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Continenence problems can limit the lives of young people with spina bifida. A nurse-led telehealth clinic used Skype for remote discussions to develop their independence

Continenence advice by telehealth for young people

In this article...

- The effects on continence problems on young people with spina bifida
- Setting up a nurse-led telehealth clinic
- Lessons learnt from the initiative

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Abstract: McAlpine C et al (2014) Continence advice by telehealth for young people. Nursing Times; 110: 17, 15-17. Children and young people operate in an advanced technological world where new, exciting opportunities exist for remote interactions. To engage with these service users, we set up a nurse-led telehealth facility that enabled young people with spina bifida to access specialist continence service from home. This article describes efforts to embed this innovation into practice and offer insight to some of the challenges we faced in the process. It offers practical guidance on setting up similar services.

Living with spina bifida brings many challenges to those affected and their families. For many young people with this neurological condition who require complex interventions, the paediatric hospital becomes a familiar and generally safe environment where care is offered by trusted health professionals.

Attending frequent hospital appointments can also have a major impact on family life – for each outpatient appointment and planned admission to hospital, parents may need to negotiate child care for siblings, consider travel costs and time off work and plan how best to support their child’s changing needs. Parents’ attention to the care of their child enshrines their dominant role in decision-making; very often, they are present during healthcare consultations, thereby reducing the chance of the young person becoming more confident in making decisions about their own health or self-care.

Young people felt in control online
The tension between parents and young people with spina bifida growing up and needing more control has been noted in a number of studies. Researchers found that many young people with spina bifida depend on parents in self-care areas such as continence management and responsibility at home. In this situation, parents with spina bifida accept ongoing parental involvement because it ensures optimal health outcomes at home in general; Davis et al. (2008) found that adolescents with the condition were increasingly drawn into the sensitive and intimate healthcare provision at a distance, as elicited by Garrett et al. (2011). We offered a small group of service users already had at home. This was to be an extension to other telehealth services offered by the SSBA.

Reviewing the evidence on the use of telehealth to support young people, we set out to address many of the challenges raised during the recruitment of young people to sensitive and intimate healthcare provision at a distance, as elicited by Garrett et al. (2011). We offered a small group of service users and their families an opportunity to explore whether remote access to a telephone or video consultation would overcome some of the challenges they face. The objective was to have weekly telehealth sessions with each young person, from home, with a goal of enabling them to be sufficiently independent to attend a residential summer camp away from home.

Getting started and agreeing an inclusion criteria

The overall objectives for the project were agreed by an advisory group convened to support the project, while individual objectives had to be agreed with participants and their families.

To encourage the young people who would benefit most from taking part in the project, we devised inclusion criteria and a clinical diagnostic measure. The continued development and testing of electronic case notes of potential participants aged 12–18 years. They had to:

- Be dependent on parents for their self-care and social support;
- Have good dexterity;
- Have experienced a face-to-face interaction with a nurse specialist on their own, and in the presence of their parents; and
- Be willing to participate in the project.

The senior nurse, who knew all participants and their families, identified those who were most likely to be able to participate, on their own, in a residential summer camp. Of the entire service user population, 25 young people were identified as potential candidates and they and their families were contacted by post. The letter offered further information about the project and an invitation to contact us if they were interested in participating. We decided to approach families as integral units from the outset, as parents have a major role in enabling their children to gain independence in being beyond dependence. Fifteen families were interested in knowing more about the project. The initial face-to-face contact and assessment of these families were carried out with 11 of them; the other four decided not to take part. Each family had an initial assessment co-ordinated by a monthly youth club meeting run at the SSBA centre. We hoped that offering a clinic when the young people were already at the centre would help with recruitment of participants. After this initial assessment, where further information was given and obtained, families were informed whether they were eligible to take part in the planned project.

Technology • “Fit” and new practice

We envisaged that participants would be given laptops linked to broadcast at a distance, so that specialist video consultation could be offered for the first time. The software could be used to link the nurse and service users.

However, we faced a number of challenges as well as the practicalities and limitations of acquiring sufficient hardware and software licences. After considering published evidence (Armfield et al., 2012; Ciccia et al., 2011; Pakyurek et al., 2010) and the fact that other healthcare organisations from across the globe were using Skype, a free online communication tool, to deliver clinical services, we decided to use this, along with computers or tablets that service users already had at home. Participants who had never used Skype before the project, including the specialist nurse, were given a demonstration and offered access in downloading and configuring the software onto their computer. A few families brought their laptops to the SSBA building, while others received home visits or telephone assistance. All users were offered headsets to ensure confidentiality, and the sessions could be kept confidential.

Having tested and agreed on the technical and professional issues associated with the whole procedure. This type of programme enabled the young people and their families to feel they were progressing well and encouraged them to try the next small step along the self-care journey. As expected, using the technology acted as an incentive for “attending” the virtual clinic, where young people felt they were in control. One participant noted she was relieved to be able to see the nurse on screen, rather than at the clinic, where she could be asked for blood samples. Others were initially reluctant to take an active role in virtual interactions leaving their parents to take charge. However, in time, they were increasingly drawn into the interactions that took place in their own home and, if preferred, own rooms. Parents who were asked to comment on the success or otherwise of the project said it had given their children a tremendous boost to confidence and hope for the future in terms of self-care. Five young people commented on the fact that they now felt much more comfortable and confident with healthcare professionals rather than letting their parent do all the talking.

Lessons learnt

Using technology and accessing a dedicated service from their own home were the main factors that enticed young people to take part in the project. However, adolescence is a challenging period when young people may find it hard to talk to healthcare professionals and share issues concerning their body image and continence.

The relationships we were able to build through the virtual clinic helped to break communication barriers and offered an opportunity for honest and intimate discussions to take place.

Skype proved extremely easy to master and an effective means of communication. Setting realistic expectations with service users and getting them to verbal signals helped the nurse to gain a better understanding of information shared during the interaction. Any service users’ fears about using Skype were quickly overcome through effective support and encouragement. This initial set-up should ensure practitioners are comfortable with operating the technology and assured about issues such as privacy, confidentiality and ethical and competent clinical conduct at a distance.

Setting realistic expectations with service users and involving parents from the outset should enable “ground rules” to be respected. These rules should govern availability of the service, anticipated outcomes and the level of involvement expected from both parents and young people themselves.

Our experience demonstrates that a nurse-led telehealth service to support young people with complex needs is an effective way to extend and enhance the quality and outcomes of nursing services. Setting up, for telehealth to be embedded within core nursing services offered by the NHS, a number of prerequisites are needed (Harvey et al., 2010); these include accurate and reliable information about costs and benefits of telehealth, incentives for use by clinicians, and robust and reliable infrastructures that can offer safe and secure remote interactions.

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References


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