

End-of-Life and Living Technologies, *The role of Telemedicine in palliative care of children and young people*

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Abstract

For many, the home environment is the embodiment of independent “living” - in which technology is used to enhance and support good quality of life. Home assistive technologies were initially developed to support people with special needs and elderly people – and among other things - to help them remain within their homes and communities for as long as is feasible and safe. Our work focuses on the other end of the technology and design spectrum: one where Tele-medicine is used to support optimal palliative care at home, for children at the end of their lives. We present preliminary results of a pilot study. We argue that remote care provision should be considered as an integral part of care, to complement and enhance current end of life care – as well as providing advice and support –, regardless of where patients reside. We advocate that future developments in assistive living technologies adopt an increasingly holistic “whole-of-life” approach, including the too often understudied and under-reported end-of-life phase.

Keywords: Telemedicine; Palliative Care; Care at home; Children and young people

1 Introduction

For many, the home environment is a place of living, care, support and health. Evidence suggest that palliative care provision closer to or in the family home is particularly beneficial to those who care for terminally ill children. Provision of home-care enables a child to remain in familiar surroundings and with the people who love them most, throughout the palliative and end of life care. Yet, the intense support needed to cater for the needs of this population is a challenge for healthcare professionals. Technically, this would require designing systems with a comprehensive and dynamic range of care, in which services could need to be altered rapidly and at short notice.

Difficulties in communication and lack of out of hours support are often cited as primary reasons for parental stress and anxiety for parents caring for severely ill-children. This often lead these parents to experience feelings of isolation and even despair [5]. Poorly controlled symptoms – with associated significant decrease in quality of life for patients – are often cited as a reasons for failing to sustain home-care for this population [12].

Tele-medicine is defined as the delivery of remote medical-care, including transfer of health information [11]. It provide potential options to overcome some of the health-care challenges previously highlighted.

We here report on a pilot study, designed as the first phase of a project aiming to maximize the potential of technology for end-of-life palliative care. It is designed to evaluate the outcomes of using remote home-based tele-healthcare provision for children with complex and palliative care needs. The project is being piloted throughout Scotland and is supported by a grant from the National Delivery Plan¹.

The aim is that lessons learned in this project will contribute towards the gathering of evidence and will be used in future as part of a national roll out of Telemedicine. It is anticipated that optimal care at home for children, young people and families could rely on tried and tested technology for remote care provision.

2 Assistive Technologies and Palliative Care at Home

There has in recent years been a significant policy shift towards rebalancing the provision of care away from acute hospitals towards provision of care in the community or in the home environment (self-care) [1, 2]. Cancer services for both adults and children have seen significant changes, with

¹http://www.playfieldinstitute.co.uk/information/pdfs/publications/government_scotland/BetterHealth_BetterCare.pdf

treatments and management of side effects being increasingly delivered at home. Information and Communication Technologies (ICT) solutions are now provided to some patients in an effort to help them manage treatment and related symptoms [6]. These “patient-driven technologies” put patients in charge of reporting their symptoms, which enable the clinical team to access appropriate data. This can then be used to detect and prevent rapid deterioration in a patient’s condition.

Early discharge from hospital and continued support in the community are often reported in terms of benefits in cost savings and reduced bed occupancy [9]. Yet, there is evidence to suggest that patients and carers also benefit from an increased quality-of-life and higher satisfaction with the overall treatment when care is provided in the home environment [7].

Technologies for palliative care in Scotland were recently reviewed in a study by Kidd et al. [8]. In this study, the authors suggest that: “*there is a relative lack of evidence-based research in the use of Telehealth in palliative care in the UK*”. The study also asserts that “*Telehealth is gaining wide spread acceptance and is perceived to be both usable and acceptable to both patients and professionals in palliative care settings*”. This study and other reports from research conducted in North America and Australia were used in developing the methodological approach adopted in our study [4].

3 Pilot Study Description

3.1 Engaging with Stakeholders

The original drive for innovation within the care-at-home study was motivated by lobbying from paediatric medical consultants within the NHS. As palliative care is essentially a team-based service, it was important that the Multi-Disciplinary Team (MDT) was involved and taken on board in order to drive the proposed study forward.

An initial contact with a paediatric nurse specialist was made at the very outset of the project and other members of the MDT colleagues were approached again when the technological “kit” was ready for roll-out to pilot sites. A presentation at the MDT meeting was critical in facilitating participation from all stakeholders. It enabled to ease some of the concerns certain practitioners had with regards ending up with an increased workload, the appropriateness of the technology in palliative care clinical practice and the possible challenges involved in maintaining confidentiality of clinical information. The evaluation of the pilot was also then discussed and the need for a suitable approach to testing and evaluating the technology, as well as the implications of this with regards to clinical practice, care and support.

3.2 Participants Recruitment

This study has been approved by a NHS Ethics Committee. Previous literature reviewed had identified a number of challenges with regards participants recruitment and retention in paediatric palliative telemedicine studies but our experience so far has been very positive. The clinical team has provided considerable support in identifying and recruiting families to help us with our study. Each family is approached by the treating clinicians to discuss how they feel about participating in the pilot. Once an initial interest is confirmed, the family is then approached by the project-lead who describes to them the aims, objectives and methodology that govern the evaluation of the study. The family is then given an opportunity to seek additional information, read further literature about the project and ask any questions prior to consenting to taking part in the pilot. They can opt out of the study at any stage.

The home installation process includes a brief training session and the testing of the network with another remote site. Participants are given a contact helpdesk number to call if any technical issues are being encountered. They are also assured that regular clinical support and access to treatment is unaffected by opting or not to join the pilot. The family and the clinicians have a range of options to interact with one another, including face-to-face, at home or in hospital, over the phone or via VC.

3.3 Technical Set-up

We undertook the evaluation of a few possible modalities for remote care provision and decided that Video Conferencing (VC) software on a lap-top computer would best suit our population for a number of practical and economical reasons. Patients at home were required to link the pilot laptop onto their home broadband and health professionals were able to link to that unit via a second pilot laptop. The laptop was provided health professionals so that it could both be used from hospital or their own home.

Apart from a site-to-site call between the 2 units, it was also possible to link the units via an external bridge. That option also enabled us to connect the home unit onto one of the static paediatric VC units, which are available in all paediatric inpatient units across Scotland. A clinical pathway was developed to ensure parents were contacted by phone initially in order to set an agreed time for a VC interaction - if it was deemed necessary and appropriate by all parties.

There are several benefits to using a laptop from home rather than a designated communication “pod” which has no other usage, apart from linking users via a dedicated network. The laptop enabled us to provide clinicians the option to add documents, policies and guidelines onto the core set-up, so that useful and relevant documents were in one acces-

sible place for the patients. We also considered the option of having a dedicated clinical login to the home unit, which would enable primary care staff to access their “own” dedicated zone within this home machine. The content within this dedicated zone would be set by the General Practitioners (GP) and other community-health staff and be driven by their clinical requirements and training needs. The idea behind this provision was to support shared-care, between hospital and the community based teams. Effectively, the technology would be used to enhance communications and the sharing of best-practice. We also wanted to offer home-users the option of browsing the internet and access support groups to offer help and facilities, beyond those offered by the health services. Collating - with the consent of patients – “bookmarks” could potentially enable us to compile a comprehensive list of useful sites and resources and share it with other service users.

Users were asked to sign an acceptable usage form outlining their responsibilities and expectations from the study. The laptop Internet settings could have set to restricted access to the clinical application, to avoid the risks of potential misuse of the technology. In practice, however, we did not place any restrictions on users Internet access so that they could complete an on-line evaluation form and support the automated process systems upgrades.

For the lap-top, we opted for an average specification for (e.g. around £350) but purchased a more expensive digital web-camera (e.g. £250) to ensure that excellent image quality would be available from the home environment.

It was anticipated that the camera could potentially be used to capture in detail specific body parts to a remote clinician if necessary for medical opinion or diagnosis. A usability evaluation was undertaken with one of the laptops with the help of both service users and a member of an NHS (National Health Service) staff. It was suggested that - while operating the VC set-up was rather simple and intuitive – a head set would be needed to overcome the problem of voice “echoing” experienced by the users. This set-up limits interaction to one person per machine but it also enhanced confidentiality so that sensitive issues could be described and discussed in relative privacy. This particular aspect was a rather important concern from health professionals from the very outset of our study.

4 Preliminary Feed-back

Over the first week of the pilot there were a number of Telemedicine sessions conducted, involving the patient and family members consulting nursing and medical staff. As this was an innovative and in many respects a unique set-up, it has taken some time to adjust to the medium and the new ways of working. With the consent of all involved, the

first few consultations were observed to identify and address teething issues and difficulties with both the technology and the clinical work flows. We initially observed that interaction from users, particularly parents, was rather formal, which included making a special effort to dress - up while on screen. There was a sense that even though the home environment was an “informal setting”, the Telemedicine interaction transformed the access point within the house into a “formal place”. However, this initial reaction quickly faded and the family adapted quickly adopted a more informal way of interacting with the technology, and became more confident in deciding *when or if* they wanted to use it.

In addition to the initial technical setup, the participating families were shown how to access a link to a web based survey, which has 10 questions around the theme of “patient centeredness” [10]. This was intended as a formal evaluation framework to the remote interaction technology. The families will also given an opportunity to reflect on their experience during an interview which is planned to take place a few months after the last VC session. Doctors and nurses are asked to complete a paper-based survey which is based on Guy’s Communication Questionnaire (GCQ) [3]. This tool includes 5 questions, including the scope for recruiting free text comments and observations.

From a clinical point of view, the MDT experimented with various possibilities of connecting to the home from various VC settings, as well as using the home-end camera as a diagnostic tool. Symptom control is found to be the main focus of the interaction and on some occasions, medical staff have been found to be conducting physical examination of the child remotely, with the support of nursing staff on site.

Preliminary qualitative reactions to the nature of the remote interaction with the technology have been broadly positive. Clearly, remote consultation have on a number of occasions saved patients the need to travel to hospital. It was also noted that parental anxiety could be noticed on screen. For this reason, clinicians involved rated the VC interaction as an improvement on voice only (i.e. telephone) interaction. However, it is also already clear that for certain discussions and interventions, there is no real substitution to a face-to-face clinical encounter. While these are only preliminary feed-back reactions from the pilot, a formal evaluation is currently underway and we intend to report fully our results once data is analysed and the evaluation is completed.

5 Conclusion

We have presented preliminary results from a work-in-progress study of a tele-health setting for palliative care for children in end-of-life care. We argue that telehealth could be considered as a viable mechanism to support access to

around-the-clock care and support for children with complex health conditions, particularly when they are at their end of life. Embedding new communication technologies and associated innovative practices may enhance the universal provision of palliative care that supports continuous symptom assessment, review and control. It may also support better access to specialist advice, which is crucial for the delivery of person centred care - one that values patients as true partners in the decision making process regarding their care.

We further suggest that future developments in assistive living technologies attempt to adopt a holistic “whole of life” approach to technology implementation and evaluation, which would include the understudied and under-reported end-of-life phase, where appropriate services are delivered - sometimes remotely- regardless of where the patient resides. For healthcare providers - key issues relating to information governance such as information sharing and confidentiality, as well as other ethical issues concerning the usage of tele-health in this context could be included in clinical and professional education.

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