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Review article

Parents' experiences and views of caring for a child with a tracheostomy: A literature review

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ABSTRACT

Objectives: To review the published/reported experiences and views of parents' whose child has had a tracheostomy. To date, no review has focused specifically on parents' experiences and views of having a child with a tracheostomy.

Methods: MEDLINE, CINAHL, PsycINFO and Embase were systematically searched from 1990 to 2012 and a review of reference lists was conducted. The review draws on articles where parents' views of caring for their child's tracheostomy were either the sole focus of the research or where parental views of caring for their child's tracheostomy have been sought as a subsidiary aim. Studies relating to the aims of the review were examined using quality appraisal tools and in line with criteria for inclusion of studies. Studies were excluded if findings were about adults, studies that only focused on children's or sibling's views were not based on empirical work (e.g. literature reviews or expert commentary) or were not published in the English language. Findings were summarised under thematic headings.

Results: The systematic database search identified 442 citations of which 10 were eligible for inclusion in the review. Of those 10 studies six were quantitative and four qualitative. Only one paper published qualitative data specifically on parents' experiences about their tracheotomised child. The three main themes identified were parents' experiences of caregiving, their social experiences and experiences of service delivery of having a child with a tracheostomy. Although parents encountered emotional and social challenges, some positive responses to these challenges were reported.

Conclusion: This review identifies a lack of qualitative research on parents' views of having a child with a tracheostomy. Issues surrounding parental management of tracheostomy require further investigation. This review has identified the need to elicit parents' longitudinal experiences of having a child with a tracheostomy.

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1. Background

Tracheostomies are becoming increasingly commonplace within both the acute hospital and community care settings on an international scale [1]. A tracheostomy provides a channel for effective respiration and removal of tracheobronchial secretions [2]. Tracheostomies are performed in children who either have an airway obstruction or a neurological impairment [3]. The duration an individual has a tracheostomy varies. Potential risks associated with tracheostomies include airway obstruction, mucus plugging, tube displacement, bleeding and infection [4]. Some of these risks can lead to a respiratory arrest [5]. Parents of children who have a tracheostomy must acquire skills in tracheostomy care and demonstrate competency in tracheostomy care. Training parents to care for their child's tracheostomy requires careful planning and a systematic education programme, which includes providing suction, stoma care, tube changes and resuscitation ability [6]. The expectation, knowledge and confidence in delivering this type of care, can remain a challenge for parents [7]. Reports from clinical practice suggest that parents are often initially overwhelmed because they are concerned about their ability to provide the necessary tracheostomy care. For most parents, the tracheostomy is likely to represent the child's most significant medical intervention.

This review draws on articles where the experiences of parents' whose child has a tracheostomy has either been the sole focus of the research or where parental views of caring for their child's tracheostomy have been sought as a subsidiary aim. To date, no review has focused on parents' experiences or views from this patient group. Previous reviews [8–10] which have included findings about parental views of caring for a child with a tracheostomy have focused on children who require long term ventilation (LTV). Children on LTV have life-limiting or progressing neurological conditions and as such may represent quite a different life experience for their parents. Tracheostomy care is often just one element reported in these studies. This review addresses specifically tracheotomised children who are not on LTV.

2. Methods

2.1. Search strategy

The search strategy which informed the review of the literature was conducted in January 2013 (see Table 1).

Key databases were searched using key words, MeSH terms and Boolean operators. The reference lists of all identified articles were searched (Table 2).

The database search resulted in the initial identification of 442 studies. Studies not meeting the inclusion criteria were excluded. Criteria for inclusion of studies were that they, reported research relating to aims of the review and were published from 1990 to 2012.Studies were excluded if findings were about adults, only focused on children's or sibling's views, were not based on empirical work (e.g. literature reviews or expert commentary) or were not published in the English language. This left 50 potential studies for further review. Critical appraisal of qualitative studies was guided by the seven criteria outlined in Carter and Goodacre [11]. These being epistemology; theoretical perspective; methodology; methods of data collection; sampling; methods of data analysis, and reporting. Critical Appraisal Skills Programme (CASP) guidelines were followed for quantitative studies. The purpose was to ensure the reliability and rigour of the findings and to identify any biases in the studies. This resulted in 10 articles for inclusion in the review.

2.2. Study characteristics

Ten studies are included in the review; six qualitative and four quantitative. When combined the samples represented in the qualitative studies were mothers' views ($n = 94$), fathers' views ($n = 49$), and parents' views ($n = 8$). The quantitative studies the sample represented were families'/parents'/caregivers views' ($n = 226$). Across all studies the ages of children studied ranged from 2 to 18 years of age. The qualitative studies reported a range of methodologies: grounded theory [12,15], ethnographic [16] and sense-making methodology [14]. Two studies were described as qualitative with no specific methodology applied [13,17]. The standard methods used in the studies were interviews (in-depth, semi-structured, and structured), questionnaires/surveys and photo voice.

2.3. Quality of studies

The quality of studies was assessed using CASP and Carter and Goodacre's [11] guidelines. The quality of the included studies was variable. The number of studies where parents were interviewed together was small in number and more often it was mothers' views that were sought [12–16]. Fathers' views appeared to be under-represented although it is difficult to ascertain in the quantitative studies whether it was mothers and/or fathers who responded to the data collection methods. Most of the studies were comprised mainly of cross-sectional assessment, with no longitudinal work exploring views over an extended period.

2.4. Synthesis

The findings are structured into three main themes and their associated sub themes.

1. Caregiving experiences of having a child with a tracheostomy. (Sub themes: coping; and time).

Table 1
Literature search strategy.

Databases searched
Academic search elite
CINAHL PLUS (Cumulative index to nursing and allied health literature)
MEDLINE
PsycINFO
Embase
Years covered by the search
1990–2012
Search terms
Parent* Mother* Father* Care*
Tracheotom* Tracheostom* Complex needs*
View* Experience* Perspective*
Child* Infant* Adolescen* Baby* Teenager*
MeSH terms
Parental attitudes
Medically fragile
Caregiver burden