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Transitions in tracheostomy care: from childhood to adulthood

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Abstract

Purpose of review: The purpose of this review is to explore the evidence around children and young people who require a tracheostomy and transition into adult services, reflecting on the challenges and considerations for clinical practice as these needs increase.

Recent findings: There are a lack of data on the incidence and prevalence of children and young people with a tracheostomy transitioning to adult services for ongoing care. There are significant variations in care needs, technology and previous experiences that demand more than a simple handover process. Examples of service models that support the transition of care exist, however these lack specificity for children and young people with a tracheostomy.

Summary: Further exploration of the needs of children and young people requiring airway technology is indicated, particularly considering the short and long-term education, health, and social care needs.

Keywords: tracheostomy, transition, paediatric, airway, children and young people

Introduction

A tracheostomy is a medical device made of polyvinyl chloride (PVC) or silicone that, in the paediatric population, is typically inserted as part of a planned, surgical procedure to maintain a patent airway and effective ventilation [1]. A tracheostomy can be placed anytime from birth as an EXIT (ex-utero intrapartum treatment) procedure [2] and across the age continuum to safeguard the airway and respiratory system.

In high income countries, recent advances in healthcare, technology, and clinical expertise have increased survivability of many paediatric conditions that were previously life-limiting through compromised respiratory function. This has resulted in lower thresholds for paediatric tracheostomy insertion as a long-term solution for life maintenance. In low- or middle-income countries, the on-going challenges of managing complex airways in the paediatric population are acknowledged, although detailed data are limited [3-4**].

Indications for short-term tracheostomy placement in children and young people (CYP) due to chronic airway obstruction secondary to infections, are infrequent due to mass immunisation programmes [5**]. Current indications for tracheostomy in children and young people reflect the advances in managing respiratory conditions, particularly associated with prematurity resulting in long-term ventilation, and identification of congenital upper airway obstruction in utero or early infancy [6, 7*]. Additionally, advancing pharmacological and clinical expertise have enabled survival from significant acquired conditions such as brain injury and trauma [8].

Placement of a tracheostomy, particularly for paediatric populations is associated with significant mortality and morbidity risks, although it is debated whether this relates to factors of the underlying diagnoses [9*], as management of the device (tracheostomy) remains a significant risk factor for mortality [5**, 10, 11*].

Whilst clinically, mortality has decreased in CYP with a range of underlying conditions (Table 1), morbidity and complexity have increased with greater survival and need for lifelong care. This requires an effective transition into adult services [9*, 12], with collaboration between adult and paediatric colleagues to understand the context of lifelong paediatric conditions, whether acquired, developmental or degenerative.

Table 1: Paediatric conditions associated with requiring long-term tracheostomy

Developmental, psychological, and social context

The presence and management of a tracheostomy is likely to be embedded into the life and daily schedule of CYP, with all the considerations of childhood development, inclusion, and identity [13] needed by the time they transition into adult services. Additionally, with reportedly increasing prevalence of such technology needs in CYP, the impact on healthcare systems [14], including transition, is highlighted.

Issues at the point of transition have been highlighted in this population, along with similar populations such as CYP with neurodisabilities [15**]. Psychosocial issues for the child are emphasised as they may grapple with identity and difference in social and education

environments that focus on the piece of equipment (tracheostomy) or underlying disease, rather than the skills and strengths of the young person [16*].

Acknowledging the individual beyond technology is essential in supporting a safe and successful transition into adulthood, and therefore navigating adult services [17*].

In order to understand the long-term tracheostomy needs of CYP it is important to understand the evidence around removal of the tracheostomy (decannulation) as a clinical goal and how this affects transition to adult services.

Decannulation

Decannulation rates in the paediatric population range have been variably cited in the literature from 28-52% [11*] to 31 - 75% [18*] although long term data is lacking. The Global Tracheostomy Collaborative (GTC) has reported on a number of initiatives to improve tracheostomy care, including highlighting the importance of multidisciplinary clinics, applicable to the adult as much as paediatric populations [4**]. Their review of paediatric and adult data from 62 institutions across six countries showed the paediatric population had an increase in duration of tracheostomy placement (median 16 vs. 36 days) and reduced decannulation rate (4% vs. 52%). A recent longitudinal study in a single centre in the United Kingdom (UK) identified a 44.4% decannulation rate in 172 children over an eight year period and a mortality rate of 22.1% [19]. They report a median duration of 397 days with a tracheostomy. Another single site review over 11 years reported a 39% decannulation in 105 children with a median tracheostomy duration of 408 days [11*]. Compared to the adult population, where tracheostomy placement is typically short term [4**] and maintained in the acute setting, for example, due to an acquired impairment, the

goal will be decannulation after weaning from ventilation. However, CYP with a tracheostomy may require an artificial airway for a longer term and into adulthood [15**]. Success, or lack thereof, of decannulation can determine the need for long-term placement of tracheostomy. Whilst there have been significant advances in airway surgical techniques and improving outcomes, decannulation failure remains an issue due to the high frequency of airway abnormalities seen in children with tracheostomy [20**] particularly for populations with persistent lower airway impairments such as malacia or stenosis [21] so careful airway evaluation is needed before decannulation. Additionally, failure of decannulation is also particularly prevalent in at-risk populations, for example Trisomy 21 [22], those of poor socioeconomic backgrounds [23], and where failure to thrive and neurological issues exist [9*, 11*] again suggesting the need for long-term tracheostomy.

Preparing for transition

In paediatric populations, the burden of care is acknowledged and the need for resilience highlighted [24*, 25*]. In the United Kingdom and indeed in other high-income countries, typically, CYP with a tracheostomy are supported by paediatric teams across primary, secondary, and tertiary healthcare settings, including but not limited to acute Ear, Nose, and Throat (ENT) teams, acute and community paediatricians, Allied Healthcare Professionals (AHP) in health and education, and children's community nursing teams. However, as CYP transition into adult care, there remains a risk of abandonment [26] and isolation [27] with a lack of coordinated services as no equivalent of a paediatrician exists, an *'adultrician'* if you will, in adult services until geriatric services become appropriate. In contrast, there are services that lack paediatric specialists, such as in spinal cord injury, leaving them to be managed by adult services who may not have the skills to support behavioural and social

needs [28]. It is acknowledged that whilst some services exist that support continuing care and prepare for transition, for example in established Long-Term Ventilation teams, this is primarily for a population requiring on-going invasive or non-invasive ventilation [29]. Understanding of the extent of service access needs for all CYP with technology needs is lacking, particularly those not requiring ventilation.

Navigating different technologies

There may be a number of variations in the technology or tasks used with the paediatric tracheostomy population so healthcare staff in adult settings need to be aware of what is acceptable and routine practice. Typically, single lumen tracheostomy tubes are utilised until the child or young person has more adult-like upper airway anatomy, and transitions to a double lumen tube as used in adults. Cuffed tracheostomy tubes used in the adult population may have a different method of cuff management, for example air filled, compared to paediatric cuffed tubes that may be water, air, or less typically, foam filled. In the paediatric population the long-term use of water filled cuffed tracheostomy is not recommended due to risk of tracheal wall damage and difficulties managing cuff pressures [30].

Familiar and regular tasks may be differently approached or expedited in the adult setting, for example, sizing of a suction catheter and suction depths and pressures [31*]. Families and carers of CYP with a tracheostomy would have undergone significant training and skill development to support transition from an acute care setting to home and ensure 1:1 care [32]. With changing technology and management needs, this training needs revisiting and

revising in the adult setting, to optimise safety and optimise tracheostomy management which may present as a further burden to families and carers, particularly during a period of change. This raises the question as to who provides the training and at what point before a young person transitions and requires a change to tracheostomy management.

As noted, around the age that transition ideally should be discussed, there may be changes to airway and tracheostomy tube requirements and therefore implications for parents and carers and indeed healthcare clinicians previously trained in the management of single lumen tubes. Anecdotally, the change in tubes can be unfamiliar and daunting, requiring updated training and support. Double lumen tubes may come with additional features not typically experienced in paediatric, single lumen tubes, for example, subglottic suctioning ports.

Therefore, the paediatric clinician needs to be versed in the wider range of tubes, specifically double lumen tubes that may be necessary for growing CYP and more commonly used before transition. However, typically due to the underlying aetiology requiring the need for single lumen tubes into adulthood, such as craniofacial anomalies, the adult clinician is also encouraged to appreciate the variation and features of single lumen tubes to inform clinical practice, especially in emergency scenarios.

As with the adult population, the purpose of a one-way valve in paediatrics, where clinically indicated, is to optimise all upper airway functions through laryngeal (re)sensitisation, including voice, cough, bearing down, and swallowing, rather than facilitating tracheostomy weaning. Where indicated, the approach and assessment of one-way valve use may need

consideration when the young person transitions to the adult setting. It is possible that CYP may benefit from the use of open-bias one-way valves [33]. Clinically, these offer less resistance and for some children may offer greater acceptability and tolerance, particularly in the presence of sensory or neurological disabilities. Indeed, anecdotally, weaning in the paediatric population may not involve one-way valve use at all, but otherwise optimise downsizing of the tracheostomy tube and capping off of the tube whilst admitted to an acute care or increasingly within a community setting [20**, 34], taking place over consecutive days and nights as opposed to a 24-hour period for adults. There remains, however, considerable variation and lack of clarity in decannulation protocols globally [20**].

Redefining parent and carer roles

Parents and carers of CYP with a new tracheostomy typically undergo an intensive, competency and confidence-based programme of education within an acute setting to facilitate discharge into the home or community setting [35] and ensure the essential skilled, 1:1 care required to manage the tracheostomy. This education and support can take months or even years, depending on personal, social, and environmental factors. It is acknowledged that for families this can be a significant burden of care that may be lifelong, however parents have reported a sense of resilience and determination to adapt to challenging circumstances and remain hopeful [24*].

Transition may be more clearly defined for some populations, for example those requiring long-term ventilation, with examples of transition clinics noted around the UK and a recently established UK national peer support and advisory group on paediatric long-term ventilation. The group has highlighted the increasing transition from child to adult services

and plans to explore practice throughout the UK [29]. However, other populations, such as those with a tracheostomy without ventilation, may be less well served and therefore 'lost' without the scaffolding of an *'adultrician'*.

When transitioning to adult services, the role of parent and carer may be less defined and result in challenges at many stages of healthcare. Acknowledging the role of the parent and carer and ensuring space for them in the on-going care of a young person transitioning services is essential. For example, in the paediatric acute setting, parents and carers are often the primary carer, continuing their management of the tracheostomy throughout an acute admission. Furthermore, with preparation there is an opportunity to support, particularly in vulnerable young people, as well as optimise self-efficacy and participation in future planning and care [36**].

The parent and carers come with extensive knowledge and expertise in their CYP's tracheostomy. Acknowledging the expertise and working in collaboration with families and carers to negotiate and navigate health, social and education experiences is essential to ensuring adaptation [26]. Families and carers have built links and attachments with teams over decades and so change and adjustment may take time; ensuring clear and consistent communication is essential.

Preparing for adulthood

According to the UK National Health Service (NHS) Long Term Plan [37], planning for transition into adult services should occur when a child is around 14 years old, clinical evidence suggests this does not always happen and indeed the services within adulthood

may not be available. This guidance is not atypical of other countries' policy on supporting transition [36**], for example, *GOT TRANSITION®* the 'federally funded national resource centre on health care transition' [38] in the United States of America providing resources for healthcare professionals, young people and families and carers on navigating transitions.

Other informative guidance and support exists, for example, *Together for Short Lives* [39*], a charity supporting CYP with life-limiting and life-threatening conditions, documents a pathway for healthcare professionals, CYP and families alike to navigate the transition journey.

Rather than awaiting arrival or transfer into adult services, the importance of actively planning for transition is emphasised. Within the NHS in the UK, examples of healthcare services collaborating with service users to ensure safe and timely transition are apparent, for example the *Ready, Steady, Go* Programme [40] originating from University Hospitals Southampton and, although under development, available across the UK [41]. This programme starts the process of transition at the age of 11 years and aims to empower the young person to understand their condition so that they can make informed choices about their future care by the age of 18 years. The programme is generic so can be applied to a range of long-term conditions using the same framework. Globally, the importance of transition clinics to optimise outcomes for CYP has been highlighted and encouraged to commence early with involvement of clinicians, family members and young people [36**, 42]. However, a lack of consistency and transparency remains in managing transition into adult services across health, social and education settings.

Understanding the experience of navigating childhood with a tracheostomy is important to inform how a young person may have experienced identity, self-esteem, and education and how this may impact on their transition into adulthood services. Learning from individuals' lived experiences, particularly those that have navigated the transition from paediatric to adult services with a tracheostomy is essential for supporting clinicians' understanding of the challenges and opportunities faced.

Future research directions

Further research is needed to inform the epidemiology and long-term outcomes of CYP with tracheostomy transitioning to adult services. Furthermore, exploration of the health, social and education continuum and care pathways for this population may better inform service, policy, and clinical priorities. Gathering evidence of the lived experience and patient reported outcomes of those transitioning from paediatric to adult services may identify what is personally meaningful and necessary to support the transition and on-going needs into adulthood.

Conclusion

Whilst CYP with tracheostomy represent a relatively low incidence population, the associated technology, underlying diagnoses, and potential for life-long needs make them a highly complex population. The transition period to adulthood requires overlap and collaboration between paediatric and adult health, social, and education services to facilitate seamless and compassionate care. The involvement of the CYP and their family is essential to navigate these transitions and ensure engagement, inclusion, and effective transition outcomes. It is recognised globally, as discussed, collaboration should commence as early as possible in preparation for transition.

Key points

- Children and young people with long term tracheostomy need a safe and effective transition to adult services
- Their ongoing needs include adapting to education and work environments, social and psychological support
- There is an opportunity for paediatric and adult clinicians to share skills and knowledge to optimise the transition pathway

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** of outstanding interest

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Table 1: Paediatric conditions associated with requiring long-term tracheostomy

Congenital conditions	Craniofacial conditions, e.g., Apert's syndrome Laryngeal atresia Congenital heart disease
Acquired conditions (traumatic or non-traumatic)	Spinal cord injury Acquired brain injury Caustic soda ingestion Tumour Stroke
Progressive neuromuscular conditions (where non-invasive ventilation is unsupported)	Muscular dystrophy Duchenne's muscular dystrophy Spinal muscular atrophy
Respiratory conditions	Chronic ventilation needs Chronic lung disease Laryngotracheobronchomalacia