

Staff perceptions of Telehealth Adoption: Lessons learned from Care at Home pilot in Scotland

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Telehealth technologies harbour the premise of transforming care practices and delivering person centred care closer to home. The care at home project was set to explore remote support and care for children with palliative and complex care needs. Aim: To articulate clinicians' perspectives on and experiences of embedding telehealth to professional practice in different settings. Design: Descriptive qualitative evaluation using focus groups and semi structured interviews. Setting/participants: The study was conducted in four locations across Scotland and included staff from the National Health Service and a Third Sector organisation. Participants were mainly clinicians involved in the delivery of specialist paediatric palliative care and continence specialists. Results: Significant differences were found between the way telehealth was explored and used within the public and voluntary sectors. Clinicians see clear benefits in and potential risks of telehealth to their patients and own practice. Conclusion: A strong strategic steer towards a culture of innovation is needed to support effective use of telehealth. Senior managers in the NHS should facilitate and support staff and 'unleash' the good will of professionals who are eager to exploit innovation in clinical practice.

Keywords: Telehealth; Palliative care; Complex needs; Paediatrics.

1. INTRODUCTION

From the very outset, the provision of a National Paediatric Telehealth Service in Scotland was focused on specialist children's hospitals, paediatric in-patient units and rural district general hospitals.

However, the shift in Scottish Government health and social care policy (Scottish Government, 2013) (Scottish Government, 2016) (Scottish Government, 2014) and associated funding streams, towards care closer to home, propelled a radical change in the way this service was set to develop and be delivered.

To explore the potential impact of remote care at home on the provision and quality of care, for children with a range of needs, a pilot study was launched. This followed a need elicitation phase, where a range of stakeholders were approached to help shape a possible vision for a new service and operationalise the way it may be trialled in practice.

The stated aims of the project were to trial the technology, the infrastructure and associated clinical pathways as well as to assess care outcomes concerning children with complex and palliative care needs. The focus on this population was deliberate, intended to demonstrate possible technology enabled outcomes, in a context where often 'high touch' rather than 'high tech' is most appropriate.

Two different hosting organisations were chosen for the conduct of the study. The palliative care arm of the study was conducted with help from three Paediatric Oncology Outreach teams, working in the Scottish National Health Service (NHS). The trial concerning children and young people with complex needs was supported by a third sector organisation, the Scottish Spina Bifida Association (SSBA).

At the outset we established a steering group to guide each segment of this study, with meetings and feedback sessions set at regular intervals.

The group included stakeholders from a wide range of organisations including a parent and a young service user at the SSBA.

Whilst some elements from each section of the study have been reported elsewhere (Levy et al., 2014) (Levy and Steele, 2011), including the technical specifications we trialled, this paper reports the views expressed by those who delivered remote care by telehealth and identifies potential barriers and enablers to the adoption of such technology. The cultural difference between the organisations involved and the impact on the diffusion of innovative practice is considered.

2. TELEHEALTH AND CARE AT HOME FOR CHILDREN AND YOUNG PEOPLE

To explore recent developments in the use of telehealth, supporting both patients and their carers at home, a literature review was undertaken.

Published articles were identified by electronic searches of three health services related databases namely, Medline, CINAHL and the British Nursing Index. The search strategy, to identify the latest articles concerning end of life care, complex needs and remote healthcare provision, stipulated an age range that included children under 18 years old and young adults up to the age of 24. Such a strategy was adopted to fit in with the population seen and cared for by some specialist paediatric teams in Scotland. The anomaly of adults being cared for by paediatricians stems from the fact that in some cases the continuity of care is critical in supporting those who were born with complex and profound disabilities.

Reviewing the literature it seems that countries such as Australia, Ireland (Bradford et al., 2014, Mherekumombe and Collins, 2015, Bensink et al., 2008), Canada (Young et al., 2006) and the USA lead the efforts to embed evidence based research in the use of telehealth for care at home. These studies affirmed that home telehealth is feasible, useable and effective. Web based technologies were found to be simple tools to support families at home and a mechanism to reduce carers' anxiety. Telehealth was also found to be an important tool to support transition from hospitals to care in the home.

In the UK (Kidd L et al., 2010) it is noted that there is a relative lack of robust evidence regarding telehealth use within palliative care but the service is gaining widespread acceptance by patients. In Ireland (Bensink et al., 2008) it was found that domestic pain management of children with advanced malignant disease, at the end of life stage, was effective. This was aided by technology and demonstrated that such a common and significant symptom can be effectively controlled remotely.

Overall, whilst more and better evidence is needed, it is suggested that telehealth for care at home is an effective way to facilitate remote interaction with those involved in caring for children and young people. Specifically, it can reduce the burden on families at a distressing time when their child is nearing the end of life. Yet, telehealth is not widely used in specialist palliative care settings and one suggested explanation for the low uptake of such innovation is the limited understanding of the clinical perspectives in implementation efforts (Collier et al., 2015).

3. METHODS

To capture data and reflections on the entire pilot period the study used three focus groups with NHS multi-disciplinary teams and face to face semi structured interviews with stakeholders in the SSBA. The sessions were carried out during working hours and team members were asked to reflect on the overall experience, the lessons learned and their perceptions on the way the service could be further developed within their locality.

The group sessions lasted up to one hour and interviews up to 45 minutes. Participants included seven Paediatric Outreach Oncology nurses, four medical consultants as well as two specialist nurses and an outreach worker from the SSBA.

Interestingly, one clinical team opted to have uni-professional sessions and the views of the paediatric nursing staff and their medical director were captured separately. With the consent of participants, data were recorded, transcribed and analysed for common themes. The author, who conducted and analysed the data, was at that time working as a telehealth nurse specialist and was involved in delivering support to the clinical teams.

4. RESULTS

Results concerning the technical set up, which for the pilot in the NHS involved a dedicated Video Conferencing facility that linked to approve software on a laptop given to patients, were generally positive.

Participants also included references to specific sessions where, for example, they could clearly see critical clinical symptoms, which then led to a rapid face to face follow up. A few noted that they were able to observe how worried the parents looked – even when the parents said they were 'fine'.

Participants also noted that remote consultation enhanced clinical education, by enabling students to observe sessions without their presence being too intrusive.

Another insightful comment suggested that the telehealth gateway enabled the young person to have access to staff without parents present – which was an opportunity the young person valued. However, clinicians stressed that the virtual interaction takes longer than regular face to face sessions – especially if the connection fails or cuts out halfway through the consultation, which it did at times. Technical problems led nursing staff at one location to describe their initial experience as a ‘disaster’.

Nurse 1: *“...the previous day we went out to the family and set it up for remote consultation but on the day – when we had the consultant in the room – we could hear them but they could not hear us. Mum was very distressed and you can see it through the colour of her face and we just had to stop it. We had a chat about it amongst ourselves and said that this is too much and she could not cope with it (telehealth). I think that was a very negative start for the parents using it on their own and then on the following Monday I went with (nurse 2) and I was able to adjust the volume up.”*

Nurse 2: *“The interesting thing about the second time we used the kit was that we were there but the consultant at [the hospital] got the impression that the patient was much worse than what she really was. I think it was because the patient was coughing a lot and not being able to say much and he thought she was deteriorating much worse than she was actually. If we were not there to have a first-hand view of the patient, the consultant would have gone out to the house as an emergency home visit.”*

The need for (technical) support, during the initial set-up and the ‘bedding in’ of the service, was also highlighted in interviews at other locations. Specifically, the role of the telehealth nurse specialist was highlighted as critical in changing the mind set of peers. They were seen as the agent that ensured telehealth developments are patient focused and benefit driven, rather than technology led.

A medical consultant noted the following:

“I must also mention an important point which is critical for future rollout of the service: I trusted the nurse specialist and that was a major element in trusting the IT ‘bit’ of the set-up. I knew my patients were safe and this was important for us because we are dealing with precious children with palliative care needs. Who you involve in caring for these brittle kids is of key importance to the team – even if we are not always conscious of this fact. I trusted the nurse specialist as I felt they were conducting the study with the patient in mind.”

The issue of ‘Trust’ and being ‘Comfortable’ with the technology, was also noted as an incentive for use by patients themselves: (Nurse Palliative care)

“...the patient was very comfortable with the kit herself and was able to place it where she could see and be seen and the consultant was very excited to see her and that she was taking an active part in the conversation. Mum was very much in the background and the patient had no problem with the kit at all! This is after all the digital world that teenagers feel much more comfortable with. The patient was able to sort a minor problem (screen saver) whilst talking with the consultant and looked much more comfortable than her mom the previous time and even her dad and her brother – they were like fish out of water”.

This triangle of child – parent – technology links to the decision making process and the ‘Power’ triangle between parent(s) – clinician – child. It was also associated with the concept of Choice and Family Centred Care:

“when you are on the telephone you cannot actually see the people at the other end so actually being able to see the parents and how they reacted to the various options available to them – you knew right away when they did not like what was offered to them – so that was hugely beneficial.”

The concepts of ‘Space’ and ‘Time’ were also noted. All involved acknowledged the fact that they (and the technology) were guests in a personal space of the family home. Telehealth had the potential to be an intruder and to affect the dynamics of the family coping with the end-of-life issues. It also offered more and even better care, given by those who have limited time away from the hospital setting (medical consultants). The issue of ‘Timing’ was also noted in the following reflection by a nurse:

“There are a number of patients who are palliative but are ‘well palliative’ and they would not want to have the kit in the house. They would not want it because having this laptop means that their child is dying and it is a reminder of that, sitting in a black bag in the corner of the room. Attending the hospital means the ‘sickness’ is left there and there is nothing brought home with them. However, with the patient we had I think she would have used it more had we introduced it earlier but it is very difficult to judge when is the right time to do it.”

Unlike the defined and limited phase of the end-of-life, those young people with complex needs face a range of chronic ill health conditions, which for many require specialist support from birth. Continence care, offered remotely, was the intervention sought to explore the use of telehealth where an intimate and personal discussion is needed. Compared to the NHS, where IT provision, training and support are most often provided by a dedicated ‘department’, the third sector has very limited resources for IT.

For this reason a pragmatic decision was taken to use SKYPE, a freely available software that could be downloaded onto hardware already used by families at home.

Similar software (Facetime) was also tested in one NHS location but stringent firewall rules and results of a risk assessment, which was carried out on site, prevented rapid progress there.

The sense of both 'bravery' and 'fear' are noted in many diary entries by nursing staff at the SSBA. Yet, despite the fact (or possibly because) they are part of a small organisation, with limited resources and minimum clinical supervision, they were eager to try out new practices. Interestingly, talking about extended scope of practice with peers from the NHS helped:

"Tried the technology out - managed it quite well - quite pleased with myself....Met with continence nurse at [hospital] was worried she wouldn't be on board but she thinks it's a great idea ...as does the stoma nurse. Relief that they are both ...think it's a worthwhile project."

More detailed descriptions of findings from this part of the study are noted elsewhere (Levy et al., 2014).

5. DISCUSSION

Theories and models to predict and explain technology behaviour have been widely accepted and used in a range of areas, including healthcare. Diffusion Theory (Rogers, 2010) examines the process by which an innovation is accepted or rejected by a particular individual or organisation over a period of time. A systematic review concerning the Diffusion of Innovations in (health) service organisations (Greenhalgh et al., 2004), notes six key attributes of innovation. These are used here as themes to link the discussion to overall findings.

Relative Advantage: Telehealth was introduced as a tool to enhance current services, rather than to replace them. This point was reiterated by many interviewees who articulated clear benefits to using telehealth as a remote means to support their patients. However, as was noted by others (Joseph et al., 2011), (Finch et al., 2007) clinicians were cognisant of pressures such as 'time targets' or financial constraints and reviewed telehealth within this context.

In the NHS the potential advantages were also seen as a possible threat to future roles for staff. Some interviewees noted their reservations to taking part in the study as they were concerned that findings may give managers an opportunity to replace staff with technology provision. This issue, related to the topic of Trust, was perceived differently by staff at the SSBA.

Knowing that the demand for their services outstrips current provision, staff were eager to maximise the outreach capacity of telehealth. They perceived the new remote service as an opportunity to affirm their key role within the organisation and cement the commitment of the organisation to continue and offer specialist nursing support to users.

Compatibility: The staff that support children and their families, whilst they face the burden of living with complex needs or of dying from their illness, are very committed. The close therapeutic relationship they form, to support a family centred care, is driven by their desire to offer more and better care to their patients. Yet, in the NHS, whilst all healthcare professionals strive to provide optimal care, telehealth is most often promoted as a tool to support effective and efficient care of older people.

This emphasis on a specific population is anchored as an organisational norm and may affect the willingness of NHS managers to consider implementation of telehealth amongst a relatively smaller section of their users (paediatrics). The much smaller size of the population, which is the focus of third sector organisations such as the SSBA, makes it easier fully to adopt a family centred care ethos. This, and the high level of autonomy for SSBA nursing staff, helps in the adoption process of telehealth as a care delivery mechanism for children and young people.

It was also noted that where a strong team ethos was present, the more successful the diffusion process was, over the study period. It came as no surprise that the location where clinicians opted to have separate interviews, as medical and nursing teams, the perceived usefulness of telehealth was limited.

Complexity: The end users of telehealth wanted to be 'comfortable' with it and voiced a desire for the technology to be simple to use. The training and support offered to all users was limited to 'working hours', whilst the care offered to families was often 'around the clock'. This potential challenge was addressed by ensuring there were processes and procedures that mitigated risks in practice.

In the NHS, the management of risks, concerning critical clinical scenarios, has to be robust and there is a low tolerance to failure of clinical technology. However, these organisational behaviours may act to stifle innovation and many interviewees from the NHS noted their frustration with rigid clinical IT systems and the level of support they received from their dedicated IT helpdesk.

In contrast, the care of long term conditions in the third sector is not as clinically critical as in the acute sector. Their perception of risks and security of clinical systems, is not necessarily the same as those held by IT managers in the NHS.

Trialability: the training which was designed and delivered prior to the study going 'live', offered a number of scenarios to be considered. It used the technology to work through potential problems and guided them how to overcome simple user errors. Staff in the NHS were limited to the approved and available set-up, within their clinical areas, which often was a large Video Conferencing (VC) suit.

These facilities were used at least once weekly for remote multi-disciplinary meetings in each location. The specification of the laptops, which were given to families, is described elsewhere (Levy and Steele, 2011). SSBA staff trialled a number of technologies and opted to use SKYPE which they found easy to use. This meant that many more users were able to download the software on their own machines at home, rather than rely on the limited kit, being provided for them.

Observability: The benefits of seeing the young people at home, for the SSBA team, were clear and instant. For the NHS teams, who have used VC in a hospital setting previously, the access to and from patients' homes was a novelty. However, many commented on the fact that the service was configured around available kit rather than being flexible to support the use of advanced mobile devices.

Reinvention: As noted, the limited scope to adapt, refine or modify the technology settings, in NHS localities, resulted in enforced restrictions and revised guidelines to ensure a stricter process. An example was the option of laptop users, at patients' homes, dialling into NHS ports to get a better quality of sound and vision. This was seen as opening the service to risks from unauthorised access and a one way traffic (NHS into homes) was imposed.

In contrast staff at the SSBA had the option of choosing the software and were able to link users on PCs, laptops and tablets – whichever device was used by the family.

The six 'standard' attributes, as noted by Greenhalgh et al (Greenhalgh et al., 2004), are necessary but not sufficient by themselves to explain the adoption of innovation, such as telehealth, within healthcare settings. The authors note concepts such as 'system readiness', 'innovation-system fit' and 'risk' as additional important factors to support assimilation of complex innovations within complex organisations.

This last point – the degree of uncertainty of outcome that the individual perceives as personally risky – is extremely relevant to NHS staff. Front line clinicians who care and support young people with palliative care needs are willing to take professional risks to support their patients on a daily basis.

The 'work arounds' that some staff adopted to ensure they can support families remotely, were highly imaginative.

For example, staff used the kit from home to get away from restrictive firewall policies so that they could be available whenever needed. This stand puts them at odds with managers in formal positions of power who align risks to the organisation with their own hierarchical status.

Maintaining the status quo of an institution centred provision, as regards technology enabled care carries a lower level of risks and stifles innovation. In contrast, staff at the SSBA, where the organisation is much smaller and the structure is far less formal, are actively encouraged to take risks and offer new ways to deliver innovative and person centred care.

6. CONCLUSION

The study presented here compares outcomes of efforts to use telehealth in support of care at home for children with complex and palliative care needs.

A number of attributes, aligned to the diffusion of innovation theory, served to illustrate findings from data gathered in both the public and third sector organisations. It seems that planning to introduce telehealth in complex organisations, such as the NHS in the UK, requires a strong strategic steer towards a culture of innovation. It needs a shift in organisational mind-set and a significant change to perceptions of risks and attitudes to failure.

Yet, such radical transformation must be set in a context where there is a shift from interventions that focus on ill health to ones that support wellness.

Care at home supported by telehealth was well received by most clinicians and service users in our study. It is suggested that if it works for children with complex and palliative care needs, it would work in many other settings too. It may offer a better way for citizens and healthcare professionals to interact remotely.

However, as noted in the study, staff need to be empowered to unleash their creativity and to drive change within the organisation. It is therefore suggested that top managers be 'brave' and act decisively to empower their staff and embrace the good will, dedication and the burning desire they have, to offer optimal patient care. That includes trying to do things differently and to maximise the potential of telehealth.

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