Hospital to Home Paediatric Enteral nutrition - Parents Need Support

Abstract:
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Abstract
This study assessed the provision of education and support to parents of children on home enteral nutrition (HEN), the challenges facing parents and carers post discharge. 39 of 301 (13%) responses were analysed; 16 written questionnaires and 23 interviews based on the same questionnaire. 29 (83%, n=35) parents suggested services for HEN need improvement, 29 (74%, n=39) parents wanted more structured follow up and co-ordination across all health care services. 36% of parents reported a need for further education of health care professionals (HCP). Hospital dietitians were the most common HCPs reported to provide support to patients following discharge. Specialist paediatric HEN dietetic services working in a dedicated HEN team, who would provide accurate training and education and liaise with both parents and community care services post discharge should be in place. This would facilitate transfer to community care, reduce hospital re-admissions, outpatient department attendances and costs.

Introduction
Prevalence of HEN is increasing as greater efforts are made to prevent the adverse nutritional consequences of chronic disease. 288 children were discharged on home enteral nutrition (HEN) from Childrens University Hospital (CUH) Temple St, Dublin from January 2005 – 2010. While HEN provides cost savings for hospitals, it places greater demands on carers in the community, particularly family members. It is recommended that children receiving HEN obtain regular reviews in a multidisciplinary area which has focused on clinical issues, health outcomes, risk and complication management of long term HEN. Little literature is available on the perceptions of parents and carers of children on HEN. Challenges reported include psychosocial issues, stress and quality of life (QOL) levels and carers opinion of supplies and education. Most common reasons cited HEN reported a need for more support and improved co-ordination between hospital and community services to monitor patients nutritional status. With this in mind it has become increasingly important to understand the perceptions of those directly involved in the provision of care for children receiving HEN. This study aims to assess the provision of education and multidisciplinary support to parents of children on HEN, the dietetic support provided and to understand the challenges facing parents and carers, highlighting improvements that may be required.

Methods
A mixed method cross-sectional study design was used. A questionnaire was developed using available literature and input from clinical dietitians. (10) Verbal consent was obtained. Participants returned written questionnaires and were not interviewed as they did not consent to it and/or due to time restraints. Interviews were recorded, transcribed verbatim, and analysed (including written questionnaires) using thematic analysis aided by NVivo 10 Data analysis software. Quantitative data was described using Microsoft Excel 2010. Themes were reviewed by all researchers involved in the project to ensure agreement. The Scientific Committee of the Childrens University Hospital, Temple Street granted ethical approval for the study.

Results
39 of 301 (13%) responses were analysed. 16 written questionnaires and 23 interviews based on the same questionnaire. HEN patients had a range of medical conditions including neurological conditions (12), Renal disease (6), Cystic Fibrosis (5), metabolic conditions (4) and other diagnoses (12). All parents reported that LTET feeding did or is benefitting their child. 23% of parents reported that it is not without extra work or difficulties but benefits to child and family outweigh these problems. 80% of parents would tell other parents how beneficial a LTET has been for their child. 29% would advise other parents to make an informed decision, be very sure it's what you want and want for your child and family before making that decision. 85% of parents received information at time of LTET placement. 89% felt that all of their questions were answered at the time of LTET placement.

Follow up services
74% reported a need for more structure and support at different stages of the HEN process. Parents that did not need more support were under regular review by a specialist hospital dietitian and nurse i.e. Cystic Fibrosis and metabolic patients. Many parents wished that LTET feeding was seen as a long term condition (83%, n=35) parents suggested services for HEN need improvement. 15% had no suggestions or were happy with all services provided. The main themes identified were a need for education for parents and HCPs, structured support and follow up plan and co-ordination across all health care services.

Discussion
This study provides an insight to the experiences and opinions of a small group of parents or carers of LTET fed children in a specialist paediatric hospital in Dublin. It must be acknowledged that these are retrospective views of those who chose to respond and should be interpreted accordingly. Difficulty recalling past events may contribute to bias. This may be a common problem in wide-scale surveys; techniques to minimise nonresponse were not used as there were a satisfactory number of responses. Bias response may affect results; parents with strong opinions on this subject may have been more likely to respond. The combination of written questionnaires (16) and more detailed verbal interviews (23) collected may have also skewed results. As found by Brotherton et al., a high percentage of...
participants reported that LTET feeding did or is benefiting their child, citing a quick improvement in children's condition, improved QOL for parents and child and reduced feeding related stress since initiation. Much easier than before on both self and son.

Ferادات report that LTET feeding is perceived as a mixed blessing by some parents who was also supported in the current study as 23% of parents reported that HEN is not without extra work and difficulties but the benefits outweigh these problems. It was previously proposed that education of parents and HCPs, structured support and follow up plan in addition to co-ordination across all services were raised by this study group. Rollins found a lack of appropriate information was reported and parents expressed a need for consistent, accurate information regarding the surgery and aftercare, appearance and location of tube, benefits of tube feeding and the possibility of continuing oral feeding. It has been suggested that HCPs should discuss the quantity and type of information needed based on individual parents needs. Little information was received on daily life caring for children on HEN or the possible long term outcomes of HEN by parents in the current study. However, 85% of parents felt all their questions were answered. It was interesting that while parents are often happy with information received at the time, when discharged home they have further questions and may benefit from on-going HCP support. The role of families trained as peer advocates in an un-tapped resource in HEN, which was also suggested by this group. I think that you can learn an awful lot from speaking to other parents that are going through a similar situation. In a study by Evans most patients contacted either a community nurse (40%) or dietitian (40%) for assistance with HEN issues. In the current study, 89% of parents received support from the hospital dietitian and 82% from a hospital nurse post discharge. The DOHC primary care strategy (2001), states that it will enable primary care to lessen the current reliance on specialist services and the home team. This study in CUH, found that of 170 discharged patients on HEN, 78 were followed up by hospital based dietitians in CUH. Given that just 36% of the children in this study are followed up by a non-hospital based dietitian, and a high proportion of queries and referrals are dealt with by hospital dietitians it is unclear that there are enough dietitians to meet the need, while some cases require the input of a highly specialist dietitian, many others would be better served in the community by a HEN paediatric dietitian.

Scottish guidelines highlight the importance of communication and sharing of information between local and regional services for children on HEN to ensure best practice is achieved. The DOHC Primary Care strategy states that discharging planning will be improved, with the development of individual care plans. Nevertheless, more effective co-ordination across all services and communication between HCPs was called for by parents. Public health nurses and GPs were not always perceived to be up to date with what has happened in the hospital. I should be able to go to my GP and my GP doesn’t. Better structure on the percutaneous endoscopic gastrostomy (PEG) procedure should be in place. Support structure should be outlined and there should be coordination across all services caring for my child in Temple Street (CUH)." Rice and Normand suggest that healthcare cost saving requires a cross-sectoral approach to both service delivery and the research in CUN found that of 170 patients discharged on HEN, 78 were followed up by hospital based dietitians in CUH. Given that just 36% of the children in this study are followed up by a non-hospital based dietitian, and a high proportion of queries and referrals are dealt with by hospital dietitians it is unclear that there are enough dietitians to meet the need, while some cases require the input of a highly specialist dietitian, many others would be better served in the community by a HEN paediatric dietitian. In conclusion, HEN via LTET was deemed successful by all parents. However, the current primary care strategy is failing due to a lack of resource, particularly community dietetic posts. A specialist paediatric dietitian working in a dedicated HEN team, who would provide accurate training and education and liaise with both parents and community care services post discharge should be in place to comply with best practice guidelines and current government policy. This would support transfer of patients to community care and reduce hospital admissions, outpatient department attendances and costs.

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References


