheostomy have proven particularly adept at leveraging online forums and social media, which are likely an underutilized outlet for disseminating best practices and education [63]. Potential approaches include utilizing virtual formats that improve perceived knowledge and skills across a wide range of domains [10]. The pivot to virtual/electronic formats is evident in our survey respondents' high utilization of virtual, email, and phone appointments. Virtual education may prove particularly beneficial for addressing mental health needs, such as anxiety, fear, and depression.

5. Conclusion

People living with a tracheostomy, their families, and other caregivers have long grappled with physical, psychological, and health system-based stressors. The pandemic exacerbated these challenges due to critical shortages of supplies, limited access to care, and concerns about viral transmission. Historically, solutions to challenges in tracheostomy care have focused on implementing standardized protocols, team-based care, broad-based education, patient and family engagement, and data tracking. These tenets remain highly relevant in the pandemic era, but new challenges have additionally underscored the role of ensuring redundancy in supply chains, embracing a growing virtual footprint, and instituting safe practices for care in the community. Patients, families, caregivers, and HCPs can co-design strategies to ensure patient-centered care delivery systems. Participation in quality improvement collaboratives allows direct partnership where patient experiences can be validated, and HCP can join in actualizing collective advocacy efforts. Through authentic collaboration, diverse stakeholders can design and deliver responsive clinical services that meet needs of

Patient-Centered Tracheostomy Care

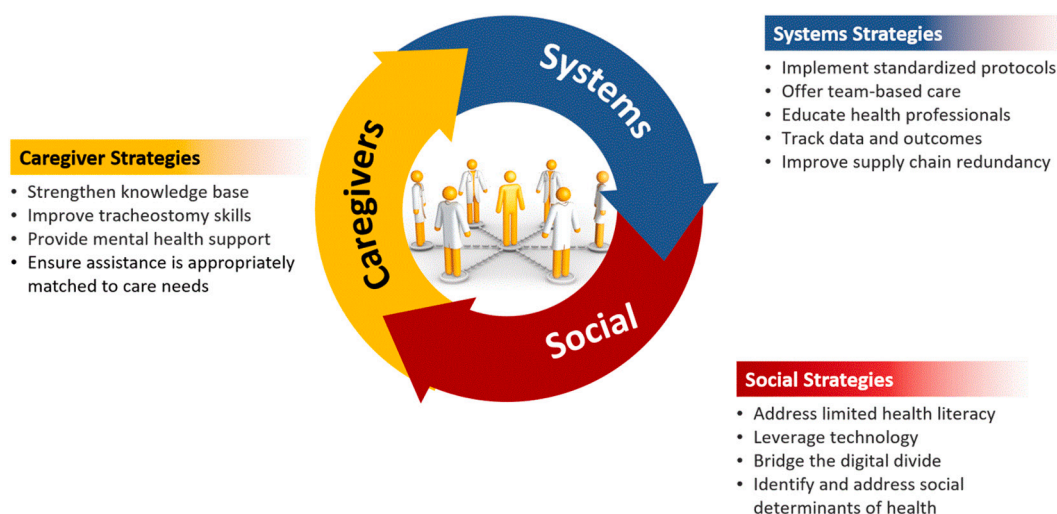


Fig. 6. Patient-centered tracheostomy care model.

this population.

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Presentations

None.

CRediT authorship contribution statement

Vinciya Pandian: Conception, drafting and analysis and interpretation of data for the work; developed tables, critically revising the work for important intellectual content; approval of the final submission; agreement to be accountable for all aspects of the work.

Brandon S. Hopkins: Drafting and analysis and interpretation of data for the work; developed tables, critically revising the work for important intellectual content; approval of the final submission; agreement to be accountable for all aspects of the work.

Christina J. Yang: Drafting, analysis and interpretation of data for the work; critically revising the work for important intellectual content; approval of the final submission; agreement to be accountable for all aspects of the work.

Erin Ward: Drafting, analysis and interpretation of data for the work; created table; critically revising the work for important intellectual content; approval of the final submission; agreement to be accountable for all aspects of the work.

Ethan D. Sperry: Analysis and interpretation of data for the work; critically revising the work for important intellectual content; approval of the final submission; agreement to be accountable for all aspects of the work.

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Prue Gregson: Analysis and interpretation of data for the work; critically revising the work for important intellectual content; approval of the final submission; agreement to be accountable for all aspects of the work.

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Amy Freeman-Sanderson: Analysis and interpretation of data for the work; critically revising the work for important intellectual content; approval of the final submission; agreement to be accountable for all aspects of the work.

Brendan A. McGrath: Analysis and interpretation of data for the work; critically revising the work for important intellectual content; approval of the final submission; agreement to be accountable for all aspects of the work.

Michael J. Brenner: Conception, design, drafting, and analysis and interpretation of data for the work; critically revising the work for important intellectual content; approval of the final submission; agreement to be accountable for all aspects of the work.

Uncited reference

[52]

Declaration of competing interest

Other authors report nothing to disclose.

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This manuscript is dedicated to the memory of Will Ward, whose passion for living life fully with a tracheostomy and advocacy for those living with a tracheostomy will always be remembered.

(Will Ward passed away during the pandemic era)

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.amjoto.2022.103525>.

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