Evaluating a telehealth intervention for urinalysis monitoring in children with neurogenic bladder

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Abstract

Telehealth as a community-monitoring project within children's urology care is an innovative development. There is limited evidence of the inclusion of staff and parents in the early-stage development and later adoption of telehealth initiatives within routine urological nursing care or families' management of their child's bladder. The aim was to explore the experiences of key stakeholders (parents, clinicians, and technical experts) of the proof of concept telehealth intervention in terms of remote community-based urinalysis monitoring by parents of their child's urine. A concurrent mixed-methods research design used soft systems methodology tools to inform data collection and analysis following interviews, observation, and e-surveys with stakeholders. Findings showed that the parents adopted aspects of the telehealth intervention (urinalysis) but were less engaged with the voiding diary and weighing. The parents gained confidence in decision-making and identified that the intervention reduced delays in their child receiving appropriate treatment, decreased the time burden, and improved engagement with general practitioners. Managing the additional workload was a challenge for the clinical team. Parental empowerment and self-efficacy were clear outcomes from the intervention. Parents exercised their confidence and control and were selective about which aspects of the intervention they perceived as having credibility and which they valued.

Keywords

Neurogenic bladder, parents, remote patient monitoring, soft systems methodology, telehealth

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Background

The management of neurogenic bladder in children with spina bifida, a neural tube defect, can be problematic for health care providers as well as their parents (National Clinical Guidance Centre, 2012; Smith et al., 2016). The personal, physical, health, and economic costs of managing neurogenic lower urinary tract dysfunction as a result of spina bifida are considerable (Ouyang et al., 2007). Children with neurogenic bladders are prone to developing urinary tract infections (UTIs) as a result of neurogenic damage and bladder management approaches, that is, intermittent catheterization (Kaye et al., 2016). Furthermore, recurrent infections, illness, and incontinence episodes can impact on short- and long-term health as well as quality of life (Lemelle et al., 2006; Padua et al., 2002). Therefore, early detection and management of the child's urine infection is important (Dik et al., 2006). Telehealth offers the potential for both improving the child's health and easing the demands made on families caring for children with complex health care needs (Cady et al., 2009).

Although telemedicine and telehealth are seen as discrete entities by some authors, both The Cochrane Library (Cochrane Library, 2010) and the WHO (World Health Organization, 2009) acknowledge that definitions overlap (Carter, 2014). Broadly, telehealth is the capacity to use technologies that enable patients and clinicians to remotely exchange information about the patient's health (Hendy et al., 2012). Such technologies are suggested to enhance health outcomes, particularly for those located in rural and remote communities who would otherwise not receive timely access to services (Fraser et al., 2017) or those marginalized due to mobility restrictions or caring responsibilities (Kruse et al., 2017). In North America (Call et al., 2015; Muttitt et al., 2004), Australasia (Caffery et al., 2017; Smith et al., 2015) and Canada there have been various levels of uptake of telemedicine and telehealth in health care settings within urban and Aboriginal contexts (Jennett et al., 2003). In the United Kingdom, digital and information technology (IT) systems within health care have mostly grown in primary and community sectors (Honeyman et al., 2016) and implementation initiatives have tended to focus on elderly care and long-term conditions such as heart failure (Taylor et al., 2015b). Aware of the need to move forward, a national advisory group reporting to the UK government highlighted the need to harness digital solutions within secondary care (Watcher, 2016). In respect of children, NHS England (2016) states that future children's services will be supported by digital transformation plans. However, Watcher (2016) warns that getting it right as opposed to doing it fast is critical if the United Kingdom is to achieve the 'triple aim' of improving care, improving population health, and reducing health care costs. Telehealth offers great promise and can expand the 'reach of medicine' (Dorsey and Topol, 2016, p. 159) but, as a 'young' health intervention (Kruse et al., 2017), evidence explaining success, failure, acceptability, and sustainability is needed (Albury et al., 2018; Greenhalgh et al., 2017a, 2017b). The challenges in the development and uptake of telehealth are multifactorial (Greenhalgh et al., 2017a; Mistry, 2012); barriers include limitations with telehealth equipment and the complexities of data sharing (Standing et al., 2018; Taylor et al., 2015a), variable organizational support (Odeh et al., 2014), low staff engagement and increased workload (MacNeill et al., 2014), and sustainability (Taylor et al., 2015b). A key challenge highlighted by Greenhalgh et al.'s work (2017a, 2017b) is the potentially 'brittle' nature (fixed and a tendency to lack resilience) of software systems as compared to flexibility embedded within human systems, which can more easily absorb and respond to changes. To address the question of how successful telehealth interventions work, a realist review (Vassilev et al., 2015) highlights that interventions can deliver benefits for patients and care providers when attention is given to (1) the relationships that can be

fostered, (2) the fit with existing lifestyles or preferred routines, and (3) enhancing the visibility/awareness of the health concern.

Few studies have explored telehealth in pediatric populations; existing research predominantly focuses on remote coordination of health care (Vigil et al., 2015) with tele-psychiatry finding a place in parent educational and coaching models (Becevic et al., 2016; Little et al., 2016). There is evidence for successful use of telehealth with small groups of children with complex needs in the home setting (Cady et al., 2008; Hepburn et al., 2016). More evidence is needed around the development and planning phase to get telehealth 'right' (Standing et al., 2018; Watcher, 2016) for children, their families, and the health care teams delivering care (Brophy, 2017; Kruse et al., 2017; Ray et al., 2017).

In this article, we describe a proof of concept six-month pilot and evaluation of a telehealth intervention for children under five years of age with neurogenic bladder. The evaluation incorporated soft systems methodology tools that guided an analysis of the interaction between the people and technology central to the home-based telehealth intervention.

The telehealth intervention

Building on national best practice guidance recommendations (National Clinical Guidance Centre, 2012) and parents' accounts of wanting to be able to better manage their child's symptoms of suspected UTI, a collaborative team of stakeholders (parents, the urology team, hospital innovation team, commercial partner, and call center staff) was established. A process-based method for project management (PRINCE2) was used to underpin the development of the intervention. The intervention ran from July 2014 to January 2015 and was underpinned by local patient safety directives and governance systems.

Development of intervention

The telehealth intervention was developed with stakeholder requirements foregrounded, in line with Vassilev et al.'s (2015) conclusions that early 'upfront consideration' should be given to the mechanisms important in determining success in development, implementation, and outcome of any telehealth approach. The early engagement approach was intended to ensure a patient-centered approach and generate additional benefits for the parents (i.e. enhanced knowledge base about their child's bladder, increased sense of empowerment in clinical consultations, and confidence in knowing when to seek further medical advice). The stakeholders wished to develop a system that would record and alert parents (e.g. through a visual indicator of symptoms) and urology nursing staff to signs of likely urine infection. It also aimed to create a mechanism for collecting and transmitting data required by secondary care providers working to meet national standards (National Clinical Guidance Centre (NICE), 2012). The final telehealth package was a digital system (see Table 1) that parents could use at home. This package monitored and recorded information about the child's urinary tract health sent data directly via a National Health Service (NHS)-approved secure server to the commercial partner's data collection centre (CPDCC). However, the commercial team project members involved in the direct implementation of the intervention did not have access to patient data. The CPDCC analysed the data according to the agreed protocol and alerted the clinical team (CT) as indicated, advising the nurse to log into the secure system and identify which patient required follow-up. As part of the proof of concept, the stakeholders were keen to explore whether the telehealth intervention was helpful or

Table I. Summary of device type and action.

Technology	URISYS 1100 (ROCHE) portable urinalysis device.
	Safety tested by provider and hospital engineering department.
	Weekly monitoring and as necessary.
Bluetooth Devices	Weight scales
	Thermometer
	Weight biweekly, temperature biweekly, and as indicated
Electronic device	Device to record weekly voiding diary data/bladder and bowel management.
	This was on a mobile system that had no telephone connection but was a midrange specification device.
	The voiding diary was informed from the NICE CG54 (2017) UTI diagnosis and management guideline. Parents and staff viewed and tested the data entry before use. Minor amendments were made to the diary in line with parental recommendations
Mobile Receivers (MR), devices receive alerts	(Daily monitoring between hours 8 and 6 pm; Monday to Friday). Low specification mobile devise to receive text messaged and alerts from call centre and families

burdensome in everyday life. Additionally, stakeholders wanted to consider the feasibility of telehealth as an approach to meet the NICE CG148 (2012) minimum standards of care for assessment and management of urinary incontinence in neurological disease.

Self-selection of families to use the intervention

All families ($n = 21$) known to the urology nursing team whose children were aged less than 5 years, had had surgically corrected spina bifida, were under the care of one of the three hospital urologists, and were being intermittently catheterized by their parent were invited by a letter to participate in the pilot study. Parents were reassured that engagement in the pilot would not impact on their child's standard care pathway, and they could continue to access the urology service if they had concerns. Self-selection was crucial because reports suggest that ambivalence toward tele-health will challenge utility (Sanders et al., 2012). Families agreed to submit biweekly voiding diary data (bladder and bowel information and urinalysis). Mobile and Bluetooth-enabled devices were to be used to collect, produce printouts, and automatically transfer the information to the analytics team, who raise alerts when recordings were outside of normal ranges. Of the 21 eligible families, 12 replied and the first 10 replies were accepted onto the intervention (due to there being only 10 intervention kits available through commercial partner provision). The families lived between 2 km and 116 km away from the hospital.

A workable telehealth system requires selection of appropriate technologies and the development of tailored training (Vassilev et al., 2015), and in this instance, frontline training was provided as detailed in Table 2.

The evaluation

The focus in this article is on the experiences of the CT and the parents, although some responses from the technical teams (TTs) are interwoven in the findings.

Table 2. Table of front line training delivered and data collection requirements.

	Clinical staff	Parent	Commercial partner
Technology (urinalysis)	Face-to-face training how to use to support parents in home context/problem-solving if failure.	Face-to-face training further supported by video tutorial (developed by nursing team) to augment learning in use, cleaning, safe use, and storage. Collection, ordering and return of (all) equipment, reporting damage and failure.	Role in data reporting, alerts, transfer issues. Shipment of disposable supplies to families.
Bluetooth (scales, thermometer)	Hands on education around connectivity and how to reboot systems.	Real-time demonstration, training and troubleshooting. Safe use and storage. Home connectivity and wireless management.	Duty to report to nursing team data omission, equipment failure, or connectivity challenges
Electronic device (ED) for data entry	Training/problem-solving skills/remote access/data input/contact history and alert training and management	Face-to-face training supported further by summative sheet of instructions on use	Duty to report to nursing team data omissions and failures False alerts and scheduling
Mobile receivers	Device training	Not applicable	Not applicable

The key aim was to explore parents', clinicians', and technical experts' experiences of telehealth intervention, including the effectiveness of the proof of concept telehealth intervention in terms of remote community urinalysis monitoring by parents of their child's urine.

Evaluation design

This evaluation used a concurrent mixed-methods research design (Creswell and Creswell, 2018); our methods involved interviews and observation (qualitative) and e-surveys for the clinicians and a researcher-administered survey for parents (quantitative). In addition, to structure both data collection and analysis, we used two evaluation-oriented tools: a strengths, challenges, opportunities, and barriers (SCOB) matrix and from soft systems methodology the, customers, actors, transformation, worldview, ownership, environmental constraints (CATWOE) analysis (Checkland, 2000; Checkland and Scholes, 1999). This soft systems methodology initially frames real-world situations in a fairly unstructured yet problem-focused way working from a root definition (statement of purpose) toward conceptual model thinking and finally exploring solution orientated actions. This approach can be helpful in untangling the evaluative lessons from projects that have multiple goals often linked to the perspectives of each stakeholder (Burge, 2015).

Sample

Our sample was drawn from three stakeholder groups who were involved in the telehealth intervention: the parents of children who met the inclusion criteria for the intervention, as previously

described; members of the nursing team from the children's urology service and the technical experts (six from the commercial partner and five from the hospital). All potential participants were sent detailed participant information sheets that explained the project and their rights to decline to participate and withdraw from the study if they wished without their child's care (parent participants) or their working life (clinicians) being affected.

Data collection

Qualitative data (interviews and observation). We undertook semi-structured interviews with parents at three time points (TPs). These were undertaken either face-to-face or by telephone, depending on the parents' preferences; most preferred telephone interviews as they were 'easier to fit into a busy life'. At TP1 baseline, we focused on generating baseline data on parents' previous experiences/ outcomes with their child's UTIs and on their perspectives and understanding of telehealth. At TP2, midway through the intervention, we focused on the parents' experiences of using with the equipment and drilled down to explore any issue and challenges. At TP3, on completion of the intervention, we focused on their overall experiences and lessons learned. The CATWOE was used to help us structure the interview to ensure we focused on their perspectives and understanding of the telehealth intervention and we purposefully explored issues surrounding self-efficacy and mastery in relation to their engagement/transformation with telehealth.

Additionally, we observed group meetings that were facilitated by the clinical staff to provide additional support to the parents. Our observation of the groups was guided by the use of a template that addressed a range of issues including communication styles; opportunities for parents to demonstrate learning/issues/concerns; tone, agency, key actors, power; barriers/facilitators; time burden of being part of project; emerging ideas/solutions; and power dynamics.

Quantitative data. We sent e-surveys to the nursing team and technical experts (commercial and in house) at the same three TPs described earlier. The questions were designed around the SCOB and focused on preparation, training and day-to-day experiences of the intervention. We also administered the General Self-Efficacy Scale (Schwarzer and Jerusalem, 1995) to parents as part of our interview encounter with the parents to allow us to track changes, if any in self-efficacy over the course of the intervention. The e-surveys for clinicians and TT were mostly closed response questions with some open-ended questions. These surveys collected data on a range of subjects including their prior experience of telehealth, expectations and level of confidence with telehealth, expected beneficiaries, training for parents, burden of time taken up by telehealth intervention, and impact on standard clinical workload and strengths, successes, and barriers to implementation.

Ethics

Ethics approval (STEMH 265) was provided by the STEMH Ethics Committee at the University of Central Lancashire. Informed written consent was obtained from all participants by a member of the research team, and ongoing verbal consent was obtained from participants who engaged in more than one element of data collection (e.g. being both interviewed and observed). As the stakeholder groups were small we took considerable care to ensure anonymity and confidentiality but made it clear that anonymity was not possible to achieve between participants attending group sessions.

Data analysis

The qualitative data were analysed using thematic analysis (Attride Stirling, 2001) and we also drew on CATWOE analysis, developed from soft systems methodology (Checkland, 2000; Checkland and Scholes, 1999), as this provided a framework of six key elements for considering the root definitions of the complex intervention and allowed us to examine the consonance/dissonance of the expectations of the three key stakeholder groups. The quantitative data were analysed using descriptive statistics (mean, mode, and median), and data are presented as raw numbers and percentages, as appropriate. The following abbreviations are used: CT, TT, and parent (P).

Results

The results are presented in three sections as follows: (1) perspectives of the CT and the TT, (2) parents' perspectives, and (3) the CATWOE analysis.

Perspectives of the CT and the TT

Experiences of start-up. At the start-up stage, there was considerable positivity from all participants about what the intervention could do, such as 'change the reliance of the care pathway from a clinician centred model to a child centred model' (CT). There were some initial concerns raised during the start-up stage in relation to the intervention kit where the 'the IT kit didn't work when we had to load patient data [manually]' (CT). The key barriers initially were 'unfamiliarity with telehealth', 'lack of time', 'technical issues with the equipment', and the need for 'better communication between the us and them [CT and TT]'.

Experiences at the end of the intervention. By the end of the intervention, there was general agreement that a 'clear[er] communication should have been in place' (TT). It was also evident that the intervention was 'overlayed on the Urology team's day job rather than a fully managed service' and the time burden of the intervention on the clinical staff varied according to the 'number/content of alerts, clinical workload and staffing levels' (CT). There were some negative impacts on the regular service and some disappointment with some aspects of the intervention:

> . . . extra time, difficulty contacting families, GP and chasing results - disappointing that the families didn't complete the diary this was a key aspect of the study (CT).

There were also difficulties for the CT in contacting parents when an alert has been triggered which required a clinical response as:

> . . . many families just don't reply. It seems to depend on how you phrase the message (CT).

The CT identified the need to follow these issues up with the user group. Attitudes about the pilot ranged from frustration to varying levels of enthusiasm with particular focus on the impact the pilot had on daily nursing workload and interruption in family life. Having access to technical support as well as the dedicated resources and disposables necessary to manage the pilot project were cited as essential by staff. Staff training and the partnership approach with the commercial partner and families were considered a success in operationalizing the pilot.
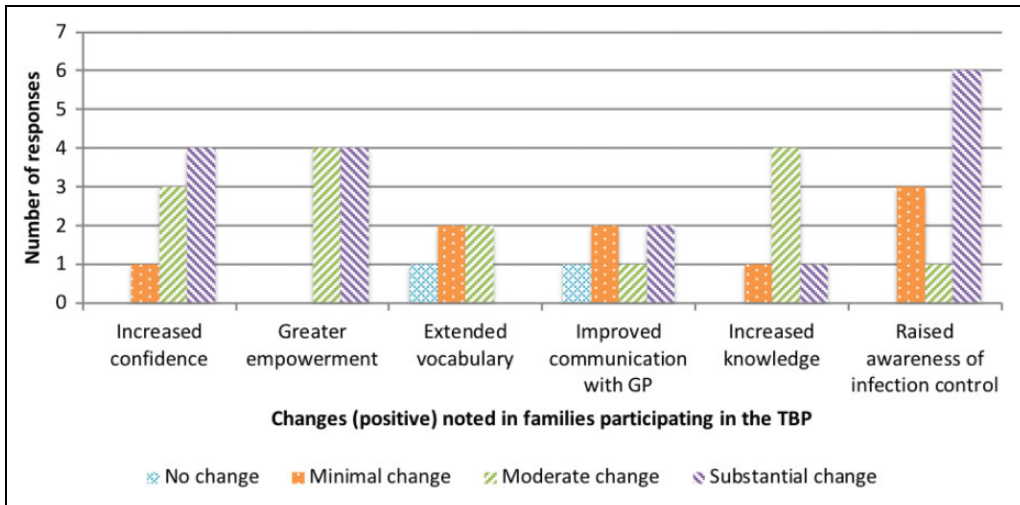
**Figure 1.** Positive changes noted by clinicians for families participating in the intervention.
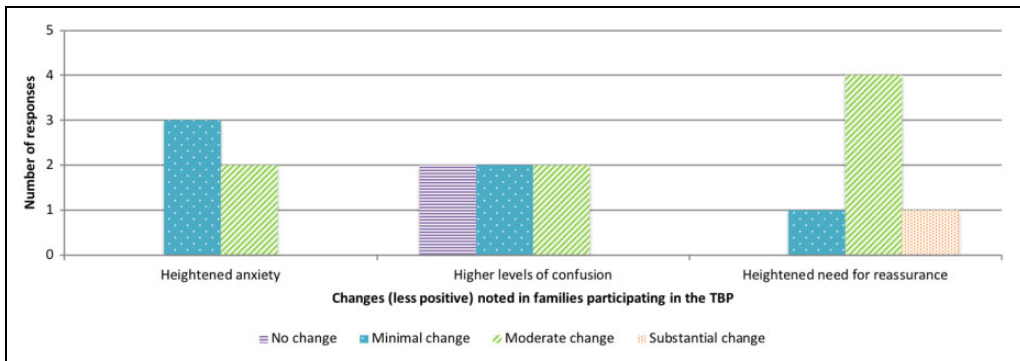
Figure 2. Less positive changes noted by clinicians for families participating in the intervention.

Changes and benefits of participation. By the end of the intervention, the CT noted a range of changes in the parents' participating in the intervention. These included greater empowerment, increased knowledge, and raised awareness of infection (see Figure 1).

However, there were some less positive changes noted, although these were generally more short term and reflected concerns at the start of the parents' engagement with the technology (see Figure 2).

Benefits for families and staff resulting from participating in the intervention. Parents were perceived to benefit from being more confident and more empowered with the lowest benefits being linked to 'extended vocabulary to talk to GP' and 'improved communication with GP' (see Figure 3). Interestingly, this was at odds with how parents described the benefits in their interviews.
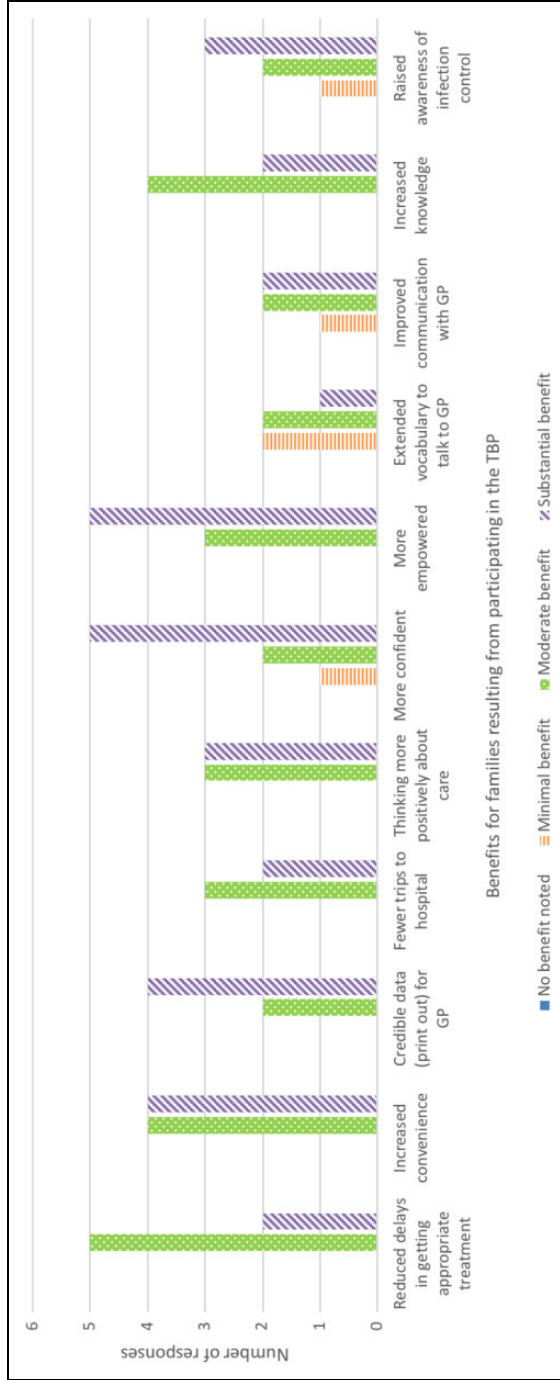
Figure 3. Benefits for families resulting from participating in the intervention.
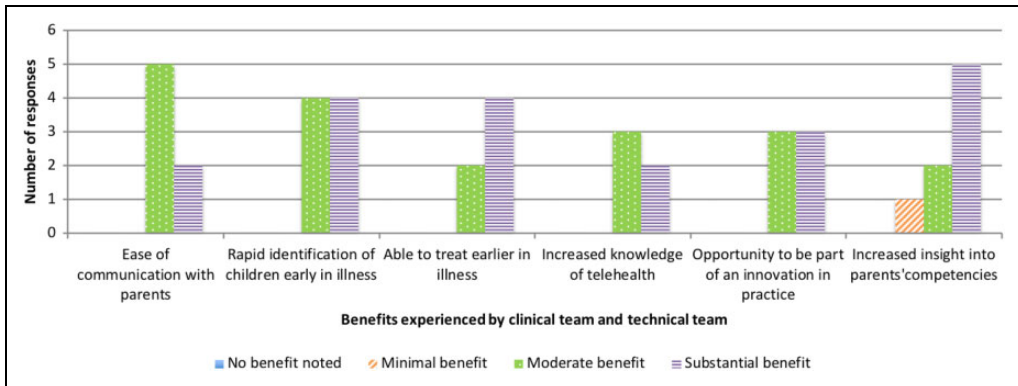
Figure 4. Benefits experienced by CT and TT from participating in the intervention. CT: clinical team; TT: technical team.

Overall, the CT and the TT reported benefiting from their engagement in the intervention as can be seen in Figure 4. These benefits broadly reflected the topics of care management, working with parents, and personal professional development.

Parents' perspectives

The parents ($n = 8$) who participated in the interviews had children aged from 16 months to 4 years. All of the parents we interviewed felt that they had benefited from the intervention and wanted to continue with the urinalysis aspect of the intervention and to retain the use of the equipment; the printout of the child's results was highly valued. However, they were much less interested in the other aspects— weight, temperature, and voiding diary. While some families tried to comply with weighing ($n = 6$) and some had tried to comply with taking their child's temperature ($n = 6$). However, compliance was inconsistent due to problems with the technology, for example, 'the thermometer was a pain initially. Coordinating into his ear. He didn't like it' (P4). There were some challenges with weighing the child such as the scales 'never working properly' or mobility-related problems such as:

> My little boy can't stand up so what I had to do was I had to stand on them and send them that result and then stand on them with my little boy and send that result. (Parent 6)

Families who had tried using the voiding diary had found 'getting the urine sample [volume], that's the hard bit!' (P1); accuracy was hard to achieve as catching the urine in a measuring jug was difficult. For some parents, this also had an impact on their daily routine as one parent explained 'I had to get her up earlier so I could fit [the monitoring] in in the morning before she was getting ready for school' (P7). There were also problems with incomplete delivery of the equipment (e.g. the jug for measuring urine):

> We didn't have as many testing strips and we didn't have as many covers for the thermometers . . . we could only do the temperature testing for about the first 2-3 weeks. (P2)

One father commented when asked about the best and worst things about the equipment explained he was 'struggling' with the 'voiding diary' as it 'hadn't been explained properly'

(P4). Another parent explained that their chief difficulty was that they had experienced a burglary and part of the equipment (the telephone) had been stolen. It had not been possible to replace the stolen equipment and so this had limited their ability to take advantage of the telehealth service.

The following two themes summarize parents' experiences of the intervention and their suggestions for improvement and the ways in which it impacted on their lives and the lives of their families.

Generating a sense of self-empowerment and self-efficacy. It was clear that parents valued the ability that telehealth gave them to be able to 'get on' with life, 'to know what was going on' and able to 'just crack on with it basically' (Parent 1). Although telehealth did not wave a magic wand and dismiss the parents' concerns and worries, life became easier when they had worries as it introduced a structured way of dealing with their concerns that fitted with their ability to make decisions and take action:

> It just made life so much easier having the equipment at home, if we were worried, if he had a temperature, the first thing we think of is test his urine. (Parent 3)

Parents felt empowered by having the 'proper equipment', knowing how to use it, being able to check things 'properly':

> . . . that way I know I'm making the right decision on whether to take her up to the hospital, take her to the doctors or make a phone call. (P7)

Many of the parents talked about how they valued the way the intervention had helped them, giving them 'a bit more confidence' about what actions to take. Another parent explained 'it gives me the confidence that I can deal with it rather than putting him through an A+E experience again' (P8). They made particular reference to the urine test print out, which provided visible and credible evidence of their concerns. Having the printout appeared to empower parents and supported a shift in the relationship dynamic with GP front desk staff. Parents explained the GP staff 'have to pay more attention, they listen to you and we get seen by a doctor quicker now'. The 'authority of the machine' also helped to increase parents' awareness and deepened their knowledge, for example, 'now I'd say that there is protein in the urine'. It also stimulated their thinking—'what do these symbols stand for?'—and acted in a pedagogical manner extending the parents' vocabulary, as one parent explained:

> I know new words now . . . . you know words that the machine says. (P1)

The parents all wanted to 'keep the machine' and were positive about the ability to test their child's urine and having a print out of results. However, the parents were less positive about weight, temperature, and the voiding diary as previously presented.

Normalizing life and reducing hassles of everyday management. The intervention helped to normalize life and reduce the hassles usually associated with managing their child's neuropathic bladder such as not having to 'drag all the kids to the doctor'. Saving parents' time was highly valued by the parents as it meant they were able to get 'the results back there and then' and they were not 'having to worry about every little thing . . . [or] rush off to hospital every time we think there is

problem'(P1). It also avoided the hassles associated with waiting to be seen by staff in the Emergency Department at the hospital and also having to repeat the child's history to a doctor who was unfamiliar with the child and having to go through 'the big rigmarole of going through all his history again' (P8). Therefore, the intervention was perceived as a means to minimize the inconvenience caused by care of a child with a neuropathic bladder and in that way it offered a 'good fit' with their lives and preferred routines.

The best thing is it's easy to test instead of going to the Doctors. (P2)

One of the parents talked of telehealth being a 'godsend' and explained that she was the 'first one to volunteer' (P5).

However, there were some drawbacks to telehealth as the alerts were not always helpful. While these 'unhelpful' alerts were a bit of an issue, they were viewed as being much less of a 'hassle' and more easily sorted than having to 'drag' the family up to the hospital. Lessons were learned during the course of the intervention so that these machine-related hassles such as 'false positives' were more easily managed, understood and overcome. Another parent explained that even though 'it's not always accurate and the testing sticks sometimes gave wrong readings' that they would be 'lost without it [machine]' (P2).

The root definition and CATWOE analysis

The core components of the evaluation were to understand the system purpose, the various stakeholder perspectives, and the transformation generated by the system. The Root Definition (system purpose) was established as part of the telehealth intervention development phase and informed the CATWOE analysis embedded within the evaluation phase. Table 3 summarizes data set against the CATWOE six key elements at time points one and three and illustrates system features that impacted positively and negatively on the effectiveness of the telehealth intervention.

The CATWOE analysis shows that over time the child remains the core customer, though additional actors, contributing to the system purpose, are identified, that is, general practice staff. As transformations take effect, new environmental, ownership, and world view features become apparent. For example, using and learning from the technology, parents use new resources (personal confidence and material printouts) to advocate for their child. Use of the technology, also generates 'alerts' and a need for regular supplies of disposable equipment, placing new demands on the CT, owners of the integral support system required for operating the telehealth intervention. Errors in the technical system that generate false-positive alerts and equipment/monitoring systems that have a poor fit with parents' care practices create negative impacts on some of the environment features and world view thinking.

As noted, the CT own the support system required to operationalize the intervention; however, it is the commercial partner who own the product and knowledge of how it works. This means that when technical glitches occur, the CT do not have the 'know-how' to correct these and cannot offset the burden that glitches introduce. For the CT, this increases workload and frustration with the intervention. When the project was operational, these local environmental features became prominent and overshadowed the national environmental features (policy) originally used as motivators for setting up the pilot.

Table 3. Overview of CATWOE findings.

Root Definition—Telehealth intervention	CATWOE and TP1	CATWOE and TP3
The pilot project represents a joint venture between the private and public sector that offers opportunities to benefit child health and the service ability to comply with national (NICE) data monitoring standards. It centres on a digital product owned by the private company, operated by parents and clinical staff. Provision of the equipment (by the private partner) and training in equipment use (provided by the private and public partners) will allow parents to regularly assess and parents and clinical team to take early action to limit the development of urinary tract infection (UTI) and associated complications for children with neuropathic bladder.	Customer: child Actors: parents, CT, private company Transformation: The installation of health connecting technology in the home; parents and clinicians trained in using technology; parents have a system to follow; print out to learn from and share World view: Technology is an 'ordinary' feature of life, technology can release time, make regular assessment and monitoring easier. Ownership: The commercial partner and the clinical team shared the project Environment: National policy supports digital solutions. National (NICE) guidance on monitoring and assessment	Customer: child Actors: arents, CT, private company, health gatekeepers, GPs Transformation: Parent involved in regular urinalysis assessment; timely and easier action, use new language/communication, sense of confidence, belief in ability to act, gates opened; alerts sent to clinical team World view: Technology (machine) generates authoritative information (printout) for legitimate action (access to medical treatment); some monitoring too demanding, for example, diary Ownership: Product owned by the commercial partner; action owned by parent; support system owned by clinical team Environment: Local work pressure from alerts; frustration from false-positive alerts; disposable equipment availability; challenge of pediatric situation and monitoring plan fit with family practices

Discussion

The findings clearly show the ways in which the parents developed a greater sense of self-efficacy in relation to the management of their child's neuropathic bladder. The concept of self-efficacy encompasses the belief a person has in their own ability to act (Bandura, 1982 Please provide complete reference details for Bandura, 1982or allow us to delete the citation here.]). Self-efficacy encompasses issues such as engagement, mastery, and feedback; these components figured strongly within the parents' feedback. The parents reported that they felt they were better positioned to act and more confident in the decisions they were making and the actions they were taking as a result of components of the telehealth intervention. Other studies included within a systematic review of patient satisfaction with telehealth demonstrate that enhanced confidence, self-efficacy, self-awareness and self-management, and timely diagnosis due to increased access to care are from the patient perspective, some of the most positive outcomes (Kruse et al., 2017). Other evidence indicates too that telehealth can be acceptable to young people and families Gur et al. (2016).

The adoption of the telehealth intervention was partial as parents were selective in which aspects of the intervention they engaged with showing a strong attachment to the urinalysis machine and lack of engagement with those aspects they did not highly value such as weight scales and diary; this is also seen in studies where technology that does not meet the needs of the parent/caregiver is not adopted (Bradford et al., 2016). Realist review evidence argues that successful telehealth interventions are argued to operate through mechanisms of enabling professional relationships, lifestyle fit, and visibility of issues (Vassilev et al., 2015). Consistent with this, parents engaged with the component of the intervention that fitted with family priorities, supported health issue awareness, and enabled helpful interactions with professionals. While the CT might have hoped for a whole scale adoption of the intervention as a means of improving practice and ensuring compliance with best practice guidelines, the parents' partial engagement indicated that only parts of the intervention embedded the necessary mechanisms required for success. Furthermore, the parents' decisions to exert control over the intervention and be selective do strongly reflect the parents' self-efficacy about making choices. It appeared, as elsewhere (Radhakrishnan et al., 2016), parents' satisfaction levels with telehealth outstrip those of clinicians.

Parents gained mastery through their acquisition of knowledge and their extended vocabularies and found that the 'authority of the technology' gave them an additional tool to use in dialogues with GPs and their staff. The ability of the parents to be able to undertake 'chart talk' (Mattingly, 1991) communicate in a way that conveyed a sense of speaking the same language as providers seemed to elevate their requests and insights from those of 'just' being a parent, to a more informed position. This, from the parent perspective, transformed interactions between parents and GPs and their staff and supported interactions that resulted in accessing timely support for their child.

Parents were clear about their level of satisfaction with the technology and were direct in their critical feedback of situations when their needs were not being met. For example, the breakdown in the supply chain impacted on the quality of the intervention package. The parents were also insightful about the fact that some pieces of technology (e.g. the scales) were not perceived to be fit for purpose. Greenhalgh et al. (2017b) indicate that managing technology 'brittleness' means innovations need design work beyond the development phase and on into implementation when multiple users engage differently with the technology. The most successful telehealth interventions are the ones that are tailored to the needs of the patients (Radhakrishnan et al., 2016), and finding the 'sweet spot' where an innovation achieves full purpose therefore requires continual development.

Overall, the proof of concept telehealth intervention was effective in terms of demonstrating that remote community urinalysis monitoring by parents of their child's urine was possible. To a considerable extent, this was the result of early inclusion and cognitive participation of parents and other stakeholders in the development and design of the intervention and in the ongoing challenges of overcoming barriers as seen in other studies (Mair et al., 2012). The CT had to manage a fluctuating telehealth workload, and this created challenges on top of an existing full workload. However, although telehealth was a new innovation in this setting, there are drivers external to the organization and internal drivers such as the families' desire to undertake monitoring at home, which means telehealth is likely to become a more common aspect of future practice (Jury and Kornberg, 2016) and part of the everyday clinical workload.

Limitations

A limitation of this study is that it was a small-scale pilot study of one specific telehealth intervention from one tertiary children's hospital. As such, the findings cannot be generalized to a wider

population. The intervention was in place for a relatively short space of time and, therefore, the effects seen may not be sustained over a longer period of time.

Conclusion and implications

The telehealth intervention was evaluated as a system, with a number of stakeholders experiencing different outcomes. Parental empowerment and self-efficacy were clear outcomes for parents who exercised confidence and control in selecting aspects of the intervention they perceived as having credibility and which were of value to them. This mainly included the urinalysis testing system, an element that fitted with their priorities (reduce wasted time) and that provided a credible resource (print out) to make health concerns more visible. Familiarity and use of with the testing system helped parents articulate their needs and enter into health dialogues with GPs. This supported easier access to timely help for their child, which in turn reduced family disruption. However, other system features that had a poor fit with parental priorities (diary recording) were not used and therefore benefits for the CT (collection of routine data to meet national standards) were not realized. Furthermore, the part of the system that was used by parents, sometimes generated false-positive alerts due to technical glitches, and while not troublesome for parents, these alerts placed additional demand on the CT. This uneven picture exemplified how innovation needs to continue while technology products are being implemented, otherwise a good fit for all stakeholders will not be realized and the potential for the product to offer benefits will be lost.

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