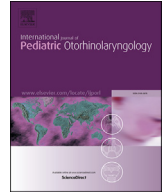




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# Improving access to school based education for South African children in rural areas who have a tracheostomy: A case series and recommendations



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## ABSTRACT

**Objectives:** Currently few children with tracheostomies attend rural mainstreams schools in South Africa limiting their ability to gain an education. We sought to document the current school experience for the few children attending school who have tracheostomies and devise educational tools for teachers and administrators that will facilitate greater acceptance and safety in classrooms for this population.

**Methods:** The four patients that are currently attending school with a tracheostomy were identified from the patient records of a tertiary hospital with a pediatric tracheostomy home based care service. With the aid of a Zulu language translator, the mothers and classroom teachers completed a semi structured interview and closed item questionnaire in their home and school, respectively. Schools were visited to understand and describe the settings in which the children and their teachers were being asked to function. Tools for education were developed in conjunction with key stakeholders at schools already hosting such children.

**Results:** The key teacher-identified barriers to enrollment were: teacher unfamiliarity with tracheostomies, uncertainty about the school's liability, and concerns about the response of other children. The safety barriers identified were: greater than 60 children per classroom - limiting teacher's ability to attend to the child with a tracheostomy, lack of running water, pit latrines separate from school threatening hygiene and isolating the child when they leave to use the latrines & sandy classrooms which can result in sand entering the airway. Identified needs for successful school placement include providing tracheostomy supplies and suctioning equipment, hand hygiene materials and training teachers in: identification of respiratory distress, performance of emergency tracheostomy changes, CPR. **Conclusions:** Children with tracheostomies could likely successfully attend South African rural mainstream public schools with a training program for teachers. As a first step, an introductory booklet for teachers that explains tracheostomies and provides educational and safety suggestions was created. A list of recommendations for successful inclusion of students in the school system was developed together with and delivered to key stakeholders.

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## 1. Introduction

It is well established that children with tracheostomies are able to attend school in well-resourced countries where dedicated

special-needs classrooms, school nurses, teacher's aids and individualized learning plans are readily accessible [1,2]. While affluent and/or special needs schools in South Africa might be able to provide comparable resources, a vast majority of the population cannot afford to attend these schools and/or live in areas where no special needs-schools are available. With this in mind, South African children with tracheostomies have no choice but to attend their local mainstream school and in rural areas, the schools can be

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overcrowded, understaffed, lack school nurses and utilities such as running water, electricity and piped sewage. The first four children from the Greys Hospital Tracheostomy Home Care Service (THCS) in Pietermaritzburg, South Africa to attend school do so under these conditions.

The THCS was started in 2006 with the aim of allowing children with tracheostomies to be cared for by their families at home. The THCS is only the second such program in South Africa and has discharged 71 children to trained parents and/or care-givers. Modeled on the Red Cross Children's Hospital in Cape Town, South Africa home based tracheostomy program [3], the THCS has three central tenets (1) training parents to maintain a tracheostomy and manage common complications at home (2) monthly home visits by nursing staff or social workers & (3) scheduled visits to a dedicated tracheostomy clinic with multidisciplinary specialists. The benefits of the program [4] include freeing up beds within wards, tracheostomy tubes being changed daily as opposed to weekly, cost savings for the hospital and families being able to stay together as opposed to the child living in a hospital for an indefinite period of time.

Despite the recognized benefits of home-based-tracheostomy-care to patients, families, hospitals and taxpayers, only three cities in the South Africa are utilizing the model. Part of the hesitancy stems from the South African Department of Health's limited support for these programs as in-patient care remains the gold standard. As such, the existing programs are supported through philanthropy and Non-Governmental Organizations [4].

Many advocate for the expansion of home based tracheostomy care programs in South Africa [4] because the ability of children's care givers to successfully provide tracheostomy care at home in rural settings has been documented [3,5]. If such an expansion were to occur there would be implications for the local education systems that have not been fully studied. To address this concern, this study aimed to document the school experience of the first four children in the THCS to attend school and offer recommendations for how schools in rural settings can be made safer & accessible to children with tracheostomies.

## 2. Methods

### 2.1. Subjects & recruitment

After Institutional Review Board (IRB) approval was obtained from Dartmouth College, Hanover, NH, the University of Kwa-Zulu Natal, KZN, South Africa and the Kwa-Zulu Natal Department of Education, KZN, South Africa, the four children in the Greys Hospital THCS who attend school with a tracheostomy were identified from patient records. The principal study investigator, Chengetai Mahomva, B.A. was introduced to the four patient families during a monthly THCS clinic and arrangements were made to visit the families at their home. At the home visits, consent was obtained from the parents/caregivers for them and their child's teacher to complete a semi structured interview and closed item questionnaire. Only after parent/caregiver permission had been obtained, the teachers were also individually consented. All four families and their teachers were included in the study and agreed to participate.

### 2.2. Data collection

The mothers (the primary caregivers) and main classroom teachers of all four children completed an interview and orally administered questionnaire. The semi-structured interviews were recorded and lasted between 30 min to an hour while the questionnaire took 10–15 min to complete. All four of the mothers were questioned at their home and two of the fathers also participated in

the interview. All of the teachers were interviewed at their schools. Topics covered in the interviews and questionnaires gauged prior and current familiarity with tracheostomy & emergency care, process of school enrollment and preparedness, transportation to and from school, understanding classroom and social interactions. The resources of each school were also documented. All of the interviews were conducted by Chengetai Mahomva, B.A. a female second year medical student who had no prior relationship with the participants. A Zulu language translator was present at the interviews and English/Zulu translation was provided as necessary.

### 2.3. Setting

All of the families and schools included in this study are located in the midlands (~80 km from the Eastern coastline) of the province of KZN. The 2011 national census reflected the following: KZN has a population of approximately ten million 87% of whom self-identify as "black Africans" and three quarters of whom regard isiZulu as their primary language. The provincial unemployment rate is 33% and 46.6% of the households are female headed (single, divorced or widowed women). Finally, the province boasts one of the highest school enrollment rates in the country with 90.3% of children aged between 6 and 13 enrolled in primary education [6].

### 2.4. Data analysis & reporting

Each recorded interview and questioner was analyzed in English to identify major family and school characteristics as well as barriers and facilitators to school attendance with a tracheostomy in a rural setting. The Consolidated criteria for reporting Qualitative research (COREQ) publication guidelines were used for the design and reporting of this work [7]. Based on the results of the analysis an introductory booklet, Fig. 1, for teachers that explains tracheostomies and provides educational and safety suggestions was created. A list of recommendations for successful inclusion of students in the school system was developed together with and delivered to key stakeholders.

## 3. Results

The return and participation rate for the interviews & questionnaires was 100% from both the families and teachers.

### 3.1. Patient profile

The four pediatric patients in the study were two boys and two girls with ages between four and eleven. Three of the children had tracheostomies placed within two months of their birth and the fourth had a tracheostomy placed at age seven. While only three of the tracheostomies were placed at Greys Hospital, Pietermaritzburg, South Africa (one was placed at Inkosi Albert Luthuli Central Hospital, Durban, South Africa) all of the parents received tracheostomy training (basic tracheostomy care, operation of suction foot pump, CPR & recognizing respiratory distress) at the THCS. The tracheostomies are changed (the entire tracheostomy apparatus replaced with a clean one) on average twice a day and except for the youngest child whose secretions are removed by a suction foot pump, the children are able to cough and clear their own secretions. The children have chronic medical conditions that have been summarized in Table 1.

### 3.2. Family and home setting

One family and school are located in a semi-urban township close to the city of Pietermaritzburg while the rest are on the rural

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