Title:

Virtual Support at Home: The Impact of innovation for families with children on parenteral nutrition

Introduction:

The aims of this study are to evaluate the impact of a new innovation that puts families in charge of their child’s health and to facilitate MDT working through enhanced communication between professionals and the families of children with chronic intestinal failure.

“Patients Know Best” accounts were given to a small cohort of patients from Great Ormond Street Hospital on long term home parenteral nutrition (HPN). Patients Know Best (PKB) is a secure patient portal and case management system that allows families and patients to use secure messaging with members of their healthcare or support team, see clinical data such as blood results and helps to facilitate proactive management and remote support of patients and their families at home.

The accounts can be accessed by the family and clinicians through any device connected to the internet, and provides safe and secure accounts to share clinical information as it sits within the NHS N3 firewall.

Method:

33 patients were given PKB accounts and a retrospective analysis was performed by evaluating use of the PKB system over an 18 month period, and by completion of an online survey sent through PKB accounts to patients and their families.

As with the introduction of any innovation there are concerns about working in a new fashion with patients and families such as with PKB accounts. It was important to evaluate the impact of this innovation to see if it could be diffused elsewhere and is a sustainable solution. Questions that needed to be answered are:

- Will we generate an increased workload by introducing this system?
- Will we be able to meet patients’ expectations when introducing a new system like this?
- Will we generate anxiety by exposing clinical data on the accounts?
- Will we generate bottlenecks in the work of our clinical team as families adopt and use the system?
- Is an IT solution appropriate for supporting our patients at home?
Results:

System use was evaluated for every account and there was a 45% response rate to the online survey issued to families. Of those surveys, 87% were completed by the patient, 13% by a carer/family member.

86% of respondents reported that the PKB accounts had helped with the management of their child’s care and 92% reported they would “Absolutely” recommend PKB accounts to others. 43% of respondents said they used PKB accounts a few times a month, 29% reported only when a child was unwell, 21% a ‘few times a year’ and 7% a ‘few times a week’. The average number of messages sent by families per month was 1.5 (range 0.2-4.4).

The most useful feature of the account rated by families was the ability to communicate with healthcare providers.

*Figure 1: Whether PKB accounts facilitated contact with professionals*
Discussion:

From this evaluation we can conclude that PKB accounts are a manageable innovation for clinical teams that improves the experience of patients and families and their control of the child’s care when receiving HPN.

Further study now needs to be done on the effect of proactive management and remote support of families at home on patient outcomes when using PKB accounts.