The Journal of Laryngology and Otology (Supplement 17)

Nursing and home aspects of the care of a child with tracheostomy

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In this paper, I shall mention a survey I undertook in September 1986 on the prevalence and aetiology of tracheostomy among children in the U.K. (Jennings, 1987). Four hundred and fifty-five members of the British Association of Otolaryngologists were circulated with a questionnaire and 58 per cent responded. The total number of children with a tracheostomy was 225 and the indications for tracheostomy were:

Indication	*No:*
Subglottic stenosis	96 (43%)
Laryngeal cysts/tumours	34 (15%)
Vocal cord palsy	16 (7%)
Neurological	15 (7%)
Congenital laryngeal abnormalities	11 (5%)
Tracheomalacia	7 (3%)
Tracheal stenosis	5 (2%)
Laryngomalacia	4 (2%)
Upper airway obstruction	4 (2%)
Trauma	3 (1%)
Miscellaneous	30 (13%)

Of interest was the high proportion of such tracheostomies done on infants with subglottic stenosis. Of the 96 cases of subglottic stenosis, 40 were recorded as acquired and only three as congenital. No cause was given for the other 53.

My main study was a qualitative one looking at the problems experienced by mothers caring for a child with a tracheostomy in the first six months following discharge. There has only been one other similar study, by Wills in the U.S.A. in 1983.

The survey included 10 mothers with children under the care of University College Hospital; five children are now decannulated. The aim of the study was to try and use the findings to improve the aftercare of children at home with tracheostomies.

The initial study was retrospective and the parents were asked to record from memory the four problems recalled as the worst at that time. Nine out of 10 mentioned the tube coming out or blocking and eight mentioned equipment. The main study included an hour-long recorded interview of the mother. During the interview the mother was encouraged to talk about the problems freely and only prompted if necessary. The analysis is not yet complete but as the interviews progress, I compare the material to the previous interviews and modify the categories in which the material is put, so that the categories either grow or diminish accordingly.

The categories will be described, interspersed with quotations taken from the recorded interview of the mother. The children's names are fictitious.

The first category concerns the parents going home with the child and there are two aspects to this. One is that the attitude of the staff seemed very important. All the parents mentioned that the staff assumed from the beginning that the child would go home and they obviously felt that was significant. All the parents were very keen to take the child home; some of them badgered to quite some degree and two mentioned that they were concerned about the relationship with the baby, having had the baby in hospital for so long from birth. The second aspect is the training side. Most parents mentioned several trainers, and the training was largely practical with nothing in writing. Most did stay for a few nights in hospital with the baby before discharge but only three out of 10 had home visits, so consequently the first night was often very traumatic.

Tape (Quotations from Interviews)

"the day we came out they showed us what to do if the tube came out—they took it out and they put it back in, and it wouldn't go" "when I said I wanted to learn how to change the tube, three or four different nurses showed me and then they went and said "we'll leave you, if you want help, we're just outside".
"all nurses seem to have a different way of doing it"

The equipment category was regarded as the worst by two parents for several reasons. First, discharge from hospital may have been delayed due to lack of equipment—up to a month in one case. Second, and more serious, was that some babies went home without equipment. In the case of electrical suction machines, one family did not have one for six months and one family never had one. In the case of the portable suction machine, one family waited for "ages", one for two years, two for three years and one eventually bought their own. There is also difficulty in replacing equipment and most people in community health seem not to believe that a family can quite easily go through a hundred catheters a week.

Sister, University College Hospital, London

Tape

"one time I got very low on catheters and I went to the local hospital and they gave me six"

Equipment also broke down or was of no use.

Tape

"one time the suction broke down and it was really traumatic because I was having to suck him out by mouth—it took two weeks to mend and he was in hospital for all of that time"

Families also found it very awkward taking suction equipment everywhere they went.

The third category is of disasters, most of which were associated with tube changes. Parents always mentioned the difficulty of these, particularly the single mothers. In couples it was often the fathers who did the tube change, with the mother as assistant. Grandparents were rarely involved in tube changes, and all relatives who were concerned with the child's distress and the vomiting found it a very fearful procedure.

Tape

"when I got home I couldn't do it any more"
"I thought I was going to faint"
"it happened frequently—the second time we were asleep—we didn't know about it—and then one of us woke up and we saw she was changing colour because she couldn't breathe"
"one time my mother rang me up at work and said 'I can't get the secretions out, you'll have to come home and change the tube'—it was twenty miles!"

Feeding was a particular problem in two families where the child was still being fed by nasogastric tube after discharge.

Tape

"passing a new nasogastric tube was much worse than the trachy tube"

Poor weight gain and poor feeding often delayed discharge and continued to be a problem once the baby was home, although it usually ceased to be a problem weaning was established. Vomiting was often regarded as a big problem, which parents found difficult to deal with. It involved endless washing and some families had to manage without a washing machine.

Tape

"give her a bottle of eight ounces and she'd take all day to finish it"
"it seemed to be continuous mopping up"
"just have a big plastic sheet ready"

The fifth category is communication. All parents found the child's crying without any noise most distressing and worried about the ability of the child to attract their attention. Most babies apparently did this by altering their breathing pattern. Parents were also afraid the child would not speak, and several children did not actually make any sound until three or four years of age.

Tape

"I'd hear him coughing and find him with tears running down his face"
"I had to make a conscious effort to talk to her"
"we did worry that perhaps she wouldn't ever speak"

The most alarming category concerned the parents' fear of death. Their expressed anxiety was over hearing the child in difficulties, particularly at night, and this led to sleeplessness. Regardless of whether the child was cannulated or not many parents still went into their child's room in the morning with the fear of him having died in the night. This fear never left them, regardless of the tracheostomy.

Tape

"it took a long time to realise she might pull through"
"I had grave doubts as to whether she'd survive the first year—she seemed so frail she never seemed to come to terms with getting on with life"
"I was so frightened I used to lay her on the sofa—by the time I'd walked out of the room I used to have to go back in to make sure she was alright"
"I remember throwing him on the bed and saying to him, 'for God's sake breathe'"
"one thing I dreaded was falling asleep and waking up and finding him dead"
"pure, blind, utter fear"

The next category, relationships, brought a varied response. Some couples felt that the situation put a strain on their relationship.

Tape

"a crisis pushes you apart"
"I don't think we'd had much of a sex life during that time at all"

Others thought it had a strengthening effect and brought them together. Fathers often took second place in day to day care, but at the same time their wives felt they could not have managed without them.

Tape

"he never liked sucking her out—he still doesn't"

Married women felt managing on their own would have been very hard, and single women mentioned how difficult it was to form new relationships.

Tape

"it would be awful—you really do need someone to share it all with"
"it put a strain on the relationship—he forgot to ask me out after a while"

The eighth category concerned siblings. Those parents whose tracheostomy child was their first did not feel that having had a well child first would have helped particularly. Those whose tracheostomy child was their second or subsequent felt that it had eased the situation.

Tape

"I think it made it easier already having a baby—I think if Robin had been my first I'd have been in even more of a panic"

Parents did notice quite a marked effect on the siblings of children with tracheostomies—disturbed behaviour, anxiety, precocious behaviour, jealousy of the tracheostomy child and a need for much reassurance.

Tape

"I'd phoned the Capital Radio helpline because I was worried about Gerald, because I was finding I was losing my temper"
"his speech was reflecting John's—who was missing off the ends of words"

Tracheostomy children have a notable effect on the size of the family, in other words most parents decided not to have any more children or at least delay them.

Tape

"if she'd have been my first, I don't think I'd have wanted to have any more ever again"

Parents who had their tracheostomy child second or later felt it was helpful having already had a well child, but all mothers felt the general problems of rearing were insignificant compared to the tracheostomy. All found discipline a problem. The children used their breathing, made themselves sick, or pulled out the tube in order to attract attention. The parents noted that the children had a very unnatural amount of adult one-to-one attention and several parents mentioned the minimal professional support in this area.

Tape

"he would always make himself quite gurgly if he wasn't getting enough attention"
"he knows how to work his way on you"
"he did what he wanted—I just thought whatever time he has got left, let it be happy"

Hospitalisation was the next category. Returning to hospital was considered quite a relief by at least two families as it brought the first opportunity of an unbroken night's sleep for a while. Most parents were fearful of going back into hospital and dreaded it, largely related to the attitude of the nursing staff. Most knew a lot more about tracheostomies than the nurses, which was obviously disconcerting.

Tape

"hate it! I feel she's had so much suffering—she knows as soon as we get her to the station"
"I had to do the care because they didn't know how to"
"they would suck her out when she had just had a feed and then of course she'd be sick"
"I think they were a bit apprehensive"
"you'd get a nurse come to use my son as a guinea pig to teach a trainee nurse"

Hospitalisation also involved many practical problems with travelling and looking after the siblings, particularly for working mothers. Some found it difficult to know when to approach the hospital or when to approach their GP and the relationship there was quite difficult. Generally there was a tremendous lack of help or professional support from health visitors and GPs. Two parents mentioned the community staff's fear, and one mother had no visits from her health visitor for six months.

Tape

"if she came round she said, 'oh well you're coping alright, you know more than I do"
"I said 'do you think someone could come round once a week to help me change the tapes?'—they said 'you could do it like this' and 'you could do it like that', I said, 'well do it and show me', but they insisted I could do it on my own"

There was, however, specific mention of good care notably with the existence of a Home Care Service.

Tape

"she gave me more confidence—she was a friend really"
"my GP was a darling, he said, 'I know nothing at all about trachy's, whatever I can do, I don't care what it is, I will do it'—if it was just a question of listening to me pray, he would'

The twelfth category was about non-professional help.

Tape

"we felt very much on our own"

The impression left was of a parent or parents completely unsupported by friends and family as well as by professionals. A second person was rarely taught the care of the child, even in the case of a couple. Grandparents were not usually taught and most found it something they could only just cope with, if at all. Of the five families where the grandparents did help, two to an enormous extent, none were very confident about actually changing the tube.

Tape

"eventually she took over because in the end I had to go back to work"
"everytime it got really hard she was always there—we had to take it in turns to sleep—I would have dreaded being on my own"

Mothers did not usually initiate discussion on the financial implications. However, it was clear that there was quite a profound effect on some families, with the mother prevented from going back to work in three cases and only just managing to return with a great deal of help from their own mother in two other cases. The husband's work was also affected by the amount of time required for hospital visits and several mentioned having used up annual leave for this. Many parents were unaware initially of what benefits they could claim and felt quite badly about this later. Several mentioned the illogicality of not being able to claim the attendance allowance until the child was two years old, on the basis that any child under two needs looking after.

The need for extra clothes was mentioned and also a washing machine. Parents used a lot of convenience foods, taxis or extra petrol, and one mother was sufficiently desperate to pawn her jewellery. Life-style changed and parents mentioned not being able to smoke, restricting their drinking, being unable to have a dog, and needing to vacuum frequently to keep the dust levels down. All mothers felt they had been changed as people by the experience and most felt stronger and more patient.

Tape

"it puts everything else in perspective"
"it put a lot of people off actually coming to the house"
"I'm probably more philosophical now about some of the minor things that go wrong"

Overall the biggest problem was tiredness and the fear of being unable to cope.

Tape

"I don't think you ever get used to the lack of sleep"
"if she is awake I have to be awake"
"if Alan dozed off for an hour I just had to lie down and try to rest then as well"
"I went for nights and nights without any sleep—but Mum would take over"
"I have to manage because the baby is mine"
"sometimes I wonder how I did it myself—looking back over it, I think it takes a lot of will-power"
"because we'd had children for so long, people didn't believe that we couldn't manage"
"I remember saying "I don't think I can cope on my own", but did, because I had to"
"the day seemed very long"
"we found her a lot harder work—I don't think other people really realised"
"we very much felt that they didn't know how bad it was at home"
"we took her back to hospital reluctantly the first time because we felt we should be coping better—we felt a failure"
"if I was ill, I don't know what would happen to her"
"we just thought we were never going to get through it"
"sometimes I think back and I think "did I really do that?" "
"I suppose if I was living on my own I would have 'cracked-up' in six weeks or died"
"it was a strain—sometimes I thought I was going to—not go mad—but I was tired, very tired, suctioning and feeding and all the worries that are put on you"
"get through tomorrow—get through tomorrow"

References

Jennings, P. (1987) Tracheostomy in children. *Lancet.* **ii:** 631 (Letter).

Wills J. M. (1983) Concerns and needs of mothers providing home care for children with tracheotomy. *Maternal Child Nursing Journal.* **12:** 89–107.

P. Jennings discussion

Cinnamond

What sort of tubes were used in children who were vomiting, or in those for whom vomiting was a problem?

Jennings

One or two of the earlier children were possibly still using metal tubes. Several have had quite severe feeding problems, probably also associated with them being premature. While still on milk feeds vomiting is always a potential problem.

Sell

A large proportion of children have delayed speech and language acquistion and voice problems. VOCAL is a group representing the communication handicapped, and they have been informed by the DHSS that it is the responsibility of each District Health Authority to provide equipment.

Dinwiddie

How many babies have actually died at home with the tracheostomies *in situ*? I only know of one.

Bull

I have had two children die at home and one in hospital. One of those who died at home illustrates how you cannot prevent it happening in some instances. The father was a doctor, the mother a special care baby unit sister. The baby had severe stenosis. At nine months he was put to bed for the afternoon and died because he pulled his tube out. Nothing could have prevented that. You cannot watch children 24 hours a day and there is a mortality associated with it.

Evans

I have had five children die at home out of two hundred tracheostomies done primarily for subglottic stenosis. I suspect that mortality at home is no greater than mortality in hospital.

Graham

Mr Evans, I believe only one of yours was related to tube blockage?

Evans

For one no cause was found. One child died of tube obstruction; one child with laryngeal papillomatosis died on her way to hospital because the papilloma blocked the lower end of the tracheostomy tube and I suspect the other one was due to the tube actually coming out.

Graham

This is against a background of Fearon and Cotton's figure of 24 per cent mortality in the States.

Gillinson

The whole issue of babies dying at home is not so much whether they are likely to die at home but the fact that as a parent you have to bear that responsibility. To have to live with the fact that your child died at home, perhaps due to your lack of technique, is very hard.

Evans

It is very important to be supportive of parents in that situation and inevitably they are going to feel "could I have done something else?" We have to reassure them most strongly that in no sense have they been negligent.

Bull

It is very important to be able to admit children whenever the parent needs a rest or just wants to get out for the evening.

Cinnamond

I would go further and say that they ought to be offered and actually encouraged to come in. There really is a need to look after these children in a few large centres, so that when mothers bring their children up to the unit they are with nursing staff used to looking after such babies and the mother does not feel that the child is being experimented on.

Pearse

It is exactly the same as with a mentally or physically handicapped child, we should be counselling these parents and advising them to share their problems with each other.