

A Multidisciplinary Model of Care for Children with Feeding Difficulties

The Children's Hospital at Westmead

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Abstract

In October 2003 the first multidisciplinary Feeding Clinic in a public hospital in NSW was held at The Children's Hospital at Westmead. The clinic was established in response to a marked increase in the number of children presenting to CHW with feeding problems, either associated with complex medical conditions, or in isolation.

This increase had been observed over a number of years and the fragmented management practices of the time often resulted in delays in intervention and in the resolution of the problems.

Sucking is the primary method by which an infant feeds, involving a "dynamic and intricate co-ordination" of the skills required. These skills include sucking, swallowing and breathing, situated within a background of the infant's medical condition, behavioural state and family setting. Infant feeding is a complex and multidimensional task which is increased into infancy with a growing demand on voluntary skills. When the feeding process is disturbed or interrupted, it can place great stress on families and can be extremely difficult to manage.

As feeding encompass a range of aspects there is a need for assessment and management to match this complexity. The clinic was developed using an evidence-based integrated approach to complex feeding problems. The clinic is staffed by medical, nursing and allied health professionals.

Since the establishment of the clinic the number of patients referred has been steadily increasing. In 2009 a total of 98 individual patients and families were seen (142 occasions of service at 43 clinics), with many families seen on two to five occasions throughout the year. The clinic was also utilising a Tele-Health service for rural and remote patients which allowed the local therapists and medical/nursing staff to be part of the clinic session. (This service is currently no longer available).

Aim

The aim of the Multidisciplinary Feeding Clinic is to provide a seamless service to improve the feeding outcomes of infants and young children who present with complex feeding problems or of infants whose potential for oral feeding has yet to be established. These problems may result from, or be part of an underlying medical condition eg, cardiac, renal and mild to moderate disability. Infants and children who have feeding difficulties and in whom there is no background medical condition are also seen by the team.

Background

It is well documented that there is a high incidence of immature and abnormal feeding patterns in neonates (Hawdon et al, 2000). These patterns contribute to failure to thrive and

ongoing feeding difficulties. Early intervention is essential if the long term outcome of full oral feeding is to be achieved. If not diagnosed and treated, feeding difficulties, either associated with complex medical conditions, or occurring in isolation can become chronic. Supplemental feeding via nasogastric tubes or gastrostomy is costly in terms of health outcomes and the well-being of our patients and their families. In addition there is the obvious associated financial burden for the family and the health system.

The symptomatic, medical model of care for infants and children with complex feeding needs often results in a fragmented, compartmentalised approach. This can be a source of frustration for families who are already under considerable stress. The alternative is a model of care which acknowledges the interplay between medical, social, behavioural and environmental factors (Arvedson and Brodsky, 2002). The Children's Hospital at Westmead (CHW) established an innovative Multidisciplinary Feeding Clinic, staffed by medical, nursing and allied health professionals, as a response to best practice methodology.

Methodology

The Hospital's Speech Pathologists had been involved in the feeding assessment and therapeutic management of children with a range of complex needs for many years. This involvement gradually extended to other groups of patients presenting with symptoms of feeding difficulty and dysphagia or swallowing problems. In the acute setting, feeding difficulties, as a speech pathology diagnosis, came to equal that of communication disorders. In addition, video-fluoroscopic assessment for patients at risk of aspiration was increasingly requested by referring medical practitioners as an adjunct to clinical assessment.

The Department of Nutrition and Dietetics was facing similar challenges with many of their patients needing long-term feeding assistance and/or enteral feeding management.

The increase in patient presentation over five years was significant enough to seek enhancement of allied health time to manage the caseload. Additionally, it was felt that the nature of the caseload demanded a more comprehensive approach to patient care, and that prevailing management practices did not fit the multidisciplinary best practice model that the research advocated.

Therefore in 2001, CHW submitted a proposal for funding through the Government Action Plan for Health. This was based on the service needs of a population of children with complex systemic medical problems requiring high levels of specialised feeding and nutritional support. It was demonstrated that the lack of a coordinated approach to the care of these patients had implications for equity of access, resource allocation and cost effectiveness.

Planning and implementation

Following the successful acquisition of funding for a part-time Speech Pathologist and Dietitian, a Paediatrician was appointed to engage in discussion with other clinical, nursing and allied health departments with the view to establishing the multidisciplinary Clinic. The concept was met with great enthusiasm due to the long-held belief that this type of service was crucial in a large paediatric public hospital. A core team of health professionals, including a Paediatrician, Dietitian, Speech Pathologist, and three Clinical Nurse Consultants in Child and Family Health, Enteral nutrition and stomal therapy, was formed. An Occupational Therapist and Psychologist agreed to be available in an on-call capacity.

Access to the clinic was state-wide, with referral to the paediatrician by name required for each patient from a general practitioner, paediatrician or neonatologist.

The core business of the clinic was to provide assessment, management and follow-up of infants and children with feeding difficulties, dysphagia and enteral feeding problems for inpatients, outpatients as well as those transferring from inpatient to outpatient status. Outcomes were monitored in this population to inform future practice and to provide education

to community-based personnel to facilitate appropriate referral back to regional health centres.

Outcomes and evaluation

The first Multidisciplinary Feeding Clinic commenced on 31 October, 2003. For the first six months, clinics were held fortnightly. Due to demand the frequency of the clinic then increased to weekly.

The multidisciplinary nature of the clinic ensures that, in one consultation, medical issues that impact on the children's feeding difficulties are addressed, a psycho-social assessment of the child and family is completed, enteral and nutritional intake is monitored, therapy techniques to improve oral-motor and swallowing skills are discussed and stomal care is attended to as necessary. The overall continuum of care into the community is assured and referrals to appropriate services are made.

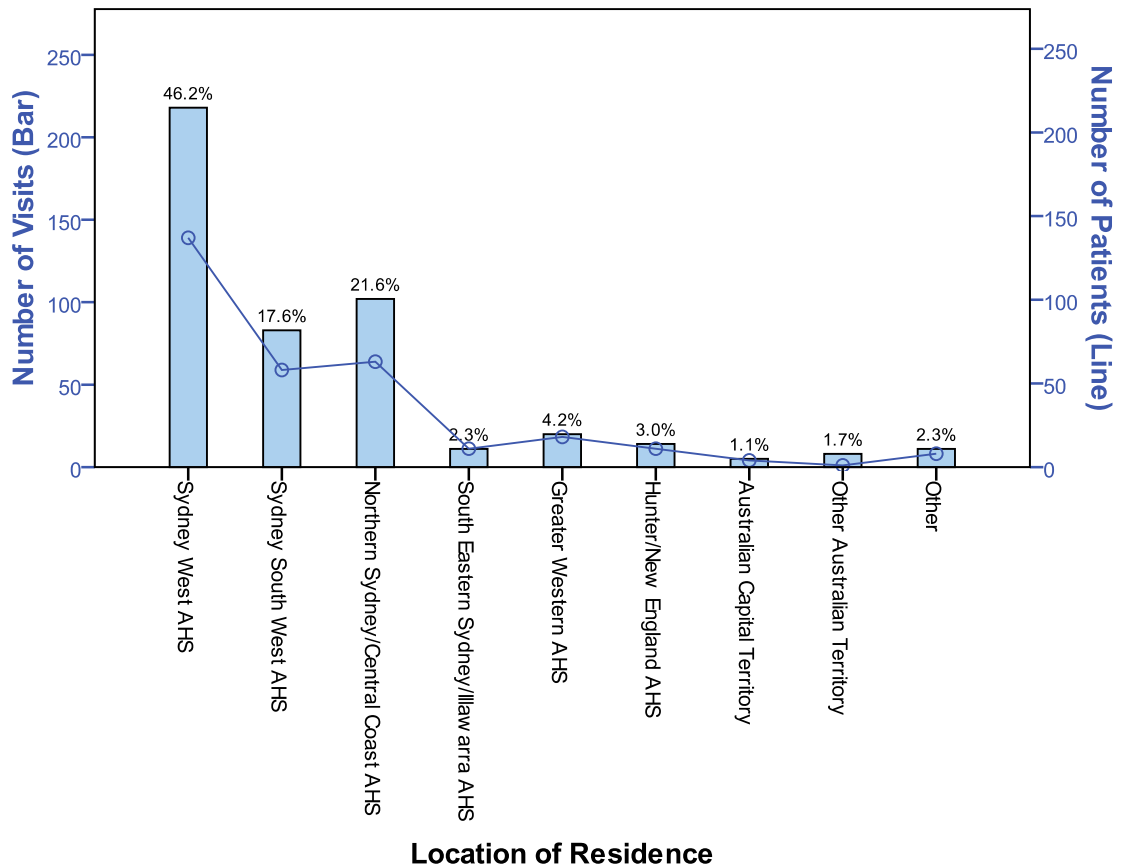
In the five years to June 2009 a total of 539 appointments were booked with a total of 472 patients attending their appointments. Individual patients and families have been seen between 1 – 9 times (as per Table 1).

Visiting Frequency^a	Number of Patients
1	218
2	56
3	22
4	8
5	4
7	1
8	1
9	1

Note: a. *Visiting Frequency=Number of Visits by Individual Patients in the 5-Year Period*

An average of three patients were seen per clinic with the duration of appointments being 60 – 75 minutes as these are often patients with chronic conditions who require a great deal of time. However from April 2009 the number of patients seen per clinic has risen to 4 with each patient being allocated 60 minutes per consultation. There are 2 appointment types within the clinic – for new patients (Feeding new) and for patients seen previously (Feeding follow up). In the 5 years to June 2009 a total of 330 patients were seen as Feeding New, with 142 seen as Feeding follow up. The overall attendance rate over the 5 years has been over 87.6 per cent.

Patient demographics clearly demonstrate the clinic's goal to provide a service without boundaries. The services of the clinic have been accessed state-wide as show in Figure 2.



Due to the success of the Feeding Clinic in achieving its aims, funding was granted via the NSW Health Innovation Fund to set up a tele-health service. The tele-health initiative provided equitable access to the service for families in rural and remote NSW, or families for whom travel to a metropolitan hospital was not a viable option. This had further positive implications for the provision of training and education to rural and remote practitioners who are presented with patients with complex feeding difficulties. This service is no longer available.

Over the last 2-3 years the team have also been involved with the successful management of several infants and children as inpatients. These infants/children have been admitted for a variety of reasons including failure to grow, transitioning off nasogastric tube feeds in a supportive environment allowing the parents to be 'in charge' but guided by professionals. Monitoring children's meal time eating and behaviours, specific parent training/education or in order to trial a variety of different feeding techniques. This practice has also been very successful as an adjunct to the clinics work.

Future scope

Families, in formal and informal feedback, have expressed their satisfaction with the service and the quality of care provided.

“The team were very enthusiastic and concerned. I thought they did a great job – even with our unusual and difficult problem – but keep us inspired – you have the experience and knowledge.”

“The strength of the team and the way a plan is offered on the day is most appreciated. Thank you to all team members who all were very empathetic and helpful.”

“What keeps me strong throughout x’s journey is the fact that I have you all at the feeding team to fall back on when times are tough (just like now); it is very reassuring that I have your expertise, understanding and compassion.”

“We often think of you all there and the magic you weave □ “

A Client Satisfaction Survey was designed by the team with the help of the CHW Service Improvement Unit. The survey was conducted from January to December 2007, and informed changes to different aspects of the Clinic. As a direct result of parent feedback:

- the team has moved to a larger room helping to make the experience feel less overwhelming for parents/children
- a high chair has been obtained for the clinic for mealtime assessments
- there is access to other specialised seating equipment to use as needed
- the Information letter about the clinic has been revised to contain all details regarding the appointment including: the average length of the appointment, the structure and timeline of the clinic and the number and role of health professional in the room during the appointment
- the team have provided a workshop for rural allied health professionals which was aimed at improving the links with local therapists
- education is provided when there is the opportunity within conferences, to increase knowledge of feeding difficulties in children and the feeding clinics role

Due to the demand on the clinic, waiting lists can become quite lengthy with referrals being triaged by the Clinical Nurse Consultants into categories depending on the severity of the problem and the age of the infant or child. In order to manage this some patients, who face a lengthy wait for an appointment, may be seen in the Speech Pathology Feeding Service prior to their appointment with Feeding Clinic if this is deemed necessary. Other families may be contacted by phone on a number of occasions while awaiting an appointment. Patients and families are also reviewed by phone on a regular basis to monitor weight and feeding/eating in between reviews and to provide parents with support and guidance until they can be seen again in the clinic team.

This successful model of assessing and managing infants and children with complex feeding problems using a multidisciplinary team would be suitable for use in other children's hospitals in Australia.

References

- Arvedson J, Brodsky L 2002 *Paediatric swallowing and feeding: Assessment and management* 2nd edition, San Diego: Singular Press.
- Hawdon et al, 2000 *Developmental Medicine & Child Neurology* 'Identification of neonates at risk of developing feeding problems in infancy'- Volume 42, Issue 4, pages 235–239