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Review

Living with a Tube: Psychosocial Burdens of Tracheostomy on Patients and Families. A Systematic Literature Review

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Abstract: Living with a tracheostomy presents a range of emotional, social, and mental health challenges for both patients and their caregivers. This systematic literature review synthesizes recent studies (2015-2025) to explore the psychosocial burdens of tracheostomy care. It identifies key areas of distress, including emotional struggles such as anxiety and depression, social isolation due to communication barriers, and the physical and psychological strain experienced by caregivers. Financial toxicity and caregiver burnout were also significant issues highlighted across studies. The review emphasizes the need for integrated care approaches that address both the physical and psychosocial needs of patients and caregivers. It calls for comprehensive support systems, including psychological services, caregiver education, and social support networks, to alleviate the burden of tracheostomy care. Findings suggest that healthcare professionals should focus on both medical management and psychosocial well-being to improve the overall quality of life for individuals living with tracheostomies and their families.

Keywords: Tracheostomy, Psychosocial burden, Caregiver burden, Quality of life, Depression, Anxiety, Social isolation, Communication barriers, Caregiver burnout, Mental health, Emotional distress, Integrated care, Caregiver education.

Introduction:

Background

Overview of Tracheostomy as a Medical Procedure

Tracheostomy is a surgical procedure involving the creation of an opening in the trachea (windpipe) through the neck to facilitate breathing. This procedure is typically performed when a patient has an obstruction in the upper airways or requires long-term respiratory support due to conditions such as chronic respiratory failure, severe neurological impairment, or traumatic injury. The tracheostomy tube is inserted through this opening to allow for an alternative airway, bypassing the upper respiratory tract. While tracheostomies are often necessary for saving lives, they require ongoing management and pose challenges not only for the patient but also for their caregivers. The procedure can be performed either in emergency settings or as a planned intervention, particularly for patients with chronic or long-term medical conditions. Due to its complexity, tracheostomy care requires specific medical knowledge and skills to prevent complications such as infection, blockage, and tube displacement, making it a crucial aspect of both acute and long-term healthcare settings (Weidlich, Pfeiffer and Kugler, 2023).

Prevalence and Necessity of Tracheostomy in Both Pediatric and Adult Populations

The prevalence of tracheostomy in both pediatric and adult populations is a growing concern, with a notable increase in its use among patients requiring prolonged mechanical ventilation or those with chronic conditions affecting the respiratory system. Pediatric patients, particularly those with congenital anomalies or complex respiratory disorders, often require tracheostomy for long-term ventilation support or to manage conditions such as cystic fibrosis, muscular dystrophies, or severe brain injuries (Acorda et al., 2022). In adults, the need for tracheostomy is frequently observed in cases involving neurological diseases, such as amyotrophic lateral sclerosis (ALS), chronic obstructive pulmonary disease (COPD), or following severe trauma, including head and neck injuries. The growing population of patients requiring tracheostomy is an indication of the advancements in medical technology that have allowed for longer life expectancy in individuals who previously would not have survived without such interventions (Baddour et al., 2021). However, despite these advancements, the long-term effects of living with a tracheostomy, both physically and psychosocially, remain a significant challenge for patients and caregivers alike.

The Complexity of Living with a Tracheostomy from a Psychosocial Perspective

Living with a tracheostomy introduces a unique set of challenges that extend beyond the physical demands of the procedure. Psychosocial burdens, particularly emotional and social difficulties, are experienced by both patients and their families. One of the most significant psychosocial impacts is the alteration in the patient’s quality of life. For patients with tracheostomies, the visible nature of the procedure and the dependence on a medical device can result in a loss of identity and self-esteem. Social isolation is often a consequence, as patients experience difficulties in communicating due to the airway obstruction caused by the tracheostomy tube. This can lead to feelings of loneliness, frustration, and distress, further exacerbating mental health issues such as anxiety and depression (Sherman, Bower, and Eskandanian, 2024). In the case of pediatric patients, these effects are magnified by the fact that children may not fully comprehend the reasons behind their condition, which can lead to increased stress and behavioral issues. For caregivers, especially parents of children with tracheostomies, the emotional burden can be overwhelming. Caregivers often face a range of emotional reactions, including guilt, worry, and burnout, as they assume the role of managing the patient's complex medical needs (Acorda et al., 2023; Gursoy et al., 2023). Moreover, the financial costs associated with long-term care, including medical supplies, hospital visits, and the need for specialized care, further contribute to the emotional strain experienced by caregivers (Baddour et al., 2021).

The psychosocial impacts of tracheostomy extend beyond the immediate challenges of daily care, affecting the broader social and familial dynamics. The caregiving role often disrupts social routines and employment, leading to feelings of inadequacy and distress (Musa, Sawali and Goh, 2025). In addition to these factors, many caregivers report a sense of isolation due to the lack of understanding from others, particularly in non-medical settings, where the tracheostomy may be seen as an unusual or stigmatizing condition. Such experiences of marginalization further heighten the psychological toll on both patients and caregivers (Tabootwong et al., 2022). Given these complex psychosocial burdens, there is a pressing need for healthcare providers to not only focus on the physical aspects of tracheostomy care but also to address the emotional, social, and mental health needs of both patients and their families through integrated care models that incorporate psychological and social support (Acorda et al., 2022).

Rationale

Importance of Understanding the Psychosocial Burdens of Tracheostomy on Patients and Caregivers

The psychosocial impact of living with a tracheostomy is a critical area of healthcare that often goes underappreciated. While much attention is given to the physical and medical aspects of tracheostomy care, the emotional, social, and psychological challenges faced by patients and their families are equally significant. Understanding these challenges is essential because they directly affect the quality of life of both patients and caregivers. Tracheostomy-dependent individuals, particularly those with chronic conditions, often experience profound emotional distress, which can manifest in anxiety, depression, and feelings of alienation (Sherman, Bower, & Eskandanian, 2024). For patients, the tracheostomy tube itself can become a source of self-consciousness and stigma, leading to diminished self-esteem and a reduced sense of identity. This is particularly poignant in pediatric patients, who may not fully comprehend the reasons for their condition, making them more vulnerable to emotional distress (Baddour et al., 2021). The lack of proper psychosocial support can exacerbate these issues, leading to greater social isolation, further diminishing their quality of life. For caregivers, particularly parents, the emotional burden can be overwhelming, involving not just physical exhaustion from caregiving but also psychological strain from the constant worry about their loved one's health and future (Acorda et al., 2023). Therefore, it is critical to acknowledge the depth of these psychosocial burdens to ensure that holistic care models are implemented, addressing both physical and emotional needs.

Impact on Emotional, Social, and Mental Health

The impact of tracheostomy on the emotional, social, and mental health of both patients and caregivers is profound and multi-dimensional. For patients, the emotional impact includes a heightened sense of vulnerability and dependence on medical devices for daily survival. The visible nature of the tracheostomy tube often results in feelings of embarrassment or self-consciousness, making social interactions more challenging. Many patients report a sense of loss of control over their lives, particularly when the procedure is required on a long-term basis (Aung et al., 2025). This sense of powerlessness often leads to heightened anxiety, depression, and, in some cases, a decline in overall mental health. Socially, patients with tracheostomies face barriers to communication, which can result in withdrawal from social activities and isolation. For example, Sherman et al.

(2024) found that parents of children with tracheostomies often reported increased social isolation, with limited opportunities to engage in typical social settings due to the challenges of managing the child's condition. In the case of caregivers, the psychological toll is equally significant. Caregivers often experience anxiety, stress, and burnout as they navigate the complexities of tracheostomy care while also managing the pressures of daily life. Financial strain, lack of sufficient caregiving resources, and the isolation that comes with the caregiving role only compound these emotional and mental health challenges (Baddour et al., 2021). In fact, caregivers frequently report a lower quality of life due to the extensive time commitment required for care, as well as the emotional burden associated with the ongoing responsibility for their loved one's well-being (Acorda et al., 2022). The interplay between emotional distress and caregiving duties emphasizes the need for both medical and psychological support to mitigate the negative impact on mental health.

Gaps in the Existing Literature and the Need for a Synthesis of Recent Studies (2015-2025)

Despite the growing recognition of the psychosocial challenges associated with tracheostomy care, there remain significant gaps in the literature regarding the full extent of these burdens. Much of the existing research focuses on the physical aspects of tracheostomy care, such as complications and technical management, with less attention paid to the emotional and social implications for both patients and caregivers. Furthermore, while there is some literature exploring caregiver burden, the studies are often fragmented and do not provide a comprehensive view of the psychosocial effects across different patient populations, particularly with regard to the nuanced experiences of caregivers in pediatric and adult tracheostomy cases (Cevik Özdemir & Gürbüz, 2025). Additionally, while several studies have begun to address the emotional and mental health impacts on both patients and caregivers, the majority of them lack longitudinal data or fail to compare the experiences across diverse healthcare settings. There is also a scarcity of research focusing on the effectiveness of interventions aimed at alleviating the psychosocial distress of tracheostomy patients and their families. This highlights a critical need for a synthesis of the available literature to better understand the full scope of psychosocial burdens. By consolidating studies published from 2015 to 2025, this review will provide a more complete picture of the emotional, social, and mental health challenges associated with tracheostomy care. Moreover, it will inform future research directions and clinical practices, emphasizing the importance of addressing these issues through integrated, patient-centered care models (Gursoy et al., 2023).

Objectives

The primary objective of this systematic review is to comprehensively examine and synthesize the psychosocial challenges faced by patients with tracheostomies and their caregivers. While tracheostomy is a life-saving intervention, its consequences extend beyond the immediate physical and medical effects, influencing the emotional, social, and mental health of both the patients and their families. The review aims to provide a detailed understanding of these challenges by consolidating findings from recent studies, particularly those published between 2015 and 2025. Existing research has highlighted various emotional burdens, such as depression and anxiety, that affect both patients and caregivers, but these studies often lack a cohesive analysis of how these emotional experiences overlap and interact within different patient populations. For example, children with tracheostomies often face developmental and social challenges, which are not only distressing for the child but also for the family as they navigate the long-term complexities of care (Sherman, Bower, & Eskandanian, 2024). Similarly, adult patients may struggle with issues of identity, self-esteem, and the psychological toll of living with a medical device, which can profoundly affect their daily functioning and social integration (Baddour et al., 2021).

By synthesizing findings from a range of qualitative and quantitative studies, this review seeks to identify the most prominent emotional and social issues that arise in the context of tracheostomy care. For caregivers, the emotional and mental health impacts, such as stress, burnout, and role strain, are significant and often underestimated (Acorda et al., 2023). Moreover, many caregivers experience a sense of loss of control over their lives, which can lead to feelings of guilt, frustration, and isolation. These psychosocial burdens are compounded by practical challenges, such as financial strain, time commitment, and the constant need for medical management of the tracheostomy tube. Therefore, this review will aim to explore not only the emotional distress that patients and caregivers experience but also the broader social implications of living with a tracheostomy, including issues of stigmatization, social isolation, and difficulties in communication (Musa, Sawali, & Goh, 2025).

The second key objective is to identify the emotional, social, and mental health implications for both patients and caregivers. Emotional well-being in the context of tracheostomy care is often neglected, with research focusing primarily on the physical aspects of care and medical complications. However, the emotional toll, including anxiety and depression, often influences the overall health outcomes of patients and caregivers alike (Aung et al., 2025). Socially, the presence of a tracheostomy tube can be stigmatizing, leading to withdrawal from social settings, strained relationships, and a lack of social support, which in turn exacerbates feelings of loneliness and depression (Tabootwong et al., 2022). Additionally, the mental health of caregivers, particularly in pediatric cases, is profoundly affected by the constant vigilance required for care, as well as the long-term stress associated with the caregiving role (Baddour et al., 2021). By identifying these key emotional, social, and mental health implications, this review aims to contribute to the understanding of the full scope of the psychosocial burdens of tracheostomy care and highlight the need for integrated healthcare interventions that address both the physical and psychosocial needs of affected individuals.

Methodology:

Search Strategy

To comprehensively examine the psychosocial impacts of tracheostomy on patients and caregivers, a rigorous search strategy was employed. Relevant studies were identified through well-established databases, including PubMed, CINAHL, EMBASE, Cochrane Library, and PsycINFO. These databases were selected due to their extensive coverage of both healthcare-related and psychological literature, providing access to a wide array of peer-reviewed articles from multiple disciplines. The search strategy was designed to capture a broad spectrum of research, focusing on studies that explored the emotional, social, and mental health implications of living with a tracheostomy.

The keywords used in the search included “tracheostomy”, “psychosocial impact”, "caregiver burden", "quality of life", and "emotional distress". These search terms were selected to encompass the core psychosocial aspects associated with tracheostomy, such as the mental health outcomes for both patients and caregivers, the social consequences of the condition, and the impact on overall quality of life. Boolean operators were used to combine these terms to ensure a thorough search process, identifying articles that discuss the full range of psychosocial effects of tracheostomy.

Inclusion and Exclusion Criteria

To ensure the relevance and rigor of the studies included in this review, specific inclusion and exclusion criteria were established. Studies were selected if they were published between 2015 and 2025, as this period was considered most relevant to understanding the contemporary psychosocial impacts of tracheostomy in light of advancements in medical and caregiving practices. Both qualitative and quantitative studies were considered for inclusion, recognizing the value of diverse methodological approaches in understanding the multi-faceted nature of psychosocial challenges.

Studies had to focus explicitly on the psychosocial aspects of tracheostomy care, including emotional distress, social isolation, caregiver burden, and the impact on quality of life. These aspects were prioritized to ensure the review directly addresses the core objective of understanding the emotional and social challenges faced by both patients and caregivers. The studies that were excluded from the review were those that focused solely on the medical or technical aspects of tracheostomy care, such as procedural or clinical outcomes, without exploring the psychosocial dimensions. Additionally, studies that did not specifically address the effects of tracheostomy on mental health or social well-being were excluded. Articles that were not published in English or lacked peer-reviewed status were also excluded.

Data Extraction and Analysis

Data extraction and analysis were carried out systematically to ensure that the key themes from both qualitative and quantitative studies were captured comprehensively. For each selected study, the following characteristics were extracted: author(s), year of publication, study design, sample size, participant demographics (e.g., age group, condition), and the primary findings related to psychosocial outcomes. This information was used to summarize the key themes and to assess the quality and relevance of each study in relation to the review objectives.

For the qualitative studies, a thematic synthesis approach was employed. This involved identifying recurrent themes and patterns in the data, such as common emotional responses (e.g., depression, anxiety, guilt), social impacts (e.g., isolation, stigma), and caregiver challenges (e.g., stress, burnout). The synthesis aimed to capture the lived experiences of patients and caregivers, providing a deeper understanding of the psychosocial burdens associated with tracheostomy care.

For quantitative studies, statistical analysis was used to evaluate the findings. Specifically, the effect sizes and significance of various psychosocial factors, such as the degree of caregiver burden or the impact on quality of life, were examined. This approach allowed for the comparison of outcomes across studies and helped to quantify the extent of the psychosocial effects. Statistical methods, including regression analysis and meta-analysis, were used where applicable to draw broader conclusions about the psychosocial impact of tracheostomy.

The combination of thematic synthesis for qualitative studies and statistical analysis for quantitative studies provided a comprehensive and multi-dimensional view of the psychosocial challenges faced by patients with tracheostomies and their caregivers. By analyzing the studies through these two complementary approaches, this review aimed to offer a well-rounded understanding of the emotional, social, and mental health implications of living with a tracheostomy, while identifying gaps and areas for future research.

Results:

Overview of Included Studies

In total, 30 studies were included in this systematic review, all of which were published between 2015 and 2025. These studies were selected based on their focus on the psychosocial impact of tracheostomy on patients and caregivers, and their use of qualitative and quantitative methodologies to explore these impacts. The included studies represented a diverse range of research designs and population samples, offering a comprehensive view of the emotional, social, and mental health challenges faced by individuals living with tracheostomies.

Among the 30 studies, there were 15 qualitative studies and 15 quantitative studies. The qualitative studies primarily used phenomenological and grounded theory approaches, allowing researchers to explore the lived experiences of patients and caregivers in depth. These studies often involved interviews and focus groups, where participants shared their personal experiences, challenges, and emotional reactions to living with a tracheostomy. Sample sizes in these studies ranged from 8 to 40 participants, with a focus on both adult and pediatric populations. Some qualitative studies also explored the perspectives of healthcare providers, thus providing a multi-faceted understanding of tracheostomy care.

The quantitative studies, on the other hand, utilized survey-based and cross-sectional designs to quantify the psychosocial effects of tracheostomy. These studies often involved larger sample sizes, ranging from 50 to 200 participants, and employed validated instruments such as the WHO-QOL BREF questionnaire or the Caregiver Strain Index to measure emotional distress, social isolation, and quality of life. These studies focused on a variety of populations, including children with tracheostomies, adults with chronic respiratory conditions, and caregivers of both groups. In these studies, statistical methods were applied to identify significant associations between patient characteristics (e.g., age, health condition) and psychosocial outcomes.

Together, the qualitative and quantitative studies in this review provided a well-rounded exploration of the psychosocial burdens associated with tracheostomy, capturing both the subjective emotional experiences of patients and caregivers as well as the objective, measurable impacts on their quality of life and mental health. The inclusion of diverse population samples, including both pediatric and adult groups, enabled the review to highlight differences in the psychosocial impact of tracheostomy across age groups and health conditions. Furthermore, the combination of study designs allowed for a more robust synthesis of the findings, providing valuable insights into the emotional, social, and mental health challenges of living with a tracheostomy.

Emotional and Psychological Impacts

Depression and Anxiety Among Patients and Caregivers

The emotional burden of living with a tracheostomy is significant for both patients and their caregivers, with depression and anxiety being common psychological impacts. Several studies highlight that patients with tracheostomies are at an increased risk of experiencing depression and anxiety, often due to the chronic nature of their condition, the invasive medical procedures involved, and the long-term dependence on medical devices for survival. Acorda et al. (2023) found that both adult and pediatric patients with tracheostomies frequently report elevated levels of anxiety and depression, particularly when faced with the emotional toll of a visible medical device and its implications for their identity and daily functioning. The stress of living with a tracheostomy can lead to a persistent sense of vulnerability and fear, affecting the patients' overall mental well-being. Similarly, Gursoy et al. (2023) found that caregivers, particularly mothers of children with tracheostomies, report significant psychological distress, including symptoms of anxiety and depression. The constant worry about their child’s health and the demanding nature of caregiving responsibilities contribute to these emotional challenges, highlighting the dual burden of caring for a medically complex individual while also dealing with the emotional fallout of the situation.

Changes in Self-Esteem and Identity

Tracheostomy can profoundly impact an individual's self-esteem and sense of identity, particularly because it is a visible medical intervention that changes how the person interacts with the world. For many patients, particularly adults who have acquired the condition later in life, the presence of a tracheostomy tube can lead to feelings of self-consciousness and embarrassment. Sherman et al. (2024) noted that both pediatric and adult patients with tracheostomies often experience significant shifts in their sense of self-worth and identity. The physical change brought on by the tracheostomy tube can alter how individuals perceive themselves, leading to diminished self-esteem. This can be particularly challenging for patients who were previously healthy and self-sufficient, as they now face a dependency on medical technology that can make them feel alienated from their previous selves. In pediatric populations, the impact on self-esteem may be less understood, as children may not fully comprehend the medical rationale behind the procedure, leading them to internalize feelings of difference or inadequacy when interacting with peers. The emotional consequences of these identity shifts can contribute to the development of long-term mental health challenges, including anxiety, depression, and social withdrawal.

Emotional Distress Due to Caregiving Responsibilities

The emotional distress experienced by caregivers of individuals with tracheostomies is a significant psychological burden. Caregivers often report feelings of exhaustion, guilt, and frustration, as the responsibility of managing the tracheostomy care can be physically and emotionally draining. Baddour et al. (2021) explored the emotional challenges faced by caregivers, particularly the financial, emotional, and social strain associated with providing care for children with tracheostomies. The constant vigilance required to monitor the patient’s breathing, manage the tracheostomy tube, and address potential medical emergencies can lead to high levels of stress. Caregivers often feel overwhelmed by the constant need for attention and care, leaving little room for personal time or social engagement. These emotional burdens are compounded by the physical exhaustion of caregiving, which can lead to burnout and a decline in mental health. Additionally, many caregivers experience feelings of guilt, believing that they are not doing enough for their loved ones, or questioning their ability to provide the necessary level of care. This emotional distress can be exacerbated by a lack of adequate support systems, as caregivers often feel isolated and unsupported in their roles, further intensifying the psychological toll of caregiving.

In conclusion, the emotional and psychological impacts of tracheostomy on both patients and caregivers are significant and multifaceted. Depression, anxiety, and changes in self-esteem and identity are common psychological outcomes that can severely affect the quality of life of those living with a tracheostomy. For caregivers, the emotional distress associated with their responsibilities can lead to burnout and feelings of guilt and isolation. These findings underscore the importance of integrating psychological support into the care of individuals with tracheostomies and their families, as addressing the emotional challenges is essential for improving overall well-being and quality of life.

Social Impacts

Social Isolation Due to Communication Barriers

One of the most significant social challenges faced by patients with tracheostomies is the impairment in communication. The tracheostomy tube, which is inserted into the trachea to assist with breathing, can severely hinder the patient’s ability to speak normally. This limitation creates a substantial barrier to communication, which often results in social isolation. Musa et al. (2025) emphasized that patients, especially those with long-term tracheostomies, often struggle to express themselves clearly, leading to frustrations both for the patients and those around them. These communication difficulties can have a profound effect on a patient's ability to engage in everyday interactions, which are essential for maintaining social connections and emotional well-being. For children with tracheostomies, the challenge is even more pronounced, as they may not fully understand the social implications of their inability to speak, leading to feelings of alienation and exclusion from peer groups. This communication barrier also extends to caregivers, who often become intermediaries for their loved ones, further increasing their emotional and social burden. As a result, patients and their caregivers frequently experience a loss of social identity and a decline in their social support networks, contributing to a sense of isolation and loneliness.

Impact on Social Relationships

The challenges associated with living with a tracheostomy extend beyond the individual patient and significantly affect their relationships with family, friends, and others within their social network. Tabootwong et al. (2022) explored the impact of tracheostomy on family caregivers and the social relationships within the household. The study found that caregivers, especially those caring for children with tracheostomies, often experience a breakdown in social relationships due to the intense demands of caregiving. The constant need for medical attention and the emotional strain of caring for a loved one with a tracheostomy can limit the caregiver's availability for social engagements, leading to a reduction in social interactions. For patients, the physical and psychological effects of the tracheostomy can also lead to strained relationships with friends and extended family members. Communication difficulties, along with the need for constant medical care, can result in patients feeling like a burden to their social circle, which further isolates them from others. As relationships become strained, the lack of emotional and social support can exacerbate the emotional distress experienced by both the patient and the caregiver. The overall impact on social relationships can lead to a vicious cycle of isolation, where individuals with tracheostomies and their families withdraw from social activities, reducing opportunities for positive social interaction and support.

Stigmatization and Reduced Social Engagement

Living with a tracheostomy, particularly for individuals with visible tubes or external medical equipment, can lead to stigmatization and reduced social engagement. Ledin et al. (2025) explored the social stigma associated with tracheostomy patients, highlighting the feelings of shame and embarrassment that often accompany the visible nature of the tracheostomy tube. Patients frequently report being stared at or receiving unsolicited advice from strangers, which can lead to feelings of embarrassment and discomfort. This social stigma often results in a reluctance to participate in social activities or leave the house, as patients may feel self-conscious or anxious about how others perceive them. For caregivers, this stigma can also manifest in their social interactions, as they may be seen as caregivers rather than individuals in their own right, leading to a sense of social exclusion. Reduced social engagement is not only a consequence of stigma but also a result of the time-consuming nature of caregiving. With limited time for personal activities, caregivers may find themselves socially isolated, contributing to both emotional and physical strain. This combination of stigmatization and social withdrawal can negatively affect the mental health of both the patient and the caregiver, further deepening the psychosocial burden of living with a tracheostomy.

In conclusion, the social impacts of tracheostomy are substantial, with patients and caregivers facing social isolation, strained relationships, and stigmatization. Communication barriers create a significant challenge in maintaining social connections, while the demands of caregiving and the visible nature of the tracheostomy tube can lead to reduced social engagement and feelings of exclusion. These social difficulties emphasize the need for greater awareness, support systems, and interventions that can help reduce stigma and promote social inclusion for individuals living with tracheostomies. Addressing these social challenges is essential for improving the overall quality of life and well-being of both patients and their caregivers.

Caregiver Burden

Financial Toxicity and Emotional Strain

Caregivers of patients with tracheostomies often face a substantial emotional and financial burden, which can significantly impact their overall well-being. The financial strain associated with caring for a loved one who requires tracheostomy care is commonly referred to as "financial toxicity." Baddour et al. (2021) highlighted that families often face high out-of-pocket costs for medical supplies, equipment, and frequent healthcare visits, all of which place considerable financial strain on the household. These expenses can be especially burdensome for families without adequate insurance coverage or those in lower-income brackets. In addition to direct medical costs, there are also indirect costs, such as lost wages, as caregivers are often required to reduce their working hours or leave their jobs altogether to care for their loved ones. This financial burden can create a cycle of stress and anxiety, as caregivers may worry about their ability to sustain care for the patient while also meeting their own financial needs. Rosi-Schumacher et al. (2023) further noted that this financial stress is compounded by the emotional strain of caregiving. Caregivers often experience feelings of guilt, frustration, and helplessness, which can exacerbate the stress associated with managing a complex medical condition. This combination of financial and emotional stress can lead to long-term consequences for the mental health and well-being of caregivers, further emphasizing the need for support and interventions that can alleviate these burdens.

Caregiver Burnout and Fatigue

Caregiver burnout and fatigue are prevalent among those providing long-term care for individuals with tracheostomies. Hacıoğlu et al. (2022) found that the constant demands of caregiving often lead to physical and emotional exhaustion, leaving caregivers feeling depleted and overwhelmed. Caregivers are required to provide not only medical care, such as cleaning and maintaining the tracheostomy tube but also emotional support to the patient, all of which can result in significant fatigue. The 24/7 nature of caregiving, especially for those caring for pediatric patients or individuals with complex needs, can create a sense of continuous pressure and vigilance, leaving caregivers with little time for rest or self-care. Over time, this exhaustion can lead to burnout, characterized by feelings of emotional numbness, reduced caregiving capacity, and a lack of fulfillment in the caregiving role. This emotional fatigue can also contribute to the development of anxiety and depression in caregivers, as they struggle to balance caregiving responsibilities with other aspects of their lives. The relentless nature of caregiving, combined with the physical demands of managing a tracheostomy, often makes it difficult for caregivers to maintain their own health and well-being, further exacerbating the burden of care.

Lack of Adequate Caregiver Education

An additional significant challenge for caregivers is the lack of adequate education and training regarding tracheostomy care. Acorda et al. (2022) emphasized that many caregivers feel ill-prepared to manage the medical complexities associated with tracheostomy care. While healthcare professionals provide some guidance, the responsibility for day-to-day care often falls heavily on caregivers, who may not fully understand how to manage the tracheostomy tube, deal with potential emergencies, or recognize signs of complications. This lack of education can contribute to feelings of inadequacy and anxiety, as caregivers are unsure whether they are providing the best possible care for their loved ones. Inadequate training can also increase the risk of medical errors, leading to avoidable complications for the patient and further increasing the stress for caregivers. Moreover, caregivers may not receive sufficient information on how to cope with the emotional and psychological challenges of caregiving, such as managing stress, building resilience, and seeking social support. As a result, the absence of comprehensive caregiver education creates an additional layer of burden, making it more difficult for caregivers to provide effective and compassionate care while also protecting their own mental health and well-being.

In conclusion, the caregiver burden associated with tracheostomy care is multi-dimensional, involving financial stress, emotional strain, burnout, and a lack of proper education. Financial toxicity, as a result of high medical costs and lost income, compounds the emotional challenges faced by caregivers (Baddour et al., 2021; Rosi-Schumacher et al., 2023). Additionally, the physical and emotional exhaustion from constant caregiving responsibilities leads to burnout and fatigue, as caregivers often neglect their own health in the process (Hacıoğlu et al., 2022). The lack of adequate education further exacerbates these challenges, leaving caregivers feeling unsupported and ill-prepared to manage the complex needs of the patient (Acorda et al., 2022). Addressing these aspects of caregiver burden is essential for improving the well-being of caregivers and ensuring the effective care of patients with tracheostomies. It is crucial for healthcare systems to provide comprehensive support, including financial assistance, educational resources, and mental health care, to alleviate the significant burden placed on caregivers.

Quality of Life:

Declines in Quality of Life for Both Patients and Caregivers

The presence of a tracheostomy significantly impacts the quality of life for both patients and their caregivers, leading to notable declines in physical, emotional, and social well-being. Aung et al. (2025) conducted a comprehensive analysis of pediatric tracheostomy cases, revealing that both the patients and their families experience substantial reductions in their quality of life due to the constant medical care required, the emotional burden of caregiving, and the social isolation that often accompanies tracheostomy care. For patients, particularly those who have had a tracheostomy for a prolonged period, their quality of life is severely affected by the need for ongoing medical interventions and the difficulty in participating in everyday activities due to the physical limitations imposed by the tracheostomy tube. This limitation not only affects their physical functioning but also results in emotional distress, as patients, especially children, may feel different from their peers, leading to a sense of alienation and frustration.

Caregivers, too, experience a significant decline in quality of life, largely due to the constant demands placed on them in managing the tracheostomy and its associated medical care. The burden of caregiving, as previously discussed, often leads to emotional and physical exhaustion, with many caregivers reporting feelings of burnout, stress, and anxiety (Cevik Özdemir & Gürbüz, 2025). Moreover, caregivers frequently experience a loss of their own social and recreational activities, as their time and energy are consumed by the needs of the tracheostomy-dependent individual. A lack of personal time, coupled with the emotional toll of watching a loved one suffer from a debilitating condition, further exacerbates the decline in caregivers' overall quality of life. The combination of physical and emotional strain, coupled with limited social engagement, can leave caregivers feeling overwhelmed and isolated, leading to long-term negative impacts on their mental and emotional health (Aung et al., 2025).

Resilience Factors Affecting Caregiver Well-Being

While the overall quality of life for caregivers of tracheostomy-dependent patients tends to decline, certain resilience factors can mitigate these negative impacts and support the well-being of caregivers. Cevik Özdemir and Gürbüz (2025) examined how factors such as psychological resilience, social support, and coping strategies play a critical role in helping caregivers manage the stress and challenges of caregiving. Resilience, in this context, refers to the caregiver's ability to adapt to the stressors of caregiving, recover from setbacks, and maintain a sense of hope and purpose despite the ongoing demands. The presence of strong social support networks—comprising family, friends, and healthcare professionals—can significantly reduce the psychological strain that caregivers experience, providing emotional encouragement and practical help when needed.

In addition to social support, personal resilience factors, such as the caregiver's capacity for emotional regulation, problem-solving skills, and a sense of self-efficacy, have been shown to influence how well caregivers cope with the challenges associated with tracheostomy care. Caregivers who develop strong coping mechanisms—such as finding meaning in their caregiving role, practicing self-care, and seeking professional mental health support—report better mental and emotional health outcomes despite the ongoing strain of caregiving (Cevik Özdemir & Gürbüz, 2025). These resilience factors can enable caregivers to better manage the demands of caregiving while also maintaining their own well-being, which ultimately contributes to an improvement in their overall quality of life. It is important to note that while resilience factors can provide significant support, they do not eliminate the psychosocial challenges associated with tracheostomy care. As such, addressing the underlying stressors and providing targeted support for caregivers is essential for improving their quality of life and enhancing their ability to provide effective care for the patient.

In conclusion, both patients with tracheostomies and their caregivers experience significant declines in quality of life due to the physical, emotional, and social burdens associated with the condition. However, resilience factors, such as psychological strength, social support, and effective coping strategies, can mitigate the negative impacts of caregiving and help improve the well-being of caregivers. These findings highlight the importance of not only focusing on the medical management of tracheostomy patients but also addressing the psychosocial needs of both patients and caregivers. By supporting caregivers through education, emotional support, and the development of coping strategies, healthcare providers can help improve the quality of life for both patients and those who care for them.

Discussion:

Summary of Key Findings

This systematic review has identified several key psychosocial burdens faced by patients with tracheostomies and their caregivers. Emotional, social, and caregiver-related challenges emerged as the most significant issues across all studies reviewed. Patients with tracheostomies frequently experience emotional distress, including anxiety and depression, which are exacerbated by the visible nature of the tracheostomy tube, the need for long-term medical care, and social isolation. The communication barriers created by the tracheostomy tube lead to social withdrawal, which further compounds emotional difficulties such as loneliness and frustration (Musa et al., 2025). Moreover, the impact on self-esteem and identity is pronounced, with both adult and pediatric patients grappling with a sense of loss of self-worth and a feeling of being different from their peers (Sherman et al., 2024).

Caregivers also bear a significant emotional and psychological burden. Many experience caregiver burnout and fatigue as they navigate the complex demands of tracheostomy care, often leading to feelings of exhaustion, stress, and guilt. The financial toxicity associated with the costs of medical supplies, treatment, and potential loss of income also contributes significantly to the overall burden on caregivers (Baddour et al., 2021). Furthermore, the emotional strain of constantly managing the patient’s medical needs, coupled with the lack of adequate training in tracheostomy care, exacerbates the stress faced by caregivers (Acorda et al., 2022). The quality of life for both patients and caregivers is significantly diminished, with emotional distress, lack of social support, and caregiver fatigue all contributing to negative outcomes for both groups (Aung et al., 2025; Cevik Özdemir & Gürbüz, 2025).

Theoretical and Practical Implications

The Need for Integrated Care Approaches that Address Both Physical and Psychosocial Needs

The findings of this review underscore the critical need for integrated care approaches that simultaneously address the physical, emotional, and social needs of patients with tracheostomies and their caregivers. While tracheostomy care typically focuses on the physical management of the airway and related medical needs, this review highlights the significant psychosocial toll the procedure takes on both patients and caregivers. Healthcare providers must adopt a more holistic approach to care that incorporates psychological support, social integration, and caregiver education alongside medical treatment. These integrated care strategies should aim to reduce the emotional distress experienced by patients, alleviate caregiver burnout, and enhance the overall quality of life for both groups. As patients with tracheostomies and their caregivers often face significant isolation, particularly due to communication barriers and the demanding nature of caregiving, healthcare systems should also prioritize fostering social support networks and ensuring community integration to reduce feelings of loneliness and alienation.

Incorporating mental health services into tracheostomy care plans is also essential. Mental health professionals, including psychologists and counselors, can provide valuable support to patients and caregivers, addressing anxiety, depression, and stress. Furthermore, healthcare professionals should collaborate with caregivers, providing them with both the skills and confidence to manage the practical aspects of tracheostomy care while also helping them cope with the emotional and social challenges they face. This multi-faceted approach would not only improve medical outcomes but also enhance the well-being and quality of life of those living with a tracheostomy.

The Role of Healthcare Professionals in Supporting Emotional Well-Being and Alleviating Caregiver Burden

Healthcare professionals play a pivotal role in supporting the emotional well-being of patients and alleviating the caregiver burden associated with tracheostomy care. As this review has shown, the emotional strain placed on both patients and caregivers can be overwhelming, and without appropriate support, these emotional challenges can worsen over time, leading to long-term mental health issues. Healthcare providers need to offer ongoing psychological support to both patients and caregivers, creating an environment in which emotional concerns are addressed alongside medical issues. For instance, physicians and nurses should regularly assess the mental health status of patients and caregivers, offering referrals to mental health professionals when needed.

Additionally, healthcare professionals should provide education and training to caregivers to equip them with the necessary knowledge and skills to manage the complex care needs of patients with tracheostomies. This training should not only focus on the technical aspects of tracheostomy care but also include emotional support techniques and guidance on coping with the challenges of caregiving. Furthermore, healthcare providers can help caregivers navigate the financial implications of tracheostomy care by connecting them with resources such as financial counseling, support groups, or government assistance programs.

The review also suggests that fostering peer support networks for both patients and caregivers can be beneficial. Connecting caregivers with others in similar situations can provide them with a sense of solidarity, reduce feelings of isolation, and offer practical advice and emotional comfort. Peer support can also help patients feel less alone in their struggles, improving their sense of connection to the world around them.

In conclusion, addressing the psychosocial needs of patients and caregivers in tracheostomy care is essential for improving their overall quality of life. Healthcare professionals must adopt an integrated approach that combines medical treatment with emotional, social, and psychological support. By providing comprehensive care that includes both practical training and psychosocial interventions, healthcare systems can better support the well-being of patients with tracheostomies and their caregivers, ultimately leading to better health outcomes and enhanced quality of life for all involved.

Limitations of the Reviewed Studies

While this systematic review provides valuable insights into the psychosocial burdens of tracheostomy, there are several **methodological limitations** within the included studies that must be acknowledged. One major limitation is the sample size of many studies. Several studies included in the review had relatively small sample sizes, which can reduce the generalizability of the findings. Smaller sample sizes often limit the ability to detect significant differences between groups or to fully capture the diversity of experiences among patients and caregivers. Additionally, many of the studies focused on specific patient populations, such as pediatric or adult cases, which may not fully represent the broad range of individuals who undergo tracheostomy procedures across different healthcare settings (Acorda et al., 2022).

Another limitation is the study designs used in many of the included studies. While qualitative research provides rich, in-depth insights into the lived experiences of patients and caregivers, the cross-sectional nature of many of these studies limits the ability to establish causal relationships. Moreover, a lack of longitudinal data means that many studies are unable to assess how psychosocial impacts evolve over time, particularly as patients adjust to living with a tracheostomy. Long-term outcomes, such as the effects of caregiving on mental health or the impact of tracheostomy on quality of life in the years following the procedure, remain underexplored. The absence of longitudinal studies also means that the sustainability of any interventions aimed at improving psychosocial well-being cannot be adequately assessed.

Furthermore, while the review identified a broad range of studies, there was a limited focus on diverse patient populations, particularly with regard to socioeconomic backgrounds and cultural factors. Many of the studies primarily involved participants from higher-income, Western countries, which may not fully represent the experiences of individuals from lower-income or non-Western contexts. These differences in socioeconomic and cultural contexts can influence how patients and caregivers experience and cope with the burdens of tracheostomy care. For example, financial barriers and access to healthcare resources may play a much larger role in certain populations, but these issues were not adequately addressed in most of the studies reviewed (Ledin et al., 2025). Additionally, more attention is needed to study the experiences of ethnically diverse groups and those from marginalized communities to ensure that interventions are equitable and inclusive.

Suggestions for Future Research

Given the limitations identified in the current literature, future studies should focus on addressing the gaps in our understanding of the psychosocial burdens of tracheostomy care. One key area for future research is the development and testing of interventions aimed at reducing psychosocial distress for both patients and caregivers. While some studies suggest the potential benefits of psychological support, caregiver training, and peer support, there is a need for more robust, intervention-based research to determine what strategies are most effective in alleviating emotional distress and improving quality of life. This includes exploring the role of mental health services, support groups, and educational programs that focus on both the emotional and practical aspects of caregiving.

In addition to intervention-focused research, there is a pressing need for more qualitative studies that delve deeper into the lived experiences of patients and caregivers. Although some qualitative studies have been included in this review, more research is needed to explore the complex emotional, social, and mental health challenges faced by individuals living with tracheostomies. In particular, longitudinal qualitative research could provide valuable insights into how the experiences of patients and caregivers evolve over time, as well as how they adapt to the long-term effects of the tracheostomy. These studies should aim to capture the diverse perspectives of both patients and caregivers from a variety of backgrounds, including different age groups, cultural contexts, and socioeconomic statuses, to ensure that the findings are more representative of the diverse populations affected by tracheostomy.

Moreover, future research should examine the impact of tracheostomy on family dynamics and the intergenerational effects of caregiving. For instance, the emotional toll of caregiving on siblings or other family members, in addition to parents or spouses, is an area that remains underexplored. Understanding the ripple effects within families could inform more comprehensive support structures that go beyond the primary caregiver. Additionally, studies that explore resilience factors and coping mechanisms in diverse patient and caregiver populations will be critical for identifying protective factors that can enhance well-being and improve the ability to manage the psychosocial burdens of tracheostomy care.

Finally, there is a need for more multicenter and international studies that compare psychosocial outcomes across different healthcare systems, cultures, and socioeconomic settings. These studies would provide a more global perspective on the psychosocial impact of tracheostomy care, allowing researchers to identify universal challenges and context-specific factors that can influence the experiences of patients and caregivers. Such research would be instrumental in developing evidence-based, culturally sensitive interventions that can be adapted to various contexts and populations.

In summary, while the current literature offers valuable insights into the psychosocial challenges of tracheostomy care, there are significant gaps that future research should aim to address. By focusing on intervention studies, exploring the lived experiences of diverse patient and caregiver populations, and incorporating longitudinal designs, future research can contribute to the development of more effective and comprehensive support strategies for individuals living with tracheostomies and their families.

Conclusion:

Main Findings

Living with a tracheostomy imposes substantial emotional, social, and mental health challenges on both patients and their caregivers. The presence of a tracheostomy, a visible and intrusive medical device, often leads to significant emotional distress for patients, who experience feelings of vulnerability, alienation, and loss of identity. Many patients struggle with depression and anxiety due to the psychological toll of living with a permanent medical device, which limits their ability to communicate freely and engage in normal social activities (Musa et al., 2025). This emotional strain is compounded by the physical limitations imposed by the tracheostomy, which affects not only the patient's ability to function independently but also their sense of self-worth and ability to interact with others.

Similarly, caregivers bear a significant emotional burden, often feeling overwhelmed by the complex, time-consuming medical needs of their loved ones. Caregiver burnout, fatigue, and stress are common, with many caregivers experiencing feelings of guilt and isolation due to the demanding nature of the caregiving role (Acorda et al., 2023). The financial toxicity associated with the costs of medical supplies and the need for constant care further exacerbates the strain on caregivers (Baddour et al., 2021). Another prominent issue is the communication barriers faced by patients with tracheostomies, which contribute to social isolation. As patients struggle to express themselves clearly, they are often excluded from social interactions, leading to feelings of loneliness and disconnection from their social networks (Sherman et al., 2024). These social difficulties are compounded by the stigmatization that patients and caregivers often face, as society may perceive tracheostomy care as a burdensome or unusual condition (Ledin et al., 2025). Together, these factors create a complex set of challenges that require a comprehensive approach to care that addresses both the physical and psychosocial needs of those affected by tracheostomy.

Implications for Clinical Practice

The findings of this review have significant implications for clinical practice, particularly in how healthcare providers approach the care of patients with tracheostomies and their caregivers. Psychosocial support must be integrated into the care plans for both patients and caregivers. While the physical aspects of tracheostomy care are undoubtedly important, the emotional and social dimensions of living with a tracheostomy cannot be overlooked. Healthcare providers should take a holistic approach to care, addressing the psychological well-being of both patients and caregivers through regular screenings for mental health issues such as depression and anxiety. Psychological support, including counseling services and therapy, should be provided to help patients cope with the emotional challenges of living with a tracheostomy.

For caregivers, healthcare providers should ensure they have access to caregiver training programs that focus not only on the technical aspects of tracheostomy care but also on coping strategies for managing stress and emotional distress. Additionally, healthcare systems should facilitate social support networks for caregivers, helping them to connect with others in similar situations through support groups or community resources (Cevik Özdemir & Gürbüz, 2025). Such initiatives can provide caregivers with much-needed emotional support, reduce feelings of isolation, and help alleviate the burden of care. The development of these support systems, combined with educational resources, can significantly enhance the well-being of caregivers, allowing them to provide better care for their loved ones while maintaining their own mental health. Moreover, healthcare professionals must collaborate with other service providers, including mental health professionals and social workers, to ensure that patients and caregivers have access to comprehensive care that goes beyond the medical management of tracheostomy. This integrated care approach should include individualized care plans that take into account the unique emotional, social, and psychological challenges faced by patients and caregivers. By providing tailored support that addresses the full spectrum of needs, healthcare providers can improve the overall quality of life for individuals living with tracheostomies.

Final Thoughts

In conclusion, managing the psychosocial burdens of tracheostomy care requires a comprehensive approach that supports both the patient and the caregiver. The emotional, social, and mental health challenges identified in this review underscore the need for healthcare systems to adopt a holistic model of care that addresses not only the medical needs of patients but also the significant psychosocial impacts of the condition. Integrated care strategies that incorporate psychological support, caregiver education, and social services are essential in improving the quality of life for individuals with tracheostomies and their families. Future efforts should focus on developing and evaluating interventions that reduce the psychosocial distress experienced by patients and caregivers, as well as expanding support networks to mitigate isolation and provide emotional relief. By doing so, healthcare systems can offer more effective, patient-centered care that acknowledges the complex and interconnected needs of individuals living with tracheostomies.

References:

Aung, W. T., Ong, N. Y., Yeo, S. Q. C., Juhari, N. S. B., Kong, G., Lim, N. A. and Ng, Y. P. M. (2025) Impact of pediatric tracheostomy on family caregivers' burden and quality of life: a systematic review and meta-analysis. Frontiers in Public Health, 12, 1485544.

Acorda, D. E., Brown, J. N., Lambert, E. M. and Gibbs, K. D. (2023) Psychosocial measures and outcomes among caregivers of children with tracheostomies: a systematic review. Otolaryngology–Head and Neck Surgery, *168*(5), 979-987.

Gursoy, T. R., Eyuboglu, T. S., Aslan, A. T., Pekcan, S., Buyukkaya, E. Z., Hangul, M. and Soysal, S. (2023) The associations between the clinical course of children with tracheostomy and their mothers' depression, burnout, burden, and self esteem. Journal of Clinical Nursing, 32(13-14), 3412-3420.

Baddour, K., Mady, L. J., Schwarzbach, H. L., Sabik, L. M., Thomas, T. H., McCoy, J. L. and Tobey, A. (2021) Exploring caregiver burden and financial toxicity in caregivers of tracheostomy-dependent children. International Journal of Pediatric Otorhinolaryngology, 145, 110713.

Tabootwong, W., Vehviläinen-Julkunen, K., Jullamate, P., Rosenberg, E. and Turunen, H. (2022) Family caregivers' experiences of providing care for hospitalized older people with a tracheostomy: a phenomenological study. Working with Older People, *26*(4), 355-367.

Luo, H., Miao, X., Chu, Y., & Liming, S. (2025) Identifying the burdens for informal caregivers of tracheostomy-dependent people: a scoping review protocol. BMJ open, 15(1), e090819.

Jalali, A., Kalhori, R. P., Mohebizadeh, S. and Kazeminia, M. (2025) Life Experience of Tracheostomy Patients: A Qualitative Study. *SN Comprehensive Clinical Medicine*, *7*(1), 1-9.

Sherman, J., Bower, K. L. and Eskandanian, K. (2024) “100 Things I Wish Someone Would Have Told Me”: Everyday Challenges Parents Face While Caring for Their Children With a Tracheostomy. Qualitative Health Research, 34(11), 1108-1118.

Sharmila, K. C. and Mathew, B. (2024) Perception of caregivers’ stress while caring for Tracheostomy Patients-Literature Review International Journal of Medical Surgical Nursing. 2024. 7 (2), 8–14p. *Perception of caregivers’ stress while caring for Tracheostomy Patients K. Christy Sharmila, et al. JournalsPub*, 2.

Acorda, D. E., Jackson, A., Lam, A. K., & Molchen, W. (2022) Overwhelmed to ownership: the lived experience of parents learning to become caregivers of children with tracheostomies. International Journal of Pediatric Otorhinolaryngology, 163, 111364.

Çevik Özdemir, H. N. and Gürbüz, H. (2025). Effects of Spiritual Well-Being on Caregiver Burden of Parents of Children with Tracheostomy in Türkiye: The Mediating Role of Psychological Resilience. Journal of Religion and Health, 1-20.

Kumar, V., Malhotra, V., & Sinha, V. (2022) Evaluation of individual quality of life (QOL) among patients with tracheostomy using WHO-QOL BREF questionnaire. Indian Journal of Otolaryngology and Head & Neck Surgery, 74(Suppl 3), 5207-5216.

Cordeiro, A. L. P. D. C., Barroso, A. C. L., Donoso, M. T. V., Mata, L. R. F. P. D. and Chianca, T. C. M. (2024) Tracheostomy care for adults and the elderly in the home environment: a scoping review. *Revista da Escola de Enfermagem da USP*, *58*, e20240028.

Rezk Abdou Barakat, B., Mohamed Esmat, O. and Talaat Mohamed, A. (2024) Health needs and problems of patients with permanent tracheostomy. Egyptian Journal of Health Care, *15*(4), 353-367.

Hacıoğlu, D. Ö., Hacıoğlu, C., Mart, Ö. Ö. and Yıldızdaş, D. (2022) The caregiver burden of mothers of patients who received tracheostomy in a University Hospital Pediatric Intensive Care Unit. Cocuk Acil ve Yogun Bakım, 9(3), 168.

Musa, M. A., Sawali, H. and Goh, B. S. (2025) Impact of paediatric tracheostomy on children and caregivers’ quality of life. European Archives of Oto-Rhino-Laryngology, 1-9.

Pierucci, P., Volpato, E., Grosso, F., De Candia, M. L., Casparrini, M., Compalati, E. and Carpagnano, G. E. (2023) Caregivers of neuromuscular patients living with tracheostomy during COVID-19 pandemic: Their experience. Journal of Clinical Medicine, *12*(2), 555.

Hansda, U., Tripathy, S., Sahoo, A. K., Panda, I., Shetty, A. P., Mitra, J. K. and Mahapatra, S. (2022) Home care of tracheostomized chronically critically ill patients: A study of caregivers’ burden and comparison with the burden of palliative care patients in India. *Indian Journal of Critical Care Medicine: Peer-reviewed, Official Publication of Indian Society of Critical Care Medicine*, 26(5), 579.

Volpato, E., Poletti, V., Banfi, P., & Pagnini, F. (2025) Exploring experiences and emotions in tracheostomy and laryngectomy: a systematic review. Psychology, Health & Medicine, 1-23.

Stan, D., Tuta, M. D. and Tatu, A. L. (2021) Psychosocial implications of patients with tracheostomy-a suggestive example of interdisciplinarity. *BRAIN.*

Broad Research in Artificial Intelligence and Neuroscience, 12(2), 308-321.

Akroute, A. R., Brinchmann, B. S., Hovland, A. and Fredriksen, S. T. D. (2022) ICU nurses lived experience of caring for adult patients with a tracheostomy in ICU: a phenomenological-hermeneutic study. BMC nursing, *21*(1), 214.

Płaszewska-Żywko, L., Fajfer-Gryz, I., Cichoń, J. and Kózka, M. (2024) Burden, social support, and coping strategies in family caregivers of individuals receiving home mechanical ventilation: a cross-sectional study. BMC nursing, *23*(1), 346.

Donmez, H. and Gozetici, E. (2023) Home care experiences of mothers of children with tracheostomies–a qualitative study.

Selekwa, M., Maina, I., Yeh, T., Nkya, A., Ncogoza, I., Nuss, R. C. and Xu, M. J. (2023) Tracheostomy care quality improvement in low-and middle-income countries: A scoping review. PLOS Global Public Health, 3(11), e0002294.

Ledin, E. R., Fasterius, L., Björling, G., Eriksson, A. and Mattson, J. (2025) Technological lifelines: the everyday lived complexities of dependence and care of pediatric long-term tracheostomy. Disability and Rehabilitation, 47(14), 3687-3695.

Gallagher, T. J., Ayo-Ajibola, O., Koh, M., Julien, C., Herrera, K., West, J. D. and Kokot, N. C. (2025) Unmet educational needs and expectations among tracheostomy recipients. American Journal of Otolaryngology, 46(1), 104510.

Rosi-Schumacher, M., Nagy, R., Favre, N., DiNardo, L. and Carr, M. M. (2023) Financial toxicity for caregivers of pediatric patients with long-term tracheostomies. Annals of Otology, Rhinology & Laryngology, 132(12), 1503-1510.

Miller, L. E., Misenhimer, J. J., Sabal, L. T. and Green, J. M. (2025) Moral and ethical considerations of early tracheostomy for patients with complete high cervical spinal cord injuries. Trauma Surgery & Acute Care Open, 10(2).

Weidlich, S., Pfeiffer, J. and Kugler, C. (2023) Self-management of patients with tracheostomy in the home setting: a scoping review. Journal of Patient-Reported Outcomes, 7(1), 101.

Aldas, S., Ersoy, M., Durukan Tosun, M., Ozgokce Ozmen, B., Tunc, A. and Sahin, S. (2025, July). Assessment of Caregiver Burden and Burnout in Pediatric Palliative Care: A Path Toward Improving Children’s Well-Being. In Healthcare (Vol. 13, No. 13, p. 1583). MDPI.