

Food for thought: investigating parents' perspectives of the impact of their child's home enteral nutrition (HEN)

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Abstract

Children with severe feeding problems present unique challenges as they may fail to thrive despite parents' best efforts and require additional nutritional support. Comparatively few studies have examined the impact of tube-feeding on the lives of children and parents from the parents' perspective. This study redresses this imbalance by providing a detailed interpretive account of parents' experiences of their child's home enteral nutrition (HEN). A sample of 34 parents in South Australia were interviewed individually or in focus groups. Data were analysed using a data-driven thematic analysis technique. Participants were parents of children in the HEN service at a tertiary paediatric hospital.

The impact of tube-feeding a child at home pervaded all areas of family life. This ranged from administering dietary formulas to their child often over 24 hours, constantly planning ahead to accommodate activities, being the child's 'case manager' and primary communicator between health professionals, curtailing social activities due to lack of respite care, and coping with the negative, prejudiced attitudes of people when going out in public with their child. This study highlights the extensive physical and psychological demands that HEN places on families, and underscores support needed from health professionals to help ease the demands of caring for such a child at home. Parents' accounts of their HEN experiences provide opportunities for all children's services and professionals to improve services and approaches, for example by placing more emphasis on psychological support for parents and creating greater awareness of HEN among the general public.

Keywords: home enteral nutrition, gastrostomy, parents' experiences, qualitative research.

What is known on this topic

- HEN for children is increasingly used.
- Managing HEN can be challenging for parents.
- HEN research is predominantly medical and nutritional in emphasis.

What this paper adds

- An important Australian perspective to the international literature.
- Support for existing research, highlighting stigma experienced by parents as a result of public attitudes.
- Evidence of the need for accessible, meaningful support and respite for parents and families.

Bodies need adequate nutrition to function, and providing food and meals for a child is a major aspect of parenting. Feeding and nurturing a baby or child is an elemental dimension of the complex existential of being a mother or parent. For some parents, however, feeding their child is anything but 'natural' or easy due to complex medical issues. This study describes parents' experiences as they

tried tirelessly to provide adequate nutrition for their child, only to find that their child failed to thrive and grow and subsequently required tube-feeding at home.

The number of children receiving home enteral nutrition (HEN) is increasing¹⁻³, involving a significant shift in care and responsibility from hospital and professionals to home and

family. This shift has emotional, physical and psychosocial implications for the caregiver and their family. The experiences of these parents provide 'food for thought' and a research basis for improving health and support services that are grounded in consumer experience.

HEN in children: focused review of existing literature

The main indications for HEN are conditions leading to failure to thrive e.g. cerebral palsy, cystic fibrosis, malignancies, various major congenital malformations and metabolic disorders³. The surgical, medical and nutritional aspects of HEN have been studied extensively, but fewer studies have explored the 'everyday' experiences of these children and their parents. Using the parenting stress index, Pedersen *et al.*⁴ found high stress levels among parents caring for children with chronic illness/disability requiring enteral feeding, with the levels relative to the burden of parental care experienced.

HEN has clear benefits for the child, such as improved weight gain, growth and nutritional status^{5, 6}. Parents also report significant reductions in time spent feeding their child⁶. However, psychological implications of being unable to feed their child 'normally' often persist for parents. Researchers have found that parents struggle with feeding problems for lengthy periods and find the transition to HEN difficult, and possibly tantamount to an 'admission of failure' that they are unable to nourish their child⁷⁻⁹. Parents also reported other problems following commencement of HEN. Evans *et al.*'s¹⁰ audit showed that families experienced practical problems such as tube dislodgement, blockage, and other equipment related issues. However, the main problem cited by parents was sleep disturbance, emphasising again the psychosocial impact of HEN on parents and families.

United Kingdom research found that most HEN studies focus on medico-nutritional aspects, with less emphasis on psychosocial aspects of this intervention¹¹⁻¹⁴ despite the significant impacts of the latter. Enrione¹⁵, for example, found that caregivers rated limited ability to participate in recreational activities as their child's foremost psychosocial problem. For caregivers themselves, stress affected all areas of their home life, including marital relations and relationships with their other children.

The comparatively few studies exploring parents' experiences of HEN (see for example^{8, 12, 16-18}) recommend further research into the experience of HEN for a wider group of families. As Wang & Barnard¹⁹ argue, "Medical technology can work wonders on human physiology and survival but its impact on the way we live and survive in society has yet to be questioned and explored" (p.43).

The HEN service at the study hospital was established in 1996 and is managed by dedicated HEN clinical nurse consultants. Evaluation of the service through customer feedback surveys had been undertaken previously but a more systematic study of parents' experiences was merited to ensure that services are sensitive and responsive to family needs.

Research approach and methods

The study approach

A qualitative, interpretive approach based on principles of interpretive phenomenology^{20, 21} underpinned the central research question of understanding parents' experiences of HEN. Qualitative methods are used extensively in child and family health research for their considerable strengths in discovering and interpreting the many ways in which people articulate and understand their experiences.

The study sample

The study was approved by the hospital's research ethics committee and at all times participant confidentiality was protected. The study used purposive sampling aimed at finding information-rich cases²². The HENS clinical nurse consultant sent information packs to families who used the HENS services (n=150) and only parents who were interested contacted the researcher directly; 34 parents participated in the study. This was a pleasing response, improving on the sample size in previous HEN qualitative studies (see for example^{7, 8, 18}). A follow-up reminder was not sent as the sample was adequate and because these families are often part of other medical research projects.

Thirty females and four males participated, with 23 living in the metropolitan area and 11 in rural areas. Children had either a nasogastric or gastrostomy tube in situ (or recently removed in one case), and were aged between 8 months and 18 years of age with a mean age of 5.3 years.

Obtaining the data

Participants were offered a choice of interview methods to maximise participation and to afford convenience. Individual in-depth semi-structured interviews were conducted with 17 parents. Many of these interviews were conducted via telephone for the participants' convenience. Telephone interviewing has been used successfully in previous phenomenological research²³. Four focus groups were also conducted that involved another 17 parents. The average interview lasted approximately one hour and all were audio taped with permission.

Parents shared their experiences of their child's feeding problems. An interview guide of 'trigger questions' was used based on existing research and clinical knowledge. Areas of interest included life before and after tube-feeding, meal times, their child's general health, impact on siblings, going out and socialising, going to school/preschool, actual and desired support systems and perceived gaps in services they accessed. Little prompting was required as parents' narratives spontaneously covered many facets of their experience, including the physical, psychological and physical impact on their child, family and their role as a parent and caregiver.

Interpretation and analysis

Data collection and initial analysis were concurrent, enabling emerging themes and issues to guide subsequent interviews and workshops, thus maintaining a clearer focus on the

central study question. Interviews were transcribed verbatim with coding and thematic analysis of data informed by the data-driven, inductive approach described by Boyatzis²⁴. The identification of themes and patterns within data and assigning codes involved analysis at the 'manifest level' where information was directly observable. Emerging interpretations or 'latent level' analysis was discussed, debated, questioned and strengthened in further analytic discussion informed by interpretive phenomenology²⁰. The research team discussed and refined emerging findings as the study progressed.

Study findings

The impact of HEN pervaded all areas of family life. Parents were riding an 'emotional rollercoaster' – administering 'nutritional fluids' throughout the day, constantly planning ahead to accommodate activities, being 'case managers' and the primary communicator between health professionals and educational services, curtailing social activities due to the glaring lack of respite care, and often having to face the prejudiced and offensive attitudes of the public when out with their child. These themes are discussed below under three main headings – daily life with tube-feeding, the need for support from others, and public perception of tube-feeding.

Daily life with tube-feeding

Life before tube-feeding

Parents described life before their child commenced enteral feeding and the trying experiences of daily coping as they struggled to feed their child. Despite their best efforts, they were often unsuccessful. As these parents noted:

It was taking me 2 hours to feed him 60mls of formula and he was on 3-hourly feeds [Focus Group 4].

I was spending about 8-9 hours a day trying to feed her small amounts, she would be exhausted and fall asleep and I had to wake her to feed her again and we weren't able to keep her nutritional needs up [Interview 15].

Life after a tube was inserted

Commencing tube-feeding often brought comparative relief for parents (see also^{8, 12}). Although new regimes were required and time and effort was still intensive, their child often subsequently thrived:

I think looking back it was kind of a relief, like I remember just thinking it's got to be better than what we're doing now [Interview 9].

Gastrostomy has made life a lot better, lowered my stress levels by 100% [Interview 14].

However, initial relief was often accompanied by feelings of guilt and grief as parents acknowledged the lost dimension of feeding their child:

...because as a mum you feel she should be having something to eat [Interview 3].

At the same time, there was a disappointment that we couldn't feed her any more. I guess that hit me more when I

got home. I'll never be able to give her a bottle again and I was still expressing – partly the reason why I was doing that was the hope that I could [breast] feed her again, it was that sort of thing taken away from you [Interview 12].

However, parents acknowledged that tube-feeding also brings 'new problems'. Some related to equipment and physiological problems; however, others related to accessing assistance for their child. Parents often learned unwillingly how to re-insert a nasogastric tube to avoid returns to casualty departments, especially when some hospitals insisted that the child must return to the tertiary hospital simply for nasogastric tube re-insertion. Gastrostomy problems included granulation tissue and leakage from the gastrostomy site, often causing skin excoriation. Problems with re-insertion of gastrostomy devices were sometimes helped by using a balloon gastrostomy, thus avoiding a trip to hospital and a potentially traumatic experience for their child. Many of these physical problems were managed by the HENS nurses, or less so by community nursing services; however, the burden of responsibility for carrying out daily management fell on parents.

Taking on a new role

Although their child's health and wellbeing was the primary concern for these parents, one mother's comment encapsulated the feelings of many faced with the new role and responsibilities of providing HEN:

I thought I can't do, this it's too hard, I have to be a nurse, I just want to be a mum [Interview 11].

However, there is no choice or alternative available for parents having to provide HEN:

It was never anticipated it would be such a long process so I didn't want anything to do with it, I would use it but I didn't want to know it too well and then I realised that it was going to be worse for a while so I had to own it and make it as easy as I could for him [Focus Group 1].

As this comment implies, it takes time for parents to adjust to their new situation. We found that such adjustment could be aided by a 'staged approach' to commencing HEN.

The staged approach – nasogastric tube before gastrostomy insertion

For some parents, the need for HEN via a nasogastric tube lessened the psychological impact as it was thought of as a temporary intervention only. Parents often viewed gastrostomy as a permanent intervention and 'last resort' with 'no going back':

The nasogastric feeds, it didn't bother me that he needed to have it, because we knew he needed to put on weight; however, having the gastrostomy was a big thing [Interview 6].

Having the button [gastrostomy], it just sounds too final, where as to me the nasogastric tube there's still always a way out, there's still always just pull it out and that's it they're fine [Interview 4].

Some parents preferred the staged approach of a nasogastric tube followed by a gastrostomy to ease the psychological

adjustment of no longer feeding their child 'in the normal way':

I think having the nasogastric tube before the gastrostomy was the best thing for us as parents because we got past the stage of feeling guilty that we weren't actually giving her anything through her mouth so when we had the gastrostomy put in that was a lot easier than having the messing of her nasogastric tube [Interview 3].

Parents welcomed the progression from nasogastric to gastrostomy for the additional convenience it provided. Parents were satisfied with the decision to insert a gastrostomy when compared to the difficulties they had encountered with the nasogastric tube:

At the time we opted for a nasogastric as I didn't want a permanent thing but I was sick of racing to the hospital every couple of days because he pulled it out or vomited it out. So we opted for the gastrostomy the second time round, a hundred per cent better [Focus Group 4].

... because she had so many skin problems [on face] we were so relieved when they said they would put in a gastrostomy [Interview 17].

Regardless of the mode of HEN, it was important for parents that their child could still experience oral feeding. With HEN, parents knew their child was receiving the necessary nutrition. However, parents whose child either couldn't ingest or refused any oral food/fluids often expressed sadness that their child was deprived of the pleasure of eating. Respondents described the importance of sitting down together and maintaining family meal time routines. Experiencing the 'normality' of family life and the social dimension of eating and mealtimes was important despite the technology of HEN.

The need for support from others

Mothers described being 'nurses' and 'case managers' for their child in addition to their other family responsibilities. Most parents reported attending multiple medical and therapy appointments and were often the sole providers of 24-hour direct care for their child, with very few parents reporting any episodes of respite.

Relying on family members

Family members willing to learn to tube-feed were often the only source of respite. The need for family support sometimes involved major upheavals with parents moving closer to grandparents or vice versa:

My husband's parents lived here (rural town), which is why we moved here, because of my child basically [Interview 9].

If I want to go out somewhere I have to call mum down who's been there with me from the start. And they live on the Yorke Peninsula but mum's basically the only babysitter. They've done 62,000 kilometres in a year, just coming up and down to Adelaide [Focus Group 4].

Grandparents and especially maternal grandmothers played a vital role:

If I didn't have my mum it would have been very hard [Interview 11].

Sometimes family help was from older siblings where a sibling became a 'carer', taking on 'parental' responsibilities:

So [sibling's name] is like a second parent in a way and she's only 12, she was helping me put the nasogastric in [Focus Group 4].

Older siblings provided brief care to allow parents to run errands. However, parents with other children often felt guilty for the amount of time required to care for their child with feeding difficulties, and tried to ensure that siblings had some 'one-on-one' time with a parent. Sometimes the difficulties were more practical, requiring the other sibling to not leave any food or drink around or trying to prevent an inquisitive toddler from pulling out tubes. Overall, siblings were described as accepting and protective and demonstrated a level of understanding that was appreciated by parents.

Support groups

Parents described different levels of isolation due mainly to being the major care provider with no respite, and having restricted access to pre-schools and child care often due to risk of infections, viruses or lack of trained staff to assist with care. Those who, through luck rather than planning, managed to 'find a friend' described the valuable support gained:

The paediatrician put me in contact with a lady that lives here, whose little boy is nasogastric fed as well. We've kept in contact still now, and it was just excellent to be able to talk to her because you've kind of had the same problems [Interview 9].

I mean the hospital gives you lots of information but sometimes it's nice to actually hear from parents... you feel like you talk on their level better because they're at home doing it all the time [Interview 6].

A support group was available at the tertiary hospital at the time of the study but, following this study, advertising to parents about the support group has increased, with more parents attending. At this stage peer support for rural parents is yet to be established. Peer support was particularly valued in helping others cope with negative attitudes and behaviours displayed by some members of the public and even family and friends.

Public perception of tube-feeding

Parents described the attitudes and behaviours of the public as a major problem. A simple shopping trip could become a distressing event. People would stare or laugh at the child, comment on their tube and even ask 'what the tube was for' or 'what was wrong with their child'. Parents recalled people's disparaging remarks and when strangers openly expressed disgust when the child was tube-fed in public. This left parents feeling reluctant to do the normal, everyday things in life and feeling extremely vulnerable and angry. Although parents may have 'defended their child' publicly, the impact of disparaging comments could be profound:

She actually followed me into a shop and came up to me and told me if I had a child looking like that you shouldn't come out of the home... and I turned to her and I said there are nursing homes for people like you. The sad thing is it would be another year before I ever took [name of child] out in public again [Focus Group 4].

Parents described becoming 'hardened' to such remarks:

At first I used to worry, like people used to stare and have a look, I just don't care any more, you get used to it [Interview 16].

However on 'down days' people opted to not go out or felt they would 'bite someone's head off' that made discourteous comments as their tolerance was low. The lack of understanding and compassion by some people (including the public, family, friends and healthcare workers) highlighted that seemingly 'harmless' comments were actually very hurtful.

I heard them say 'Gee aren't we lucky to have a healthy normal baby'. I hate comments like that, they are the ones that hit [Focus Group 4].

Once again support from people 'who understand' was essential for parents to be able to debrief, seek advice or just be comforted by someone who could empathise with them.

Discussion

Caution is warranted, given that this is a comparatively small scale study carried out in one state, and thus the results cannot be generalised to all parents of children requiring HEN. It was our original intention to separately interview children as part of the study; however, parents who responded to the study indicated their child was either too young or unable to communicate easily due to a disability. Where possible, we would urge that children and young people to be included in any future service evaluation research, as their experiences would provide another invaluable perspective.

This study extends our knowledge of the experiences of parents providing HEN for their children. These Australian parents' experiences resonate with other parents – in the UK^{7, 13, 14, 17, 18}, USA¹⁶ and Canada^{4, 8, 9} – in relation to time, effort and anguish associated with feeding their child, the initial relief and subsequent sense of loss following commencement of HEN, the hours spent attending appointments and fighting for entitled support, and social restrictions associated with maintaining a routine of feeding.

Our study strongly supports Craig *et al.*'s recommendation that these families need greater practical and emotional support. Parents need to be afforded adequate preparation time to learn management of HEN for their child. Parents also need time for psychological preparation and support before enteral nutrition is introduced. Parents in this study and others^{7, 8} may view HEN as a symbol of parental 'failure' to adequately feed their child. To ease this transition for parents, healthcare professionals need to assess the readiness of parents to undertake HEN, and employ strategies

such as a staged approach of a nasogastric tube before a gastrostomy tube. For longer-term support, parents in this study benefited from being in contact with other parents to exchange information and emotional support, a strategy recommended in other studies^{16, 25}.

Managing and troubleshooting nasogastric or gastrostomy tube-feeding was acknowledged by parents as a significant learning curve requiring new knowledge and skills that seemed more 'nursing' than 'mothering' in nature. Health professionals play a key role in providing such education and ongoing support for caregivers. However, parents' accounts in this study suggest that such support is often lacking.

An important recurring theme throughout the interviews revealed the social distress experienced by many parents when taking their child out in public and when feeding them in a 'public' place. Craig & Scrambler⁷ comment on such stigmatisation, noting that such "facial disfigurement, caused in part by the NG tube and the surgical tape needed to keep the tube in place, is a very social phenomenon, rendering the child's face public property and prompting people to stare and question" (p.1120). It is difficult to prepare anyone for the hurt and torment inflicted by people who make disparaging remarks about their child, and by deprecating their parenting skills and 'worth'. Some parents were forgiving enough to feel that answering people's intrusive questions provided information that may benefit others in a similar situation. Even these parents, however, spoke of 'bad days' when they just could not face the public scrutiny and implied judgement of others.

One of the focused outcomes of this research has been to increase public awareness of children who require nutritional support via tube-feeding. However, this has achieved only limited success to date despite the assistance of a professional public relations consultant. Even some community publications for parents would not publish articles as the topic was thought not be 'appealing' to their readership. Only disability publications were interested, but these were felt by the researchers to be 'preaching to the converted'.

The hospital's annual report featured the study findings and the researchers spoke at conferences for health professionals and to community groups affiliated with the hospital. As nurses, we need to consider our broader role in relation to educating and influencing societal attitudes. We need to question how we can work toward broadening community perspectives of what is 'normal', especially in view of the increasing number of children with medical problems being cared for at home and taking part in everyday life activities.

The results of this study emphasise the need to attend to the voices of parents and to use their experiences and understandings to shape and improve current HEN service provision. By providing research-informed support for parents and caregivers, this also supports the health and wellbeing of the child who requires HEN.

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