

Carers' Experiences of Home Enteral Feeding: A Qualitative Questionnaire on Equipment Use and Medication Administering

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Originally Presented in UKSRG-2016 Conference held at Institute of Child Health, London, UK during February 4-5, 2016.

Abstract

This study investigates carer's experiences of helping with home enteral feeding, with a focus on equipment use and administering medication. Equipment such as feeding pumps and tubing is critical for administering home enteral feeding yet we did not find literature on its use and usability. Furthermore, we know that there are issues with administering medication via enteral tubing and we wanted to gather data on carers' experiences of this. We designed an online questionnaire with open-ended questions to gather experiences of home enteral feeding. A PPI (Patient and Public Involvement) advisory group informed the design of the questionnaire. They simplified questions and suggested additional areas of inquiry such as concerns about keeping patients hydrated and problems with storing feed and equipment. Forty two surveys were completed online. Results include inconsistency in the quality of training of home enteral feeding, issues with storing feed and equipment and particularly for those in small dwellings, problems with tube blockages, alarms, using pumps in low light and wanting lighter and funkier equipment for children. We also gathered hints and tips from carers that helped them prevent problems and make life easier; for example, different methods for unblocking tubing, keeping tubing tangle free, storing spare equipment in key places for emergencies, and designing a trolley so a small child pull his feed along and still move around. This data provides an opportunity to reflect on what can be done to make carer's experiences of helping with home enteral feeding better.

Citation: Furniss D, Orlu Gul M, Smith F, Blandford A. Carers' Experiences of Home Enteral Feeding: A Qualitative Questionnaire on Equipment Use and Medication Administering. Proceedings of UKSRG-2016; 2016 Feb 4-5; London, UK. J Oral Health Dent. 2017;1(S1):A0020.