International Journal of Pediatric Otorhinolaryngology 84 (2016) 161–165

Contents lists available at ScienceDirect

International Journal of Pediatric Otorhinolaryngology

journal homepage: www.elsevier.com/locate/ijporl

# Paediatric tracheostomy and ventilation home care with challenging socio-economic circumstances in South Africa

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ARTICLE INFO

*Article history:*
Received 7 February 2016
Accepted 13 March 2016
Available online 19 March 2016

*Keywords:*
Tracheostomy
Socio-economic circumstances
Resource-limited
Home care

ABSTRACT

*Background:* Children discharged home with a tracheostomy need a safe home environment and access to health care. We described the indications, clinical characteristics, socio-economic circumstances and outcomes of children enroled in a tracheostomy home care programme in South Africa.
*Methods:* We performed a retrospective chart review of children receiving a tracheostomy and enroled in the Breatheasy programme at the Red Cross War Memorial Children's Hospital, Cape Town. Medical and background characteristics were recorded. Influences of socio-economic variables and underlying medical conditions on length of hospital stay, unplanned readmissions and mortality in the first year after discharge were evaluated.
*Results:* In the period 2008–2012, 157 patients were discharged home with a tracheostomy. Median hospital stay after tracheostomy insertion was significantly longer when parents had incomplete schooling compared to completed secondary school or higher education; 30 days (IQR 21–53) versus 23 days (IQR 16–33), respectively. Unplanned readmissions in the first year were documented for 72 patients (45.9%). The risk for unplanned readmission was 2.6 times higher in families with substance abuse the risk of respiratory infections was two-fold in case of household cigarette smoke exposure (OR 2.3.) Tracheostomy-related mortality was low (1.2%). An underlying medical condition was the only independent significant risk factor for mortality (OR 5.1, 95% CI 1.8–14.3).
*Conclusion:* This study demonstrates that despite difficult socio-economic circumstances, home ventilation of children with a tracheostomy is safe, provided caregivers are adequately trained and supported.



## 1. Introduction

The earliest reports of tracheostomy date from the mid-1800s when the French physician Armand Trousseau employed the technique in patients with diphtheria-associated dyspnea [1,2]. Survival rates of critically ill children have improved and concomitantly the number of "technology-dependent paediatric patients" has increased [3]. Indications for tracheostomy in children have shifted from acute infections to long-term ventilator-dependency and congenital airway anomalies [4].

Children with a tracheostomy can be discharged home safely only when round-the-clock supervision and a safe environment with access to health care are guaranteed [5]. These conditions may not be met in resource-poor settings. In South Africa, a low-middle income country, 59.5% of children live in poverty, 35.1% live in a household without an employed adult and 64% in a house without indoor running water [6]. The Red Cross War Memorial Children's Hospital (RCWMCH) in Cape Town treats mainly children from poor socio-economic backgrounds and has been running a tracheostomy and ventilation home care programme (Breatheasy programme) for 23 years. Due to resource constraints, home-based nursing assistance cannot be provided.

Home-based tracheostomy and ventilation training programmes in Western countries have prerequisites that must be met before children can be discharged home [7]. For example,

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http://dx.doi.org/10.1016/j.ijporl.2016.03.013
0165-5876/

availability of either one or two primary caregivers [8] and training of parents or other caregivers before the child's discharge [9]. The impact of socio-economic circumstances on success of home care has not yet been adequately addressed nor do studies report how socio-economic circumstances influence outcomes [10–12].

The aim of our study was to describe the clinical characteristics and the relationship between outcomes and socio-economic circumstances of all tracheostomy patients enroled in the Breatheasy programme from 2008 to end 2012.

## 2. Methods

### 2.1. Design

Retrospective chart review.

### 2.2. Patients and setting

All children who underwent tracheostomy placement and were newly enroled in the Breatheasy programme of the RCWMCH in the years 2008–2012 were included.

The Breatheasy programme is coordinated by an advanced paediatric clinical nurse (APCN) who is a member of a multidisciplinary team including paediatric pulmonologists, otolaryngologists, a speech therapist, a social worker, an occupational therapist, a dietician, a physiotherapist and volunteers. When a tracheostomy is indicated the APCN meets the primary caregiver and family and conducts a detailed interview which explores the family structure, socio-economic circumstances and community in which they live. The APCN explains why the child requires a tracheostomy and discusses practicalities and expectations. Practical training in tracheostomy care is started when the child is medically stable and is transferred from the ICU to the step-down ward. The primary caregiver is trained to change the tracheostomy on a daily basis, suction tracheal secretions, maintain humidification of the airway and is taught basic life support techniques and skills to be employed in the event of an emergency. Caregivers of children needing tracheostomy-assisted home ventilation receive additional training and are provided with a training manual on basic principles of ventilation and the equipment.

Indigent participants in the Breatheasy programme are provided with all essential equipment, including a manually or electrically operated suction device and tracheostomy tubes (Shiley, Covidien, Maryland, USA). Patients requiring tracheostomy-assisted home ventilation are in addition provided with a ventilator suitable for home ventilation, ventilation circuits, humidifiers and a pulse oximeter.

When the child is medically stable and the caregivers' training is complete, the child is discharged home and followed by the APCN.

### 2.3. Data collection

Data until the 1st of October 2013 were retrieved. To complete a one-year follow-up for all patients, additional information on mortality and readmissions until the 1st of January 2014 was collected. Patient information was extracted from an electronic Microsoft Access database maintained by the programme coordinator with details about diagnoses, tracheostomy indications and socio-economic circumstances of all patients enroled in the Breatheasy programme. Missing data was recovered as far as possible from medical records and the ICU database.

Data on patients discharged home with a tracheostomy and on those discharged home with long-term tracheostomy-assisted ventilation was analysed separately. These data included:

- Age and gender.
- Socio-economic circumstances: primary caregiver details, housing conditions, sanitation, household cigarette smoke exposure, caregiver education level, marital status and presence of alcohol or substance abuse as reported by caregiver or family members.
- Underlying medical condition categories that may influence outcomes (neurological, cardiac, human immunodeficiency virus infection (HIV), syndrome or no underlying condition).

Outcome measures were the following: (1) length of hospital stay from tracheostomy insertion to first hospital discharge; (2) unplanned readmissions of patients discharged home with a tracheostomy in the first twelve months after receiving a tracheostomy; (3) mortality and cause of death. A pulmonologist (MZ) and the APCN (JB) assessed cause of death from the medical records and post mortem interviews and categorized it as either 'related to the tracheostomy' or 'related to the underlying medical condition'.

### 2.4. Data analysis

Normally distributed variables are summarized as mean (standard deviation). Non-normally distributed variables are presented as median (interquartile range). Nominal data are presented as number (percentage). Fisher exact tests were applied to determine whether education, substance abuse and housing are associated with unplanned readmissions. The Kruskal–Wallis test served to determine whether level of education of parents was related to length of stay in hospital since tracheostomy insertion. A logistic regression analysis was used with unplanned readmissions and mortality rate in the first year ($y/n$) as outcome variables and the following predictor variables: long-term ventilation, cardiac disease, neurological disease and underlying condition present or absent. Also level of education (incomplete and no schooling versus schooling), substance abuse yes/no and housing (informal/formal) were included as predictor variables. Length of stay was log transformed to apply as outcome variable in a multiple regression analysis using the same predictors as for unplanned readmissions and mortality. Mann–Whitney U test was applied to determine whether substance abuse and housing conditions are related to length of stay in hospital since tracheostomy insertion. All analyses were performed with SPSS 21.0. A $p$-value of $<0.05$ was considered statistically significant.

## 3. Results

Over the 5-year period, 237 patients received a tracheostomy of which 134 (65.5%) were boys. The median age at time of tracheostomy placement was 14 months (IQR 3–48). In 145 cases the tracheostomy was indicated for upper airway obstruction (61.2%), in 79 for long-term ventilation (33.3%) and in 13 for both (5.5%).

Of the total sample, 157 (66%) were discharged home with a tracheostomy (flow chart Fig. 1)

Demographics, clinical characteristics, tracheostomy indications and socio-economic circumstances of patients discharged home with tracheostomy ($n = 157$)

Tables 1 and 2 show underlying diagnoses and indications for tracheostomy of the 157 children discharged home with tracheostomy. Median age at discharge was 8 months (IQR 2–28).

Table 3 describes the background and socio-economic circumstances. At the reference date of the 1st of October 2013, 64 children (40.7%) had been decannulated and twenty (12.7%) were home ventilated. Almost a quarter of the patients (24.3%) lived in an informal house or dwelling.