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

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CRD summary
The authors concluded this mixed-methods review with three identified themes that reflected positive and negative feelings in relation to caring for a child with a tracheostomy. Potential methodological limitations in relation to the quality of the included studies and a poorly-reported review process make the reliability of the authors' conclusions unclear.

Authors' objectives
To explore parents' experiences and views of caring for a child with a tracheostomy.

Searching
MEDLINE, CINAHL, PsycINFO, EMBASE and Academic Search Elite were searched from 1990 to 2012 for published studies in English. Search terms were reported. Reference lists were screened for additional studies.

Study selection
Eligible studies were of parents' experience and views of caring for a child with a tracheostomy. Children who were receiving long term ventilation were excluded.

The included studies were conducted in the United States, UK, New Zealand and Canada. Children were aged from two to 18 years. Parents and caregivers views were collected. Health professionals formed part of the sample in some studies but it was unclear whether their views were sought. Fathers' views were under-represented. Outcomes were measured in qualitative studies by interviews and Photovoice. Quantitative studies used questionnaires or a specific health status instrument.

The authors did not state how many reviewers were involved in study selection.

Assessment of study quality
Quantitative studies were assessed using the Critical Appraisals Skills Programme (CASP) checklist. Qualitative studies were assessed using published guidance covering epistemology, theoretical perspective, methodology, methods of data collection, sampling, methods of data analysis and reporting.

The authors did not state how many reviewers carried out the quality assessment.

Data extraction
Interpretations of the extracted data were presented in a table. The authors did not state how many reviewers extracted the data. The authors explained neither the process of data extraction nor how interpretations were developed.

Methods of synthesis
A narrative synthesis was presented and incorporated findings from qualitative and quantitative studies under three main thematic headings.

Results of the review
Ten studies were included in the review: six qualitative studies (151 participants) and four quantitative studies (226 participants). Study quality was reported to be variable. Limitations included: low survey response rate; lack of clarity, variation or limited numbers in terms of the study sample; and measurement instrument not validated (full quality results were not reported).

Caregiving experiences of having a child with a tracheostomy (four qualitative studies; three quantitative studies): A consistent theme was the perceived domination of assumed clinical responsibility and parents subsequently feeling unable to distinguish their role as a parent or a nurse. Other studies showed mixed results. Some noted increased pressure and stress associated with these clinical responsibilities; others demonstrated coping strategies to help maintain
normality. Mixed results were found in terms of building confidence and acceptance in relation to care-giving over time.

**Social experiences related to having a child with a tracheostomy (three qualitative studies; four quantitative studies):**
Care-giving was associated with social isolation that arose from fears of leaving the home and the social stigma of having a child with a tracheostomy. Broken marriage was a consequence of care-giving in two studies. Reducing social isolation was an integral part of wanting to improve quality of life for the child. Quantitative studies reported significant detrimental impact of care-giving on parents' quality of life.

**Experiences of service organisation and delivery of care (six qualitative studies; two quantitative studies):** The importance of having parents' expert role valued by health professionals and in developing trusting and equal relationships between the two parties was noted. Parents had a central role in delivery of care packages and expressed the importance of shared written information about the child. Several studies reported concerns about supplies, delays in discharge planning, provision of respite care, unskilled carers and poorly defined roles and responsibilities. The need for support was echoed across many studies and in particular having an accessible and familiar professional contact.

**Authors’ conclusions**
Three themes were identified, reflecting positive and negative feelings in relation to caring for a child with a tracheostomy. The quality of research to date has been variable.

**CRD commentary**
The review question was clear. Inclusion criteria were adequately specified. Appropriate sources were searched to locate studies for the review. Language and publication restrictions may mean that some relevant studies were overlooked. The review process was poorly reported and results of the quality assessment of included studies were not given in full. It was difficult to rule out possible error and bias in the review process and the reliability of the included studies was unclear.

A narrative synthesis of included studies seemed appropriate but it was unclear how interpretations of qualitative and quantitative data were developed. This represented a substantial limitation of this mixed-methods review. The reliability of the authors’ conclusion is unclear.

**Implications of the review for practice and research**
**Practice:** The authors did not state any implications for practice.

**Research:** The authors stated that parental management of tracheostomy needed further investigation. Longitudinal experiences of parents caring for a child with a tracheostomy, together with more qualitative research, appeared to be needed.

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