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Psychosocial Measures and Outcomes Among Caregivers of Children With Tracheostomies: A Systematic Review

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Abstract

Objective. Children with tracheostomies have complex medical issues that require long-term technology dependence and continuous medical care at home. Parents of tracheostomy-dependent children often assume the majority of their child's home care leading to a shift in family dynamics and a decrease in caregiver quality of life. This systematic review sought to identify instruments to measure caregiver psychosocial outcomes after their child's tracheostomy and report on the findings.

Data Sources. A systematic review was performed using Medline, CINAHL, and EMBASE.

Review Methods. Studies that evaluated psychosocial outcomes in caregivers of tracheostomy-dependent children were included.

Results. We screened a total of 1286 nonduplicate records to include a total of 12 studies assessing the psychosocial outcomes of parents of tracheostomy-dependent children. Fourteen instruments were identified. Caregivers reported lower quality of life when compared to other chronic caregiver groups. They experienced high degrees of stress, struggled to cope individually and as a family unit, and experienced decision regret and conflict.

Conclusion. Findings from this review suggest a significant impact on caregiver psychosocial well-being, but few quantitative studies investigated this dynamic with measures validated in this caregiver population. This review demonstrates the need for longitudinal studies using validated tools to assess the long-term impacts and outcomes of caregivers of the tracheostomy-dependent child.

Keywords

caregiver, instrument, pediatric, psychosocial outcomes, systematic review, tracheostomy

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Every year, approximately 4000 to 5000 new pediatric tracheostomies are placed in the United States, with a growing proportion of

medically complex children who require extensive care and life-sustaining technologies such as a mechanical ventilator.¹ Family caregivers, primarily the parents, must learn advanced clinical skills to provide daily care and emergency interventions, often without a prior medical background. Many children with tracheostomies receive home nursing assistance, but the support hours vary, and parents report challenges including varied standards in care and nursing experience, cancellations, and staffing challenges.² Consequently, families must often assume all of the care resulting in many struggling to transition to the home environment.

Qualitative studies in this caregiver population report significant psychological, physical, and emotional impacts posttracheostomy.²⁻⁵ Although parents adapt to some degree, many report depression, anxiety, stress, caregiver burden, emotional frustration, and poor physical health, including significant fatigue.^{3,4} Parents also struggle with financial and social strains unique to caring for a child with a tracheostomy—they feel lonely, socially isolated, and stigmatized by family, friends, and society.^{5,6} Compared to parents of nontracheostomy-dependent children, they have impaired family functioning and lower quality of life.⁴ Parents also report centering family decisions on the needs of their child while simultaneously neglecting their own physical and emotional health.⁴

When parents are not well, their caregiving ability declines placing their children at risk for maltreatment, neglect, and increased risk for adverse outcomes.⁷ Children with disabilities and special health care needs are especially vulnerable. They are 1.8 to 3.76 times more likely to be neglected and 1.6 to 3.79 times more likely to be physically abused than children without disabilities.⁸ Over the last 20 years, ventilator-dependent children's accidental death rate remains at 27.5%.⁹ Forty-nine

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percent of these deaths are unexpected, with the primary causes being a lack of vigilance, improper response to emergencies, and inadequate training.^{9,10}

Most of the literature on caregivers of tracheostomy-dependent children explored caregiver experiences primarily through qualitative methods, with few using quantitative instruments to measure psychosocial status. Despite rich qualitative evidence on the psychosocial impacts on caregivers, very few intervention studies focused on improving outcomes in this population. Before formulating interventions, an understanding of the quantified psychosocial outcomes in this population is needed. To date, no systematic review has examined quantitative measures in this population. We aimed to identify previously used instruments and describe caregivers' psychosocial outcomes after tracheostomy.

Methods

Review Process

This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) reporting guidelines, and the protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO 2020 CRD42020220191).¹¹ In consultation with a medical librarian, a search strategy was crafted using the following concepts for the first search: tracheostomy, caregiver, caregiver burden, functional caregiving, psychosocial outcomes, stress, decision regret, and quality of life. Synonyms and controlled vocabulary for each concept were tailored to each database. We combined search results from Ovid/Medline, CINAHL, and Embase into a reference manager and removed duplicates. Studies that used quantitative or mixed methods to evaluate caregivers psychosocially were included. Qualitative studies, studies of psychosocial outcomes of medical professionals or caregivers of adults with tracheostomies, and studies in a language other than English were excluded from this review. Two authors (D.E.A. & K.G.) independently reviewed all titles and abstracts for eligibility. Full-text articles were obtained and reviewed for all potentially relevant titles and abstracts by 3 authors (D.A., J.B., & K.G.) for inclusion in the final phase of the review. All authors resolved conflicts through discussion.

Data Extraction

Data were extracted using a form piloted by the authors, and 2 people independently extracted data from each of the articles for each phase of the search. A third author resolved conflicts through review and discussion. Information collected from each of the included studies was first author, year of publication, country, study design, sample size, demographic characteristics of the caregivers, characteristics of the child with the tracheostomy, list of instruments used, languages offered in the instruments, and format in which they were offered. We included details

about the instruments, such as subscales, any description of reliability and validity testing within the sample, scoring, and constructs evaluated. We also extracted the results of the instruments.

Assessment of Study Quality

A formal quality assessment was not performed, given the intent of the review was to describe the instruments used in the studies and due to the heterogeneity of study designs, interventions, and outcomes reported.

Synthesis of Results

Results were compiled into tables and analyzed to reflect differences in designs, caregiver populations, instruments used, and constructs or domains measured. Quantitative synthesis was not conducted due to the heterogeneity of study designs, populations, and instruments.

Results

Study Selection

The PRISMA flow diagram listed in **Figure 1** shows the results for the search, selection process, and rationale for exclusion.¹² A total of 1625 records were identified from our searches of 4 databases. After deduplication, a total of 1286 records were reviewed independently by at least 2 authors for inclusion. Of those, 50 full-text articles were identified and compared against the inclusion criteria by 2 independent authors. Of these, a total of 12 records met inclusion criteria, and 2 authors independently extracted data using a form that was piloted and further refined.¹³⁻²⁴

Study Characteristics

Table 1 describes the characteristics of the studies. Our review identified 7 cross-sectional designs, 2 pre/postintervention assessments, 2 prospective longitudinal studies, and 1 mixed methods study. Caregiver sample sizes ranged from 8 participants to 154. The majority looked at outcomes specifically in caregivers of children with a tracheostomy (n = 10), with 2 studies looking at mixed populations. Of those 2 studies, 1 study included caregivers of children who had a tracheostomy or those who were decannulated, and another study included parents who either chose a tracheostomy for their child and those that decided against it.^{16,17} Six studies did not report the median or mean duration of the tracheostomy, and for those that did, they ranged from just over a year to 3 years.^{18,19}

Psychosocial Instruments

Fourteen individual instruments evaluating psychosocial outcomes were identified, and are shown in Supplemental Table 1, available online. Studies that met the inclusion criteria but did not report instrument results with corresponding *p* values were excluded from further

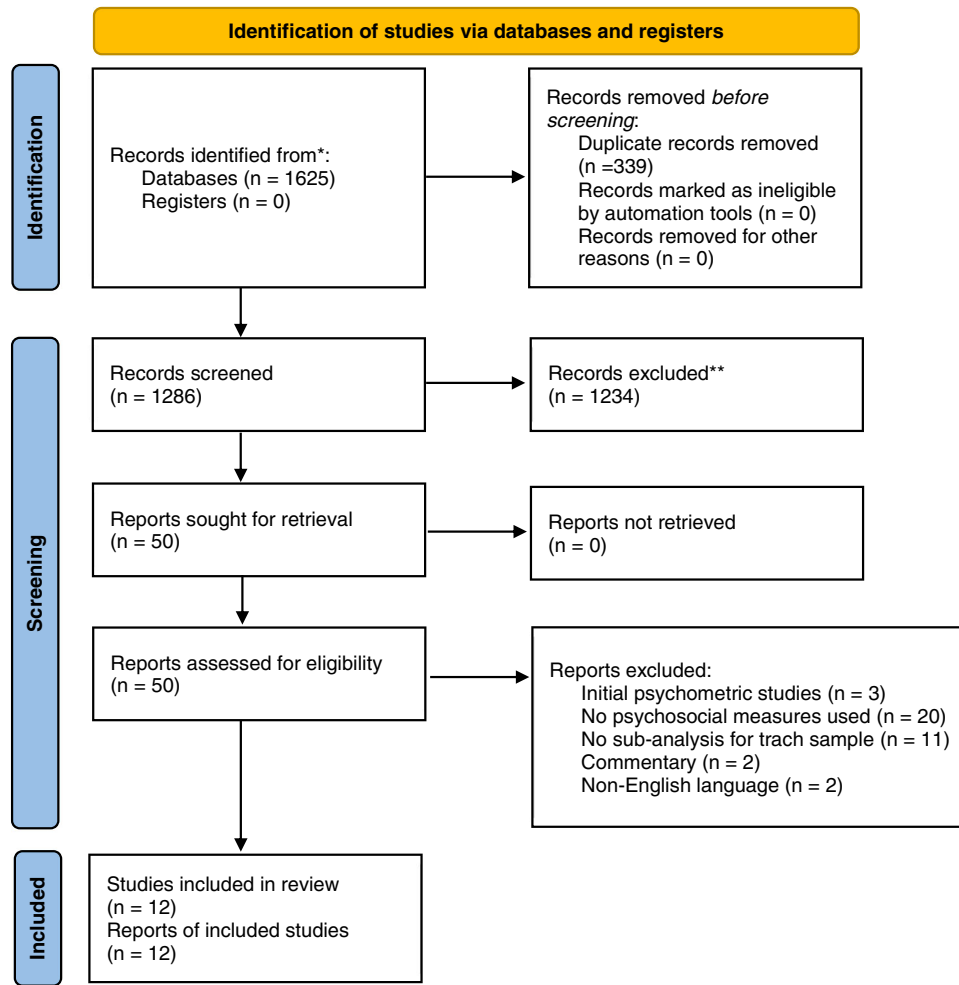


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart.

analysis. We attempted to contact the authors of the 3 excluded abstracts without success.^{12,13,15} The most used instrument was the Pediatric Tracheostomy Health Status Instrument (PTHSI) (n = 3) and the Family Crisis Oriented Personal Evaluation Scale (F-COPES) (n = 2). All the instruments were administered in the English language, and only 2 reported psychometric evaluations within their study sample.^{18,22} Major constructs explored included caregiver quality of life, caregiver burden, caregiver physical and mental health status, coping, the family impact of illness, impact on relationships and family functioning, stress, decisional conflict, and decisional regret.

Caregivers

In the studies that reported caregiver characteristics, most of the caregivers were mothers and married individuals. Of the 3 studies that reported race and ethnicity, parents identified as predominantly white (43.6%-62%).^{17,22,24} Most of the caregivers were high school graduates (53%-59%); or had some college education (38.8%-83%).^{17,18,24} Only 3 studies reported employment status, with the majority of caregivers unemployed and serving as primary caretakers for their children. Most of the children received a

tracheostomy due to respiratory failure or a respiratory condition, and the majority had other comorbidities. Only 2 studies reported on ventilator status, and of those that did, most of the children were ventilator-dependent.^{20,24} Two studies evaluated caregiver intervention using a pre-and postdesign; 1 assessed the impact of a boot camp style training program while the other evaluated the impact of a Family-Centered Care Coordination (FCCC) program.^{20,21}

Psychosocial Outcomes

Quality of Life

Six studies explored the quality of life using the Pediatric Tracheostomy Health Status Instrument (PTHSI), the Adult Caregiver Quality of Life (ACQoL), the Psychological General Well-being Index (PGWBI), and the Pediatric Quality of Life Scale (PedsQL) Family Impact Module.^{16,17,19,21-23} Of the 6, 4 were cross-sectional studies, 1 longitudinal study over a 3-month period, and 1 pre-post quality improvement report. The PTHSI was the only validated instrument in this population, and of the 4 domains, caregivers scored lowest on domain 4, assessing the rating of their own

Table 1. Characteristics of Included Studies

References	Location	Publication type	Setting	Study design	Caregiver sample size	Trach status of children	Duration of trach	Instruments
Eyuboglu et al. ¹³	Turkey	Abstract	Outpatient	Cross-sectional	45	Trach only	2.2 y (mean)	Beck Depression Scale; Maslach burnout; Rosenberg Self-Esteem and Body Perception Scale; Zarit Caregiver Burden Scale
Hartnick et al. ²³	United States	Original study	Community	Cross-sectional	154	Trach only	60% had trach placed <2 y	Pediatric Tracheostomy Health Status Index; Medical outcomes Study Short Form (SF-12)
Hartnick et al. ²¹	United States	Original study	Inpatient	Pre- and postintervention	22	Trach only	Not reported	Pediatric Tracheostomy Health Status Index
Hebert et al. ¹⁴	Not reported	Abstract	Inpatient	Prospective longitudinal	17	Trach only	Not reported	Decisional Conflict Scale (DCS); Decisional Regret Scale (DRS); Adult Caregiver Quality of Life Survey (ACQOL)
Hopkins et al. ¹⁶	United Kingdom	Original study	Inpatient	Cross-sectional	26	Mixed trach and nontrach	1-2 y (35%), 3 y (31%), >3 y (34%)	Pediatric Tracheostomy Health Status Index
Joseph et al. ²²	United States	Original study	Community	Cross-sectional	100	Trach only	18.22 mo (mean); SD = 9.59	Family Inventory of Life Events; Family Crisis Oriented Personal Evaluation Scale; Psychological General Well-Being Index
Montagnino and Maurício ¹⁸	United States	Original study	Community	Cross-sectional	18	Trach only	15 mo; range: 4-26 mo	Impact on Family Scale; Family Crisis Oriented Personal Evaluation Scale
October et al. ¹⁷	United States	Original study	Inpatient	Mixed methods	39; 28; 25	Mixed new and existing trachs	Not reported	DCS; DRS; ACQOL
Schmidt ²⁴	United States	Dissertation	Inpatient	Prospective longitudinal	12	Trach only	Not reported	Family APGAR; Feetham Family Functioning Survey; Chronicity Impact and Coping Instrument
Tanyildiz et al. ¹⁵	Turkey	Abstract	Community	Cross-sectional	8	Trachs only	Not reported	Pediatric Quality of Life Scale (PedsQL)
Van Orne et al. ²⁰	United States	Original study	Inpatient	Pre- and postintervention	34	New trachs only	Not reported	Parenting Stress Index 4th edition
Westwood et al. ¹⁹	United Kingdom	Original study	Community	Cross-sectional	25 families	Trach only	3 y (median)	Short Form (PSI-4-SF) PedsQL

caregiver burden.²³ The authors did not expand on the overall score but reported positive significant correlations between caregiver burden and parental perceptions of a child's physical health (domain 1) and economic costs to care (domain 2). In another study utilizing the PTHSI, Hopkins et al.¹⁶ found the QoL of caregivers is significantly associated with their child; however, the investigators did not report scores or expand on the domains of the PTHSI.

Other point assessments of QoL revealed that the QoL scores of caregivers of tracheostomy-dependent children were lower than those of other chronic caregiver populations. Using the PedsQL Family Impact Score, Westwood et al.¹⁹ reported deficits in the subsections of social functioning (54.9), communication (56.3), worries (49.1), and daily activities (48.9). Interestingly, caregivers generally had higher QoL scores (PedsQL Family Impact Score mean score of 63.8) than their children (PedsQL Generic Core Scales mean score of 56.2).^{16,19} Joseph et al.²² found a mean QoL score on the PGWBI of 64.07, indicating moderate distress, and was lower when compared to similar-age adults. Correlational analysis found a significant positive relationship between QoL and caregiver coping and a significant negative relationship between QoL and stress.²² On further analysis, the authors also reported that higher QoL scores were significantly associated with higher levels of coping and lower levels of stress.²² In a longitudinal study examining ACQoL and decision regret and conflict, the authors noted a decrease in ACQoL scores decreased between 2 weeks after the decision to choose tracheostomy (mean QoL score of 78.8) and 3 months after tracheostomy (mean score of 75.5); both scores indicated mid-range of QoL on the ACQoL.¹⁷

Stress

Three studies cross-sectionally evaluated stress as it relates to the impact of the child's illness on the family accounting for events related to illness, financial stress, and impact on social and personal relationships.^{18,20,22} Using the Family Inventory of Life Events and Changes (FILE) scale, Joseph et al.²² reported a mean score of 16.41 (range: 4-36; SD: 7.78), indicating lesser stress and noted that lower stress levels were significantly associated with higher QoL scores on the PWGBI. Montagnino and Mauricio¹⁸ used the Impact on Family Scale (IOFS) to measure the stress experienced by families caring for tracheostomy and gastrostomy-dependent children in the home setting, reporting a total impact score of 49.7 (range: 28-64; SD: 10.1) with higher scores in the subscales "Disruption of Social Relations" ($M = 21.2$; range: 10-28.5; SD: 5.4) and "General Negative Impact" ($M = 27$; range: 13-35; SD: 5.6).¹⁸ Higher scores indicate a greater negative impact on the family.

In the only intervention study utilizing a boot camp tracheostomy training approach consisting of 9 training sessions targeting specific tracheostomy skills, investigators

with Van Orne et al. assessed the impact on parental stress using the Parenting Stress Index (PSI-4-SF). They found significant reductions in the pre to postscores of parental distress, parent-child dysfunctional interaction, difficult child subscale scores, and total levels of stress.²⁰

Coping

Three studies evaluated coping using 2 instruments: the F-COPES, and the Chronicity Impact and Coping Instrument (CICI:PQ).^{18,22,24} Joseph et al.²² reported mean scores of 3.27 (range: 2.20-4.03; SD: 0.37) on the F-COPES indicating good coping. The authors also noted a significant positive relationship between coping and QoL ($r = .57$, $p < .01$) as measured by the PWGBI, with higher QoL scores associated with higher levels of coping. Montagnino and Mauricio¹⁸ found similar findings with the highest scores in the F-COPES subscale Mobilizing Family to Acquire and Accept Help; significant positive correlations were also found between this subscale and the IOFS subscales financial support ($r = .475$, $p < .05$), general negative impact ($r = .528$, $p < .02$), and disruption of social relations ($r = .613$, $p < .01$). The authors posit that these correlations may suggest that as the stress of caring for a child with a tracheostomy increase, caregivers in this sample coped by engaging their support systems. Schmidt²⁴ focused on the sections of self-cope and spouse cope within the CICI: PQ to understand variations in her sample of caregivers. Differences in self-copying were found between mothers and fathers at 2 and 12 weeks after discharge, with mothers scoring higher, indicating higher use of more coping strategies. Analyzed by question, there were significant differences in responses between parents for the question "Did you talk to someone?" with more mothers than fathers responding yes. There were no significant differences in responses to questions related to alcohol use, medication use, expressing or hiding feelings, exercising, and other positive and negative coping behaviors.²⁴ However, the small sample size ($n = 12$) in the Schmidt study limits findings.

Family Functioning

Two measures of family functioning were utilized by Schmidt²⁴: the Family APGAR rapidly assesses components of family function, including adaptation, partnership, and growth, and the Feetham Family Functioning Survey (FFFS) evaluates family functioning within larger systems external and internal to the family structure including economics and relationships between parents, children, and siblings. Comparing mothers and fathers, Schmidt²⁴ found greater variation in mothers' Family APGAR scores prior to discharge compared to fathers indicating more variations in mothers' perception of family functioning. However, over time the groups' scores became more similar in ranges; none of the groups were in the dysfunctional range, although some individual scores were. In the FFFS, the author reported significantly

different discrepant scores between mothers and fathers at 12 weeks after discharge; there were no significant differences in importance scores between the groups. A greater discrepancy between scores for reported activity and desired activity indicates a greater degree of dissatisfaction. Based on the findings, the author posits that compared to fathers, mothers were more dissatisfied with their situation post-discharge.

Health Status and Decision Conflict and Regret

One study measured the physical and mental health status of caregivers using the Medical Outcomes Study Short Form 12 (SF-12).²³ When compared to normative data, caregivers reported significantly lower emotional functioning.²³ Caregiver burden, as measured by the PTHSI, was significantly correlated with caregiver emotional well-being (MCS-12) ($r = 0.4$, $p = .007$), but there was no correlation between caregiver burden and caregiver physical well-being (PCS-12) ($r = -0.17$, $p = .14$). Decisional conflict and regret were explored in a longitudinal study evaluating its impact on caregiver quality of life.¹⁷ At the time of the tracheostomy decision, researchers found that most parents (89.7%) had some decisional conflict with a mean score of 19.7 (SD = 16.8), categorizing it as mild conflict. The authors outlined several contributing factors, including caregivers feeling like they had no choice, feeling uninformed, and feeling pressured, among others.¹⁷ Decisional regret was assessed at 2 weeks and 3 months posttracheostomy; at 2 weeks, 52% of parents reported mild regret, and at 3 months, more parents (72%) expressed some decisional regret with an increased mean score of 18.8 (SD: 23.2).¹⁷

Discussion

Summary of Evidence

This systematic review sought to identify instruments that measured psychosocial outcomes in caregivers of tracheostomy-dependent children and describe their findings. In this review, we identified 12 studies that used 14 instruments published from 1989 to 2020. We found only 1 instrument (PTHSI) specific to caregivers of pediatric tracheostomies. Most studies used instruments validated in other caregiver populations, and only 2 studies reported reliability estimates in their tracheostomy caregivers.^{18,22} Although there may be similarities in experience between caregivers of children with other chronic illnesses, tracheostomy-dependent children's caregivers may have unique experiences that differentiate them from other populations. Adding a tracheostomy or mechanical ventilator to an already medically complex child increases the caregiver burden compared to those caring for nontechnologically supported individuals.^{25,26} Most of the studies in this review had a mixture of ventilator dependence and complexity in their samples; exploring the relationship between psychosocial factors

and complexity may identify a higher-risk group needing more intense interventions.

To our knowledge, this is the first review to describe quantified psychosocial outcomes in this population. Findings suggest that caring for a tracheostomy-dependent child significantly impacts caregiver's quality of life, adds profound stress, and affects family structures and functioning. The heterogeneity of measures identified in this review makes it difficult to compare findings within this population; however, scores on commonly used measures such as the PedsQL and IOFS were comparable to those reported in caregivers of children with medical complexity and other chronic conditions.^{4,27-29} The total IOFS scores of carers of children with a tracheostomy and gastrostomy tube (mean 57.6) reported by Montagnino and Mauricio were higher than those reported in caregivers of children with spina bifida (mean 45), hypoxic-ischemic encephalopathy (mean 33), and the original validation population of children with multiple congenital anomalies (mean 48).^{18,30-32} However, the small sample size of the Montagnino study limits the interpretation of the findings. A revised version of the IOFS is available and has shown to be reliable in similar caregiver populations.^{33,34} Replication studies using the instruments identified in this review in larger samples are needed.

Eight constructs were identified in the studies in this review: quality of life, caregiver burden, stress, coping, family functioning, health status, decisional regret, and decisional conflict. Only 2 studies conducted a pre- and postdesign evaluation of the impact of an intervention—the rest were point assessments of psychosocial outcomes posttracheostomy.^{20,21} Constructs related to daily care and management of a tracheostomy, such as self-efficacy, confidence, and competency, were lacking. These constructs have been shown to impact stress, coping, and quality of life outcomes in adult and child-caregiver groups.³⁵⁻³⁷ The lack of measures targeting the training or learning period before the first discharge home makes it difficult to understand the impact of structured training programs on caregiver outcomes. Only 1 study assessed the result of a tracheostomy boot camp showing a significant improvement in caregiver stress pre- and postintervention.²⁰ As it was not our intent to evaluate the effectiveness of interventions, there may be studies focusing on parental education outcomes that were not included in this review. The impact of comprehensive tracheostomy training on mitigating the adverse psychosocial effects on caregivers remains unclear.

Previous studies utilized qualitative methods to understand the caregiver experience, and several of the concepts identified in these studies were not identified in this review. The qualitative literature is rich with narratives reporting a loss of authority and privacy, isolation, lack of stability, palliative care needs, decision regret and conflict, and moral dilemmas unique to a child with a tracheostomy, to name a few.³⁸ Only 1 study in this

review explored decision conflict and regret; further exploration may help guide decision-making pretracheostomy.¹⁷ Although quality of life measures provides a general overview of the state of well-being, there may be aspects of caring for a tracheostomy-dependent child not previously assessed or poorly understood but impacting caregiver quality of life.

Role conflict related to the complexity of serving multiple roles, including parent, nurse, respiratory therapist, and care coordinator, needs investigation as unique support systems may be required. A previous study examining the use of social media by tracheostomy caregivers reported the engagement of peers in finding medical equipment and other community resources, suggesting that coordination of care and resources is a significant role of caregivers that may have psychosocial impacts.³⁹ Furthermore, it is unclear if the psychosocial outcomes assessed by the measures in this review are specific to tracheostomy placement or the particular disease process of the child. Most studies reported categories of diagnoses, but the complexity and intensity of care can vary depending on the degree of medical complexity in addition to having a tracheostomy. Additionally, it is not easy to glean the true impact of the tracheostomy placement versus pre-existing psychosocial status. Most studies measured psychosocial outcomes posttracheostomy without a pretracheostomy comparison.

Two studies reported race or ethnicity,^{17,22} only 3 reported education or income.^{17,18,22} Although racial and ethnic makeups in the tracheostomy population have not been comprehensively explored, recent studies report that between 19.8% and 33% of tracheostomy, caregivers are of Hispanic ethnicity and 20.6% to 34% identify as black or African American. More diverse samples are needed to understand better the psychosocial impacts on families of different cultural and ethnic backgrounds.⁴⁰⁻⁴² Differences in quality-of-life outcomes among ethnic and racial groups, with minority caregivers reporting worse QoL scores than white caregivers, have been previously reported.⁴³ Furthermore, only 1 study explored the influence of marital status and ethnicity on QoL scores.²² Other social determinants of health as potential confounders are unexplored. All in all, more robust studies of influencing factors on diverse samples are needed to identify mediating and mitigating factors on caregiver outcomes. Validated measures in different languages are also needed to assess this unique population more broadly.

Although the majority of participants in the studies in this review identified as parents, it is widely recognized that caring for a child with a tracheostomy is a family and community effort. Negative psychosocial impacts in nonparent caregivers of chronically ill children have been noted. In a cross-sectional study comparing the QoL of siblings of children with chronic diseases compared to those who are healthy, siblings of chronically ill children reported lower QoL scores with the

lowest in siblings of children with cerebral palsy, hematologic/oncologic disease, and asthma.⁴⁴ To our knowledge, no studies have explored psychosocial impacts on nonparental caregivers or other family members of children with tracheostomies. As tracheostomy-dependent children become more complex and require extended support, more research is needed on nonparental caregivers to understand the psychosocial impact on the family as a whole. Furthermore, many children with tracheostomies are placed in foster care, or medical homes, and very few studies explored the psychosocial well-being of foster parents caring for this complex population.⁴⁵

Limitations

This systematic review has several limitations. We may have missed instruments used routinely in practice that may not have been published in academic work; we tried to include gray literature in addition to published research studies to identify these instruments. Another limitation of this review is that we only included studies published in English and may have overlooked studies published in other languages. The heterogeneity of the instruments in this review and the lack of comparison to normative data within the reports also make it difficult to compare findings.

Conclusions

Few quantitative studies have explored the psychosocial outcomes of caregivers of children with tracheostomies despite findings suggesting significant impacts on caregiver quality of life and family functioning. Our review identified several measures used for assessing psychosocial outcomes. However, only 1 was developed specifically for the pediatric tracheostomy population. More studies are needed in diverse caregiver populations using validated measures to understand the full impact of a tracheostomy on caregiver well-being. Furthermore, longitudinal studies are needed to examine the long-term impact and changes in the constructs identified in this review.

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Author Contributions

Darlene E. Acorda, design, data acquisition, analysis and interpretation, drafting, critical revision, final approval, agreement to be accountable; **Jennifer N. Brown**, design, data acquisition and interpretation, drafting, critical revision, final approval, agreement to be accountable; **Elton M. Lambert**, drafting, critical revision, final approval, agreement to be accountable; **Karen DiValerio Gibbs**, design, data acquisition and interpretation, drafting, critical revision, final approval, agreement to be accountable.

Disclosures

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Supplemental Material

Additional supporting information is available in the online version of the article.

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