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Contenance 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

Contenance 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

Authors Caroline McAlpine is continence nurse specialist; Lisa Henderson is senior nurse, both at Scottish Spina Bifida Association, Cumbernauld; Sharon Levy is lecturer, nursing studies, University of Edinburgh.

Abstract McAlpine C et al (2014) Contenance 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.

Some interventions that begin in hospital require further input by health professionals and carers in community settings. Third-sector organisations, such as the Scottish Spina Bifida Association (SSBA), also have a role to play in supporting service users and enhancing the limited availability of expert interventions offered by the NHS.

Many people with spina bifida experience incontinence, both bowel and

bladder; in our experience, this is the aspect of the condition that distresses young people most. It has a significant impact on their quality of life and affects how they interact with others at school and when socialising. Lack of facilities and the need for assistance in the toilet can prevent them from participating in social activities such as sleepovers or trips away with schools and clubs. Moreover, studies have shown that incontinence can affect children's body image, self-esteem and ability to become independent and self-confident as adults (Sawin et al, 2009).

Young people's continence problems also affect their parents and other family members; very often, social activities and outings must be arranged around the need to ensure someone is available to assist the young person with continence care. Such actual and perceived dependency on others is difficult to accept during the teenage years, when young people are trying to assert their independence and chart an individualised path into adulthood.

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.

5 key points

1 Third-sector organisations are using innovative means to provide expert interventions in addition to those available on the NHS

2 Nurse-led telehealth services are an effective and desirable means to improve self-care in young people with complex health needs

3 Technology-mediated care can give young people an incentive to attend virtual clinics

4 Sharing control in the digital environment can boost young people's self-confidence

5 Free software can be used to offer remote services, but its robustness, reliability and security must be considered



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. Blum et al (1991) found that many young people with spina bifida depend on parents in self-care areas such as continence management and responsibilities at home in general; Davis et al (2006) found that adolescents with the condition lag 2-5 years behind in acquiring many autonomy skills compared with a "typical development schedule" of their peers. Some young people with spina bifida accept ongoing parental involvement because it ensures optimal health outcomes, but that many report a desire to balance parental involvement and independent decision-making about their own care (Sawin et al, 2009).

It is against this background that the telecontinence clinic was conceived, as a way of harnessing technology to support young people with complex needs 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 by young people themselves, regarding 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 nurse specialist would help them to 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 ensure we chose the young people who would benefit most from taking part in the project, we devised inclusion criteria and a clinical diagnostic mechanism. The continence specialist nurse reviewed all electronic case notes of potential participants aged 12-18 years. They had to:

- » Be dependent on others for their continence care;
- » Have good dexterity;
- » Be able to give informed consent to participate in the project.

The senior nurse, who knew all participants and their families, identified those

BOX 1. BENEFITS OF SESSIONS FOR PATIENTS

- Technology acted as an incentive for "attending" the virtual clinic, where young people felt they were in control
- Parents said it had given their children a tremendous boost to confidence and helped them with their continence care
- Five young people said they now felt much more comfortable speaking to health professionals rather than letting their parents do all the talking

who were most likely to be able to participate, on their own, in a residential summer camp. Out 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 confidence in being independent.

Fifteen families were interested in knowing more about the project. The initial face-to-face contact and assessment appointments were carried out with 11 of these; the other four decided not to take part. The initial assessment coincided with 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 initially envisaged that participants would be given laptops linked to broadband at home, so that specialist video conferencing 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; Ciccio 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 assistance 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 information discussed in the sessions could be kept confidential.

Having tested and agreed on the technical gateway, we prepared a plan that ensured the project was carried out effectively and was acceptable to all involved. We planned to have the first assessment and goal setting with each young person as a face-to-face appointment, followed by weekly Skype meetings. Participants were to complete an evaluation form before the project, after each remote interaction and at the end of the six-month project. Clinical notes were to be completed by the specialist nurse, who was also asked to complete a personal diary of her reflections on personal and professional issues associated with the project. A senior nurse at the SSBA offered clinical supervision and guidance and mentorship was also offered by a specialist telehealth nurse who at the time worked at the Scottish Centre for Telehealth.

Critically, we had to consider the workflow of the remote clinic, the clinical pathways and the "rules of engagement" with each young person. We considered the professional persona needed on screen and evaluated the benefits of having the interaction from an informal clinical setting or the home of the specialist nurse. We also had to think of potential telehealth challenges such as:

- » What if the technology fails midway through the session?
- » What if the young person is becoming distressed and needs comforting?

We had to devise solutions to potential risks while considering ways to capture and record clinical information and learn lessons to help us refine our nursing-led virtual service.

Providing a service at a distance

After pilot testing the technology, we arranged the first remote session with a number of families. In her reflective diary, the nurse noted that the first session went better than expected.

The technology worked well and it was evident that seeing the young people while developing a therapeutic interaction and designing a care plan together was extremely beneficial. Having had the experience of offering advice via a telephone

helpline for a number of years, the nurse felt that seeing the body language and having a face-to-face interaction was far superior to a phone consultation.

The sessions improved with time and for many families and young people the virtual clinic appointment became a routine engagement on a set day and time, very few sessions were cancelled at short notice. The continuity of the service and the ongoing engagement enabled further treatment goals to be set with follow-up and monitoring done on a continuous and frequent basis. Such a sequential nursing care plan is ideal for service users with spina bifida, who benefit from breaking goals into a number of tasks they can easily attain.

The weekly sessions focused on confirming progress with a task mastered during the previous week, and moving young people onto the next step in attaining their self-care goals. An example would be giving them the responsibility of opening the catheter package themselves as a first small step to becoming more involved in and ultimately becoming responsible for 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 helped them with their continence care. Five young people commented on the fact that they now felt much more comfortable speaking to health 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 health professionals and share issues concerning their body image and continence challenges. 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. Seeing the young people and getting non-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 individual mentorship. This segment of an 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 and adhered to. Such 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. However, 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 infrastructure that can offer safe and secure remote interactions. **NT**

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