
Developing Hospice Care Over a Distance in Highland Scotland: a Knowledge Exchange Process

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Abstract

This paper describes a piece of collaborative research that aimed to develop an implementation plan for a virtual hospice. The aim of the virtual hospice in this case is to extend the reach of hospice facilities provided by the Highland Hospice in Inverness, Scotland. We chose a knowledge exchange process that included Hospice staff at every step. We began with a workshop that scoped out all of the potential virtual hospice services, which were condensed into a core set of five services. We then conducted interviews with selected Hospice staff. The final step involved presenting our recommendations to the Hospice, including a storyboard of how the virtual hospice might operate in practice. We took the Hospice's feedback and incorporated it into a final report. Overall, we feel that the knowledge exchange process generated a more accurate and realistic implementation plan.

Author Keywords

End-of-life care; health; hospice; palliative care; telehealth; technology; virtual hospice

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

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Background

Hospice is a philosophy of care that focuses on providing pain relief and symptom control, and dignity and peace, for people with incurable life-limiting illness. The first hospices date from the Middle Ages, where hospice referred to a place of shelter for weary or sick travellers. The modern hospice movement began in the UK with the opening of St Christopher's Hospice in 1967, which transformed the way we look at death and dying from 'there is nothing more that can be done' to 'there is so much more that can be done'.

Hospices exist around the world. Services are typically structured around individual need and personal choice, and can include art and complementary therapies, bereavement counseling, chaplaincy and spiritual care, occupational therapy and physiotherapy. Staff and volunteers work in multi-professional teams to provide palliative and end-of-life care within patients' own homes, hospice settings, care homes and hospitals.

Introduction

The Highlands and Islands of Scotland comprises approximately 15,000 square miles – more than half of Scotland – and over 400,000 residents [5]. Of this area 10,000 square miles and 220,000 individuals are served by a single adult hospice, Highland Hospice. The Hospice provides a 10 bed In-Patient Unit and a Day Hospice at its base in the city of Inverness, and clinical staff provides specialist support within individual's homes, care homes and hospitals. It also provides Day Hospices at several of the more remote and rural regions. The majority of clients tend to live within a 30-mile radius of Inverness mostly due to distance of travel, and mobility and transport problems. Thus, a key challenge faced by Highland Hospice is to extend

its reach, allowing more people to receive specialist palliative care support in the location of their choice. The Hospice considers that telehealth is an appropriate method for addressing this.

Telehealth can be defined as the provision of health services at a distance using a range of technologies such as the telephone, the Internet and videoconferencing. Drivers for advancement of telehealth include: equitable access to services, increased demand for services as a result of an ageing population and the associated increase in the numbers of people living with a chronic illness or disability, and changes in healthcare policy from hospital-centered to community-based models of care. The use of telehealth in hospice care has been termed e-hospice, telehospice and virtual hospice; we use the latter term.

Highland Hospice has been interested for several years in creating a virtual hospice and has carried out some scoping and feasibility studies on the subject. E.g. the ASyMSp study demonstrated the feasibility and acceptability of using mobile phone technology to monitor symptoms reported by patients being cared for at home [6]: symptoms of individuals receiving palliative care are highly changeable necessitating ongoing review and management. However, these efforts have not translated into the delivery of services at distance in any systematic way. In order to overcome this 'sticking point' a collaboration with researchers from several disciplinary backgrounds was forged in order to progress the idea of the virtual hospice into a plan for implementation.

This paper describes the process and results of that collaboration. The main contribution is to illustrate how

a knowledge exchange approach allowed us to develop an implementation plan. We hope that this new knowledge will assist others to develop home-based palliative and end-of-life services.

Related Work

A systematic review that included 26 articles published from 2000–2010 concluded that telehealth technologies hold promise to be useful and important tools for the delivery of hospice care, and that there are potential clinical outcomes and cost benefits [7]. A separate review of telehealth in palliative care in the UK included 21 published and unpublished research documents from 1999–2009 [3], one of which was included in [7]. The review identified a lack of evidence-based research and found no evidence that telehealth is integrated into palliative care services in a systematic fashion. Both reviews conclude that telehealth technologies are acceptable to staff, patients and family members.

We know of just one fully developed virtual hospice. The Canadian Virtual Hospice is a website launched in 2004 as the result of collaboration among Canadian palliative care clinicians, academics and researchers [1]. However, the service is predominantly an information resource with limited interaction between professionals, and patients and carers. In the UK, West Sussex Health Macmillan Service and Nottingham City Council also offer 'virtual hospices'. However, these do not employ telehealth technology; rather the term refers to providing support in non-hospice settings. As such, the Highland Hospice virtual hospice is a novel application of telehealth technology, which goes beyond previous work in this area.

Method

The framework for our project was based in the principles of knowledge exchange and co-production of findings [2,4]. Therefore, each stage of the project involved interaction between the academic team and Hospice staff. The theory behind this approach was that a two-way process involving academics and practitioners would lead to a meaningful exchange of ideas, learning and experiences in order to progress the development of a virtual hospice. The project involved three key stages: a workshop, interviews with Hospice staff, and a presentation of results.

The aim of the workshop was to identify service opportunities and generate a timeline for phased introduction. This approach was taken in order to actively encourage knowledge exchange and involve the project team in the discussions, generating a shared understanding. Four members of the academic group and eight staff from Highland Hospice including a Consultant Physician, General Practitioner (GP), Occupational Therapist and Physiotherapist participated in the half-day workshop held at Highland Hospice in Inverness. In addition, a Highland Hospice patient with motor neurone disease, who sadly died just a few weeks later, joined for a short time to give his view on the concept of a virtual hospice. He participated using Skype videoconferencing software and an assistive input device, illustrating that the symptoms of advanced illness need not be a barrier to accessing Internet-based services.

The workshop began with a review of the overall aims and services of a virtual hospice. Each agreed aim was assigned a color. Each agreed service was written on a card, pegged on a length of string representing a

timeline for implementation, and then dotted with the color of the aim(s) that it aligned to. This allowed us to begin to discuss which services to prioritize by visually seeing how they met our aims (or not). The group then brainstormed benefits and challenges for each service. These were written on two different colored post-it notes, which were attached to the relevant service or, if broad ranging, stuck above the timeline. This allowed us to weigh up the challenges versus the benefits of each service. The services were then reordered – reprioritized – on the timeline according to aims, benefits and challenges.

After the workshop, members of the academic team reviewed and summarized the findings. This included condensing and refining the list of possible services into a set of core services, which were considered the most readily achievable in the short to medium term. Services that had a smaller number of potential benefits or that had considerable implementation challenges were specifically excluded or demoted. The lists of benefits and challenges were grouped into broad categories.

Two researchers then returned to the Hospice to conduct informal interviews with a sample of Hospice staff: an Occupational Therapist, IT lead, Physiotherapist and a Consultant Physician. This 'sense-checking' exercise was essential in order to explore the workshop results in more detail, and potentially to uncover any additional (and possibly conflicting) views that Hospice staff may have not been willing to express in a group situation. In particular, this method allowed the researchers to explore in much greater detail the more practical aspects of actually delivering the virtual hospice to clients, including the types of technology that might be needed in clients' homes.

The penultimate stage of our research involved a presentation of the results to Hospice staff in order to generate their views and opinions. These further findings were used to refine a written final report.

Results and Recommendations

Aims of a Virtual Hospice

Four overall aims were identified:

1. To extend the Hospice's reach, allowing more people to receive palliative care
2. To provide a resource to inform and support health care professionals
3. To provide physical, emotional and spiritual support to patients and their carers and families
4. To enhance, and not replace, current services.

Key Services of a Virtual Hospice

Five core services were identified and ordered by priority for implementation:

1. Online meetings: video consultations between Highland Hospice staff and patients and carers
2. Online meetings: video link ups between Highland Hospice in Inverness and the Outreach Day Hospices
3. Telehealth: remote symptom monitoring of patients being cared for at home in the palliative stage of their illness, including tailored self-care advice
4. Online resources: information and education resources for healthcare professionals and patients and carers, such as information packs
5. Telephone advice line and messaging service: increased support for healthcare professionals (non-Hospice) and patients and carers.

Key Benefits of a Virtual Hospice

- Time, distance and cost. The Highlands and Islands of Scotland comprise the largest and most sparsely populated part of the UK with a mountainous terrain and limited transport infrastructure. A reduction in the time and cost of staff travelling large distances to and from people's homes and the Outreach Day Hospices could potentially result in more time for and/or an increased number of patient consultations.
- Equity of access to hospice care. Distance of travel, mobility and transport problems, and poor health can mean that patients are unable to access Highland Hospice services. Delivering services to people at home by means of technology may extend and improve access. E.g., remotely monitoring patients' symptoms to ensure timely interventions can allow people to remain in their own homes for as long as possible.
- Motivation to exercise. Regular exercise is important for patients at all stages of an illness and the Hospice plan of care will usually include an exercise regime. However, patients at home often find it difficult to get motivated, as they doubt that exercise will make a difference. Greater connection with the Hospice physiotherapist e.g., video consultations, could improve patients' motivation and confidence towards exercising.

Key Challenges of a Virtual Hospice

- Broadband ownership. Not all telehealth services require an Internet broadband connection, but video-conferencing – identified as a core application – does. While most homes in Scotland (99.6%) have access to broadband, take-up is just 68% (although rising) and lower than average among over-55s [8]. A related challenge is slower broadband speeds in rural areas, which the UK Government has pledged to help upgrade.

Encouragingly, the Hospice reported that a good proportion of its clients own a computer.

- Sense of dependency. The use of telehealth e.g., self-assessment tools and tailored self-care advice, can increase patients' feelings of control and autonomy. However, it also has the potential to raise patients' and carers' expectations of healthcare professionals. Rather than empowering patients, a virtual hospice could create a sense of dependency as well as increase the workload of a relatively small number of staff.
- Hospice and primary care integration. Highland Hospice works closely with primary care teams and the local district and community hospitals in the area. This relationship, or shared responsibility, helps to ensure that the care given between home, hospital and hospice is as seamless as possible. Patients are generally referred to hospice by their GP; around 20% of GPs do not refer patients, or only under very limited conditions, for reasons that are not entirely clear. Highland Hospice has responsibility for patients in its in-patient units and primary care has overall responsibility for patients in their own homes or care homes. Thus, there was a concern that virtual hospice services delivered to patients in their own homes might undermine these groups, resulting in resistance.

Recommendations

In a final written report, the academic team recommended Highland Hospice:

- Develop a key service. As a first step, the rigorous design and testing of the most-ready service identified in the project (video consultations) was recommended. Involving co-design workshops with stakeholders to design all the interactions end-users will have with the

service to help ensure that the solution is attractive, usable and appropriate; it is anticipated that working together in partnership with GPs will both increase the likelihood of the service being accepted and facilitate phasing in the other core services identified.

- Design the whole experience. The virtual hospice will incorporate multiple services and interactions over a period of time. In parallel to developing a key service, the team recommended taking a broad and holistic approach to service design to create a virtual hospice where the whole is greater than the sum of its parts.

Conclusion and Future Work

In the near future, the number of people seeking specialist palliative and end-of-life care is expected to increase considerably because more people are living longer with life-limiting illnesses. Accordingly, there will be an increased pressure on services, including highly specialized centers such as the Highland Hospice. However, some existing patients and their carers are already excluded from the potential benefits of personalized Hospice care through their rurality. Our research and approach has confirmed that telehealth technology is an appropriate medium for delivering selected Hospice services in the short to medium term.

New funding is currently being explored for continuing this project. We consider that exposing virtual hospice services to actual users under controlled conditions is an important step, preceded by appropriate co-design work with a range of stakeholders. This should be complemented by having a member of research staff embedded in the Hospice itself, continuing the process of knowledge exchange.

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