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# End of life and ‘living technologies’:

## The role of Telemedicine in palliative care of children and young people

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**For most people most of the time the home environment is the embodiment of independent living, where technology is serving to enhance and support optimal quality of life. Assistive technologies were conceived as a way of enabling mainly older people to remain at home, for as long as it is safe and desired and continue to be part of their local community. Our paper explores the opposite side of the technical spectrum where Telemedicine is used to support optimal care, at home, for children at the end of their lives. Presenting results from our pilot we argue that remote care provision, advice and support should be considered as a possible way to complement and enhance current end of life care regardless of where patients reside. We conclude by advocating that developments in assistive living technologies adopt a holistic ‘whole of life’ approach, which includes the often underserved end of life phase.**

*Telemedicine, Palliative Care, Care at home, Children and young people)*

### I. INTRODUCTION

For the majority of us the home environment is the preferred location for care, support and health nourishment. There is ample evidence to suggest that palliative care provision closer to or in the family home is especially beneficial to those who care for terminally ill children. Such a provision is enabling the 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 client group is a challenge with healthcare professionals needing to design a comprehensive yet dynamic package of care that may rapidly change at short notice.

Breakdown in communication and lack of out of hours support are often cited as primary reasons for parental stress and anxiety leading them to experience isolation and even despair [1]. Poor symptom control and a resulting significant decrease in quality of life for the patient are also noted as reasons for failure in maintaining and sustaining care for this client group at home [2].

Telemedicine, which is the delivery of healthcare and the exchange of health information across distances, offers a possible mechanism to overcome some of the noted challenges. The pilot study reported here was the first segment of a project that is set to maximize the potential of such technology and evaluate outcomes of using remote interaction in home based

care provision for children with complex and palliative care needs. The project is being piloted throughout Scotland and is supported by funding from the National Delivery Plan. It is hoped that lessons learned will strengthen the evidence and contribute towards a national roll out of Telemedicine as a core technology element on which optimal care at home for children, young people and families could be delivered - remotely.

### II. ASSISTIVE TECHNOLOGIES AND PALLIATIVE CARE AT HOME

In the last couple of years there has been a significant political drive to shift the balance of care from acute hospital settings to provision of care closer to or in the home environment. Cancer services for both adults and children have seen dramatic changes with treatments and management of side effects being increasingly delivered at home. Communication technologies are now offered to some patients in an effort to help them manage their treatment related symptoms [3]. Such ‘patient driven technologies’ make patients responsible for reporting their symptoms and enable the clinical team to access appropriate data in an attempt to detect and promptly prevent rapid deterioration in a patient’s condition.

The benefits of early discharge from hospital and continued support in the community are often reported in terms of cost savings and reduced bed occupancy for these patients [4]. Yet, there is growing evidence to suggest that patients and carers also benefit from an increased quality of life and higher satisfaction with the overall treatment and the care received [5].

The type and kind of technologies that are used in palliative care in Scotland were recently reviewed in a study by Kidd and colleagues [6]. In their conclusion the authors affirm that “there is a relative lack of evidence based research in the use of Telehealth in palliative care in the UK”. However, the study affirmed 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 UK study as well as other reports from North America and Australia all influenced the approach taken for our study [7].

### III. THE 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 suit our population best. Patients at home were required to link the Pilot laptop onto their home broadband and clinical users were able to link to that unit via a second Pilot laptop, which was given to them to be used from both the hospital ward area or from 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 to set an agreed time for a VC interaction – if that was deemed appropriate by all concerned.

There are a number of benefits to using a laptop from home rather than a designated communication ‘pod’ that has no other usage apart from linking users via a dedicated network. The laptop enables us to offer clinicians the option of adding documents, policies and guidelines onto the core set-up, so that pertinent documents are in one easy to reach 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’ zone. The content in that area would be set by the GPs and other community staff and be driven by their clinical requirements and training needs. The idea was that such provision will support shared care, amongst hospital and the community based teams and the technology would be used to enhance communications and sharing of best practice. We also wanted to offer home users the option of browsing the internet and access support groups that offer help and facilities beyond that which were offered by the health service. Collating ‘bookmarks’ could enable us to compile a comprehensive list of sites and resources and share it with other service users.

It is important to stress that users were asked to sign an acceptable usage form outlining their responsibilities and our expectations of them. In theory the laptop Internet settings could have been disabled so that users had very limited access to such a gateway and thus limit potential risks. In practice we enabled users to access the Internet so that they could complete an on-line evaluation form and support the automated process of virus and malware protection and windows updates and remote system upgrades.

We opted for an average specification for the lap top (~£350) but invested in an expensive digital web-cam (~£250) to ensure excellent image quality was available from the home environment. It was envisaged that the camera would be used to show specific body parts to a remote clinician – if the need arose. Usability testing with one of the laptops was undertaken with the help of both service users and a member of NHS staff. It was suggested that whilst operating the VC set-up was simple and intuitive, a head set was needed to overcome the problem of ‘echoing’ experienced by users. Such a set-up limits an interaction to one person per machine but confidentiality was enhanced and sensitive issues could be described and discussed in relative privacy. This was indeed one of the main

issues that clinicians were very concerned about at the outset of our study.

### IV. WINNING THE HEARTS AND MINDS OF STAKEHOLDERS

As is often the case with trailblazing innovation within the NHS, the original drive for the care at home study came from intensive lobbying of paediatric medical consultants. There could be a number of reasons for why this is the case but as palliative care is very much a team based service, the buy in of the entire Multi Disciplinary Team (MDT) was critical to drive the proposed study forward.

The initial contact with paediatric nurse specialists was made at the very outset of the project and colleagues were approached again when the ‘kit’ was ready to roll out to pilot sites. A presentation at the MDT meeting was critical in facilitating a buy in from all stakeholders. It served to ease some of the concerns practitioners have regarding an increased workload, the appropriateness of the technology in palliative care clinical practice and the possible challenges to confidentiality. The evaluation of the pilot was also discussed as was the need to have an honest and an unbiased approach to testing the technology and the implication to practice, care and support.

The literature identifies a number of challenges with patient recruitment and retention in paediatric palliative Telemedicine studies. Our experience so far is very positive and the help of the clinical team is proving extremely valuable in identifying and enticing families to help us with our study. Once the inclusion of the patient and their family is discussed and agreed by the MDT the family is approached by the treating clinicians to see how they feel about the pilot being introduced to them. If agreeable the family is then contacted 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 read further literature about the project and ask any questions prior to consenting to taking part in the pilot. They are assured that they can opt out of the study at any stage and that the study was considered and approved by the Ethics Committee that is set to safeguard clinical trials.

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 technical issues are being encountered. They are also assured that regular clinical support and access to treatment is unaffected by opting to join the pilot. It is stressed that the family and the clinicians have more choice in the means by which they interact with each other to include face to face at home or in hospital, over the phone or via VC.

### V. EVALUATION

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.

One of the most striking observations made during the initial 'bedding in' phase was that the parents made a special effort to 'dress – up' to be 'on screen'. There was a sense that even though the home environment was offering an 'informal setting' the Telemedicine interaction was an access point to a formal zone within the house. That said, it was noted the family adapted very quickly to using the technology and took charge of when and if they wanted to use it.

As part of the technical setup families are shown how to access a link to a web based survey, which has 10 questions around the theme of 'patient centeredness' [8] as an evaluation framework to the remote interaction. Families are also given an opportunity to reflect on their experience in an interview which is planned a few months after the last VC session. Doctors and nurses were asked to complete a paper based survey which is based on Guy's Communication Questionnaire (GCQ) [9]. This tool includes 5 questions with spaces to record free text comments and observations.

From the clinical end, stakeholders experimented with the possibilities of linking into 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 are conducting the 'hands –on' physical examination of the child – remotely – with the support of nursing staff on site.

To date it appears that all those who are involved in the study are very pleased with the way the set up is working and the effectiveness of remote interaction. Others, who have witnessed an interaction between the family at home and clinical staff in hospital, including students and primary care practitioners, had positive remarks to share. It is already clear that on a number of occasions the remote consultation saved patients the need to travel to hospital. It was also noted that parental anxiety can be easily noticed on screen – even if there is a conscious attempt to conceal it in the tone of voice. For this reason clinicians rate the VC interaction as much better than telephone only exchange. That said, it must be stressed that for some discussions and for some tests there is no real substitution to a face to face clinical encounter.

A formal evaluation is currently underway and results will be fully analysed at the end of the study.

## VI. CONCLUSION

Telehealth should 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.

Developments in assistive living technologies must adopt a holistic 'whole of life' approach, which includes the often underserved end of life phase. Service commissioners should consider Telehealth as an enabling element to complement or enhance a prescribed 'package of care', where appropriate services are delivered – sometimes remotely- regardless of where the child resides.

For healthcare providers - key issues relating to information governance such as information sharing and confidentiality, as well as other ethical issues concerning Telehealth practice should be embedded in on-going clinical/professional education

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