



ELSEVIER

Available online at [www.sciencedirect.com](http://www.sciencedirect.com)

SCIENCE @ DIRECT®

Telematics and Informatics 23 (2006) 117–133

TELEMATICS  
AND  
INFORMATICS

[www.elsevier.com/locate/tele](http://www.elsevier.com/locate/tele)

## The e-Hospice—Beyond traditional boundaries of palliative care

Craig E. Kuziemsky<sup>a,\*</sup>, Jens H. Jahnke<sup>b</sup>, Francis Lau<sup>a</sup>

<sup>a</sup> School of Health Information Science, University of Victoria, P.O. Box 3050 STN CSC, Victoria, BC, Canada V8W 3P5

<sup>b</sup> Department of Computer Science, University of Victoria, 3800 Finnerty Road, Victoria, BC, Canada V8W 3P6

Received 16 December 2004; received in revised form 17 May 2005; accepted 27 May 2005

---

### Abstract

The term *palliative care* refers to the care for patients with terminal conditions. Traditionally, much of this end-of-life care has been provided by hospices or acute care centres. As healthcare systems face aging patient demographics and struggle with the need to deliver quality services with fewer resources, we must find new approaches to healthcare delivery. Some of the more established areas of healthcare such as cardiac care or administration are rather advanced in terms of the application of information technologies such as clinical knowledge bases and computer-integrated service delivery models. In palliative care, partly due to its relatively recent emergence as a discipline, informatics has played only a minor role to date. In this paper, we argue that we can achieve cost reduction and increased quality of service by adopting network-enabled information systems (IS) and telematics to advance the boundaries of traditional palliative care towards the patient homes. This vision, called e-Hospice in this article, is not meant to replace but to augment the traditional brick and mortar hospices. We discuss our model of an e-Hospice along with the challenges and opportunities involved in realising it. Our experiences are based on our ongoing tight collaboration with a local hospice as well as our studies of prototype technology infrastructures we have developed in our laboratories. We present a concrete application scenario in this paper, along with a

---

\* Corresponding author. Tel.: +1 250 721 6461; fax: +1 250 472 4751.

E-mail addresses: [craigk@uvic.ca](mailto:craigk@uvic.ca) (C.E. Kuziemsky), [jens@cs.uvic.ca](mailto:jens@cs.uvic.ca) (J.H. Jahnke), [fylau@uvic.ca](mailto:fylau@uvic.ca) (F. Lau).

description of the underlying architecture and technologies that underlie the infrastructures developed.

© 2005 Elsevier Ltd. All rights reserved.

*Keywords:* e-Health; Network-enabled information systems; Home care

---

## 1. Introduction

Although modern palliative care only originated in the 1960s, the combination of our aging population and people with illnesses having longer survival times will require the delivery of increased palliative care services in the forthcoming decades. Recent government reports in Canada (Kirby and Romanow Reports) have pointed to a shortage of palliative care services. In the 1997 report *Approaching Death*, the Institute of Medicine Committee on Care at the End of Life endorsed the development of *whole-community* approaches to end-of-life care (Field and Cassell, 1997). Although increased financial resources will be needed to realize new visions for increasing palliative care delivery, governments are already under financial strain and the challenge is how to deliver more and better services with less resources. Reports from governments at all levels are identifying *increased home care* as a way of delivering needed palliative services while allowing a patient to remain in the comfort of their own home. But it is not just governments that want more homecare, half or more of terminally ill patients have expressed a desire to remain at home until death (Dunlop et al., 1989; Townsend et al., 1990). However, there are challenges to increased delivery of palliative care through homecare. Because palliative care patients are no longer seeking curative treatment much of palliative care involves the relief of symptoms. Palliative patients frequently suffer from physical symptoms such as pain, nausea, and dyspnea (shortness of breath) as well as emotional symptoms such as anxiety and depression. Studies have shown that management of symptoms at home is currently not done well. Therefore, in order to be a successful means of increased palliative care delivery, for homecare we need to enhance our abilities to manage symptoms for patients at home.

Part of the problem with managing symptoms at home is logistics as palliative patients require ongoing surveillance and responsiveness in order to effectively manage their symptoms. Management of symptoms such as pain is not a one off event but rather a continuing process where pain responses and needs develop over time (Davies and McVicar, 2000). Frequent check-up visits by physicians and nurses at the frequency required to provide timely medical care whenever needed would certainly not be neither cost effective nor practical given the time demands of clinicians. However, the ability to provide ongoing symptoms management is necessary as it has been shown that daily pain ratings provide continuity in the pain management process (Davies and McVicar, 2000), which allows proactive pain management. Therefore there is a need to develop ways of providing the means for ongoing daily pain (or other symptoms) assessments. Network-enabled information technologies have been successfully applied in other business domain to replace physical presence with

a notion of “remote presence”, e.g., in the domain of power measurement. Since the Internet is now available to and affordable by almost the entire population of Canada, we argue that a combination of telematics and network-centric information management can be used to attain the goal of increased home care for palliative patients—a vision we call the *e-Hospice*.

The term *e-health* was coined during the 1990s to refer to adopting Web-enabled services to contribute to objectives such as cost reduction, streamlining of operations and contributing to the enhancement of medical care (Bose, 2003). IT components such as decision support systems, electronic medical records, and collection of and access to electronic learning resources have enhanced the delivery of health care. However, we recognize that the use of information technology in health care has not always been a good partnership. Published scientific literature has many examples of failed projects that consumed far more resources, both personnel and financial, than they returned in improved health delivery or patient outcomes.

In this paper, we introduce a model for the e-Hospice, which is a specific instantiation of e-health that was developed to enhance symptoms management of patients receiving care at home. We describe a prototype implementation of the IT infrastructure that can drive e-Hospice and discuss main challenges involved in realizing it in practice. We emphasize three distinct categories of challenges: technology challenges, medical challenges, and governmental challenges. Each category is discussed along with our recommendations for overcoming the challenges involved. We conclude with a discussion of the opportunities that arise from e-Hospice.

## 2. Background

### 2.1. Information technology in palliative care

Recent years have seen the development of databases and computer based assessment tools that can be used in palliative care. We are involved in a related Canadian project with the objective of developing a common repository to facilitate exchange of information between the various heterogeneous palliative databases in use today. Part of this initiative is based on a coordinated data warehouse concept called CaPDN (Canadian Palliative Data network), where participating centres across Canada work towards sharing a subset of their palliative data with others on a regular basis via one or more data warehouses (Fainsinger and Fassbender, 2002). The objective behind this initiative is to provide a richer base of population data that can help to advance evidence-based medicine in the area of palliative care.

Assessment tools that can be used within palliative care have been developed for both patient and clinician use. *PAINReportIt* is computerised version of the McGill Pain Questionnaire and is run on a Windows environment such as a desktop, laptop or tablet PC (Wilkie et al., 2003). A useful feature of *PAINReportIt* is that it can be used by a patient to self-report their own pain. Although *PAINReportIt* has not been made available or tested in a homecare environment the tool does represent an

instrument that could be made available for ongoing pain assessment through e-Hospice.

Queen's University in Kingston, Ontario has developed a PDA based assessment tool for clinicians called the acute pain management service (APMS) that captures pain scores and drug-related side effects from medications (VanDenKerkhof et al., 2003). The APMS has been shown to collect data that is as efficient and content rich as traditional paper assessments but also further enhance the efficiency of patient assessments through the provision of comprehensive digital data for clinical and research uses (VanDenKerkhof et al., 2003). Although APMS was developed for clinicians the authors describe an extension of the APMS that would allow patients to complete questionnaires through a computerised interface (VanDenKerkhof et al., 2003).

PAINReportIt and APMS would make a good combination for home care as a patient could self-report their daily pain using PAINReportIt and a physician or nurse could use APMS to track pain management. The inherent challenge with respect to both the above tools is providing access to them in applicable environments such as a patient's home.

## 2.2. e-Health

The 1990s clearly represented a new direction in health informatics. The availability of the World Wide Web changed how people access information and provide services. This movement has created the term *e-health* associated with promises about better health outcomes. The arrival of hand held computers such as Palm Pilots™ and other wireless devices such as cellular phones or smart phones brought potential for mobile point-of-care data collection and analysis. Mobile computers have allowed the use of mobile knowledge bases such as e-pocrates™, which allows detailed drug information to be made available to a clinician's hand-held computer and have been credited with reducing errors due to transcription and handwriting (Fisher et al., 2003). Various forms of electronic medical records (EMRs) are currently under development with great promise in terms of pervasive access to patient information over geographical distances and electronic ordering and results retrieval. Aside from the now widely available large-scale wireless infrastructure for communication devices, such as smartphones and pagers, inexpensive technology has become broadly available to create wireless cells for short range communication through the embedding of wireless access units in buildings (Barnes, 2002). Such wireless networks enable the application of mobile technologies that can allow patients to stay connected with medical emergency services in all parts of a house rather than being confined to a fixed place. In a recent article, Ross describes several applications of such technology, many of them based on small, wireless sensors embedded in the patient's home or with the patient (Ross, 2004). Dishman describes similar research conducted within Intel Corp. (Dishman, 2004), which he refers to as "aging in place" technologies.

Some observers have argued that, despite all the hype around the term e-health, its objective has not been attained. As Kibbe points out, it is a common myth that Internet-based applications such e-business and e-health would replace traditional

businesses (Kibbe, 2001). The burst of the “dot com bubble” at the turn of the millennium has clearly demonstrated this misconception. Due to the complexity and sensitivity of the medical domain, e-health technologies face significant hurdles on their way to adoption. One of the issues is that traditional health care involves a personal relationship between patient and care provider; how will that relationship be impacted if they are separated by time and/or space? Palliative care in particular is a branch of medicine that is defined by individual attention and frequent care delivery. The challenge is how can those traits be maintained in an e-Hospice scenario? But it is crucial to remember that e-health is not a one type fit all solution but rather is a general concept that can take many forms (such as delivery of education, communication or clinical decision support) and therefore it must be molded to the specific domain of health care where it is being applied. Our vision of e-Hospice is a specific instantiation of e-health that has been developed specifically for the needs of palliative care based on substantive research in the palliative care field.

### 3. Our vision of e-Hospice

Fig. 1 illustrates our vision of e-Hospice, which relies on a combination of readily available wireless and wired information technology embedded at the patient’s home and the hospice. The figure shows that the e-Hospice model considers patients in home care (“out-patients”) as well as patients located at the hospice (“in-patients”). Each location of care has its advantages and disadvantages. Patients in a hospice have direct access to medical resources but being away from family and friends in an unfamiliar environment can negatively impact a patient’s quality of life. This

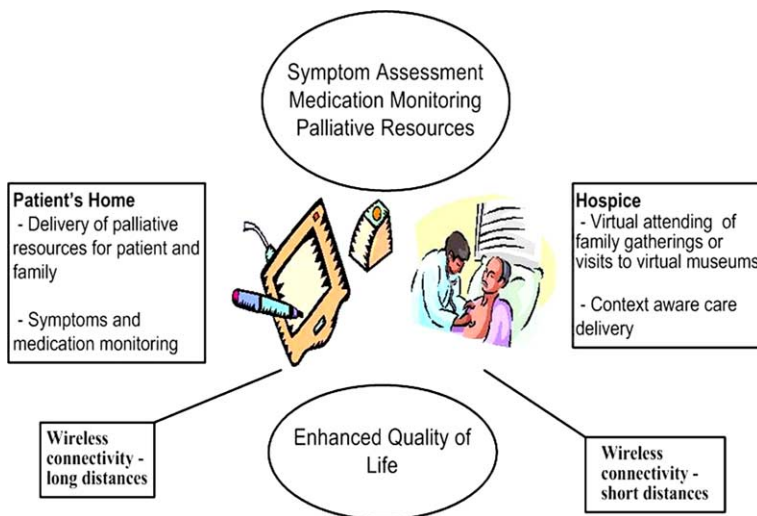


Fig. 1. Our vision of e-Hospice enhancing care delivery in patient’s homes and in hospice.

impact is particularly large if the patient's family lives far away from the hospice, which is quite likely in a sparsely populated country with the dimensions of Canada. Broadband Internet-based communication technologies installed at the patient's bedside in the hospice can provide the patient with the necessary link to stay in contact with his/her friends and family. Readily available "off-the-shelf" technologies such as Web Cams can be used for this purpose. However, dedicated software for impaired individuals might increase the level of active patient participation. While we are currently undertaking research on creating such dedicated software, the remainder of this paper focuses on the other aspect of the e-Hospice vision, namely the support for "out-patients".

Out-patients have the advantage that they can be close to family and friends and live in the comforts of their familiar environment, which can improve the quality of their lives tremendously. However, it has traditionally been difficult to manage their symptoms and obtain resources to support informal caregivers such as family. The three key problems have been to provide remote *surveillance* of patients, *assessment* of their condition, and fast *interventions* to manage their symptoms. In the e-Hospice vision, remote surveillance is supported by telematics and collected by smart devices embedded in the patient's home (wired) and embedded with the patient (mobile, wireless). Remote assessment is supported by a case-based reasoning system, using networked databases storing historical assessments collected from the hospices out-patient population. Moreover, remote assessment is facilitated by broadband audio/visual communication devices installed at the patient's home. Finally, remote interventions are supported by telematic actuators installed in medical devices at the patient's home—and by the audio/visual communication devices to instruct family members about actions to be taken.

Before we illustrate this vision with a concrete case study application and prototype infrastructure we have developed, we would like to point out that the technologies mentioned above are not meant to completely replace *personal* surveillance, assessment and intervention of out-patients. In severe cases of progressing symptoms it will still be necessary to send a palliative response team to the patient's home or transport the patient to the hospice for disease management. However, we argue that the e-Hospice model enables more palliative patients to spend time in their familiar environment with an adequate level of surveillance and intervention.

#### 4. Case study and software infrastructure

Several authors have published articles describing possible applications of telematics and embedded computing to e-health (e.g., Dishman, 2004; Ross, 2004). Most of these discussions remain on a high level of abstraction, expressing ideas of possible applications without revealing any details on which software infrastructure would be needed to integrate them. This article takes a different approach: rather than enumerating all conceivable "aging in place" applications useful for the e-Hospice vision, we focus on one representative application scenario in order to elaborate on the software infrastructure needed to realize it.

#### 4.1. An example application scenario

The following application scenario illustrates how e-Hospice can help a patient manage unrelieved symptoms at home while at the same providing support for the patient's family. The hardware and software infrastructure to support this application scenario has been implemented and tested in our lab. Some literature have stated that 60–80% of patients wish to live at home as long as possible and even to die at home if qualified help is offered (Townsend et al., 1990). However, others have countered such statements and believe that although patients may initially want to die at home they often chose to be hospitalised as their symptoms and disease progress (Fainsinger, 2001). At the hospice we are collaborating with unrelieved symptoms is the most common reason for admission to the hospice unit. From January 1993 to March 2005 there were 4849 total admissions and 1496 (31.3%) were for unrelieved symptoms (pain, nausea or dyspnea). 468 (32.0%) of the patients admitted for symptoms were discharged back to home after having their symptoms settled. But such visits are inconvenient for the patient and family and costly to the health care system. We believe e-Hospice provides the infrastructure to allow many of those patients to better manage symptoms at home, which will reduce the number of hospice admissions for unrelieved symptoms and enhance a patient's chance of dying comfortably at home.

For a specific scenario, consider a patient that requires palliative care but wishes to remain at home. The patient is able to get weekly or bi-weekly visits from a palliative home care team but ongoing day-to-day support is required. Both the patient and his family are worried about his well-being, particularly in symptoms management such as pain management.

The diagram in Fig. 2 specifies a scenario, in which a palliative home care patient receives drug for pain management from a self-administered medication pump (SAMP). The SAMP is a device embedded in the patient's home or attached to the patient. The patient can trigger the SAMP to dispense medication when he or she is in pain.

There is a daily medication limit in place in order to protect the patient from unwanted side effects of the drug. However, enforcing this limit like a strict cap is not practical, since pain profiles are difficult to predict as the patient's condition progress and the state of his social environment changes. Therefore, in the traditional in-patient setting, physicians can respond quickly, assess the situation and, potentially override this limit.

Similar responsiveness and flexibility are needed for realising the e-Hospice. On the other hand, even in the in-patient scenario, physicians are not constantly alarmed, whenever one of their patients has used up their allocated medication limit. Based on the context of the specific incident and some guidelines, other caregivers such as nurses typically make the first decision on whether to notify a doctor. Since normally there will not be a nurse at the patient's home, an informal caregiver (e.g., a family member) can make this decision. The informal caregiver does not necessarily have to be at home at this time but can be notified using wireless information technology such as a smart phone. The phone will be used to review the situation based



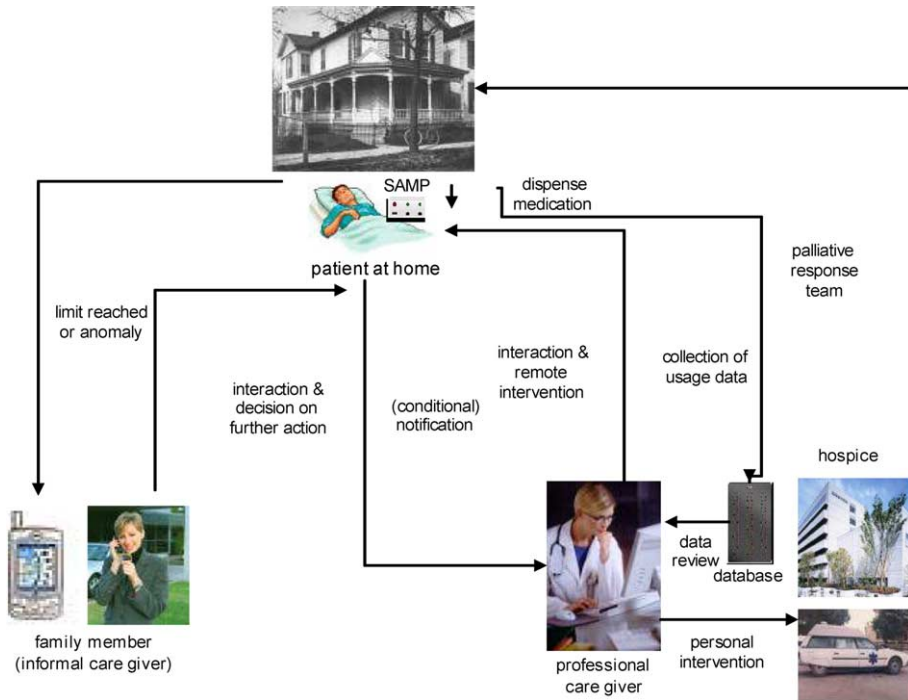


Fig. 2. Patient scenario of pain management from a self-administered medication pump (SAMP).

on parameters enclosed in the notification as well as to get in contact with the patient directly. The family member can then make a decision whether to deal with the situation herself or whether a professional should be consulted.

In the latter case—or if the informal caregiver could not be reached, the practitioner (physician or nurse) is notified using similar mobile paging technology. They can use the hospice information system to review the patient's medical record including historical usage data collected from the devices installed in the patient's home. (This data has been transmitted to the hospice database and can be used to facilitate remote assessment of the patient's condition.) The practitioner can activate broadband communication technologies (audio/video) installed in the patient's home to directly monitor the patient and interact with him. They can also compare the patient's medical record with data collected from other cases in the virtual patient population of the e-Hospice. Based on their assessment they have the option of remote intervention, e.g., to remotely change the medication limit for the patient, or personal intervention by sending the members of the palliative response team to the patient's home.

#### 4.2. Customizing the software infrastructure

The above scenario describes merely one of the many possible combinations of "aging in place" technologies. The needs of palliative patients can be different from



case to case, depending on various factors such as their specific illness, their home environment, and the availability of family members during the day. Therefore, we emphasize customisability and easy for adaptation as key economic requirements behind the development of the e-Hospice infrastructure. Customisability is a particularly important problem when it comes to the *software* part of the infrastructure. While hardware has largely been componentised with well-defined interface standards and networking protocols, much of the software that runs today's embedded applications is still being custom-built by highly trained professionals. This can only be done economically where applications are developed once and sold many times (economy of scale) or where the application is so specific that a high cost of producing it cannot be avoided. The software needed to support our vision of e-Hospice fits these categories only partially. Certainly, economy of scale applies individual mass-produced embedded technologies, such as the software that controls the above-mentioned medication pump or sensors that detect an accidental fall of an elderly patient. However, the software that is needed to *integrate* the various sensors and components selected for a specific home care scenario into custom solution that reflects the particular needs of a patient cannot be built once and used off-the-shelf in a "one size fits all" manner. Therefore, a major technical challenge on the way to realize the e-Hospice vision is finding an economic way to provide the software to integrate the various e-health devices used in a particular patient's care scenario such that they can act in a concerted fashion as required in a given care situation.

What is required here is a way of "programming" an embedded care plan that is easy enough to use such that it can be understood—and perhaps even partially created/adapted by medical experts. Funded by the Natural Science and Engineering Research Council of Canada (NSERC), we have developed a software tool that enables laypersons to "program" the interaction of embedded devices using a visual language. This software tool, called *microSynergy*, has been developed in a joint project with Intec Automation Inc., a company in the domain of component-based embedded software and hardware. For the sake of conciseness, we will only give an overview on the *microSynergy* technology and to refer (Jahnke et al., 2005) a recent, more technically detailed publication. *microSynergy* falls in the category of a generative middleware programming tool (Eisenecker and Czarnecki, 2000). The term *middleware* commonly refers to a dedicated type of software for the purpose of mediating between different software components. The term *generative programming* has been introduced for a tool-based technique to automatically generate software programs from very high-level specifications.

In the case of *microSynergy*, these high-level specifications have the form of a visual language to describe IT-based care protocols. The software that executes these protocols are then automatically created and executed on an embedded controller, called the *microSynergy hub*. The protocols can be adapted and changed remotely by authorised principals.

The visual language used to specify the protocols is based on a subset of the International Telecommunication Unions *Specification and Description Language* (SDL), a language that has recently been integrated, in part, into version 2 of the Unified Modelling Language (UML 2). Essentially, *microSynergy* specifications are a

combination of structural aspects (component diagrams) and behavioural aspects (state diagrams). Fig. 3 shows a microSynergy specification to define a possible care protocol for our example scenario. The bottom of the figure shows the four IT devices named in the scenario, namely the SAMP, the smart phone of the informal caregiver (CG), the computer of the formal caregiver and the hospice database. Note that—for the sake of simplicity—we have not distinguished between the practitioner mobile pager and their stationary PC.

The large box at the top of Fig. 3 specifies the protocol that integrates the four participating devices, by means of a state diagram. States are represented as oval, observed events are shown as rectangles with ingoing triangle, initiated actions are shown as rectangles with outgoing triangle, and decision points are represented as diamonds. The annotations attached to the lines connecting the devices on the bottom with the protocol box (coordination logic) at the top clearly define which signals can be exchanged between each device and the hub. The black circle identifies the state *active* as the initial start state. If the patient requests medication the SAMP raises the corresponding event, which leads to a *dispense* action, unless the daily limit has been reached, in which case the hub sends a notification to the informal caregivers mobile device and transitions to state *wait for informal CG*. Note, that the connection lines at the bottom also specify that each *dispense* and *notify* signal is also recorded in the patient's historical health record at the hospice database.

The informal caregiver can now respond in three possible ways: (1) she can declare the problem *resolved* (presumably after some personal communication with the patient), (2) she can overwrite the daily limit by an amount *o* that has been predefined by the practitioner, or (3) she can refer the situation to the practitioner, which triggers an activity to *alert* the appropriate person using his pager or PC. The transition labelled *default(15)* specifies that the latter is also done in case the informal caregiver does not respond within 15 min.

After analysing the patient's electronic medical record, comparison with population data of similar cases, and remote communication with the patient, the practitioner can now decide to change the limit remotely, declare the problem resolved, or send a member of the palliative response team if further investigation is warranted.

Fig. 4 shows a screen shot of a Web-based presentation of surveillance data collected for the electronic medical record of an out-patient in our e-Hospice scenario. In this case the fictitious patient has stomach cancer. The viewgraph on the right-hand side compares the patients assessed historical pain score and medication usage with statistical data collected from the population of comparable cases. Such surveillance information can help the practitioner make a decision on future management strategies. The "Limit:" input field in the upper left side of the Web view enables the doctor to remotely change the daily medication limit on the SAMP in the patient's home.

The application case study described in this section has been prototyped in our labs using the microSynergy middleware generation technology. For demonstrational purposes, we have recorded a demonstration of the application scenario as

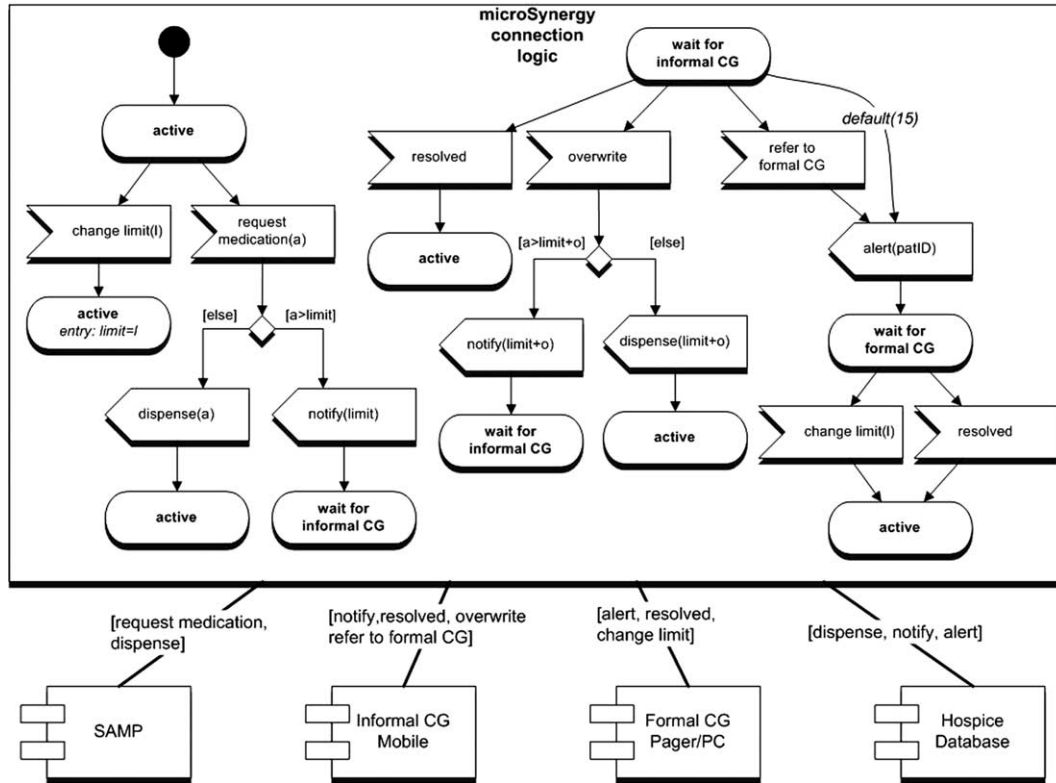


Fig. 3. MicroSynergy specification of a possible care protocol for our example scenario.

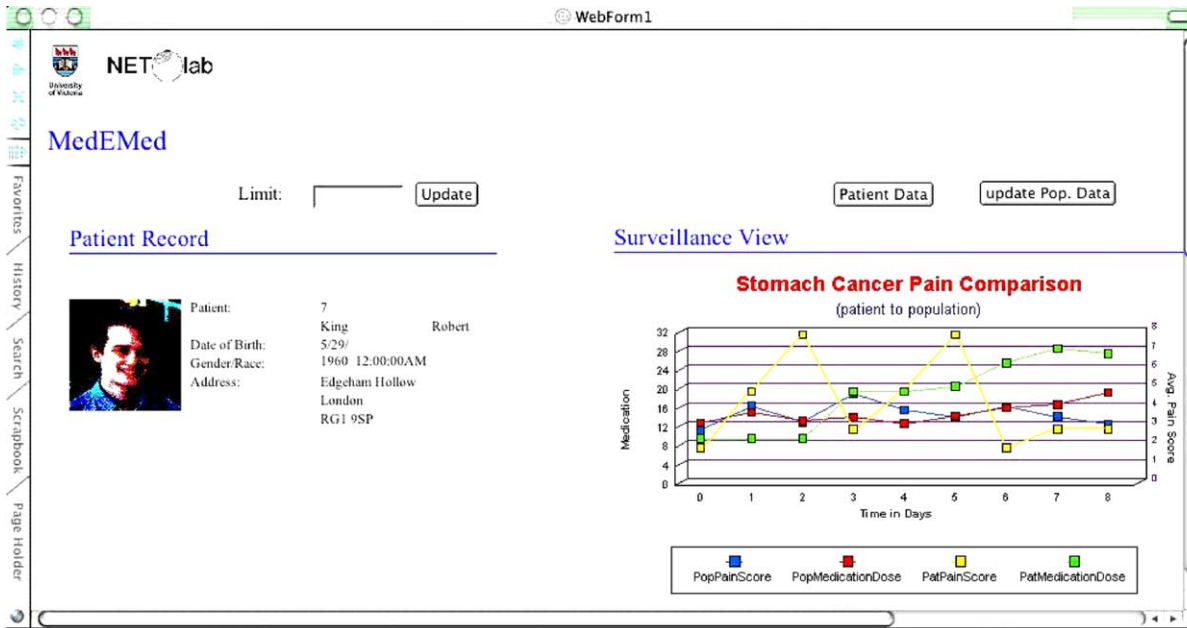


Fig. 4. Screen shot showing comparison of patient and population pain scores and medication doses.

well as a demonstration of the technology infrastructure underneath in form of a video, which is available at our Website ([netlab.uvic.ca](http://netlab.uvic.ca)) or can be ordered as a DVD.

## 5. Challenges towards realizing e-Hospice

There are a number of challenges that need to be met in order to realize the vision of e-Hospice that we presented in the preceding section. Three main categories of challenges are technology challenges, palliative care challenges and government challenges. This section briefly discusses each of those challenges.

### 5.1. Technology challenges

A recent paper presented a number of theses about what health care will be in the year 2013 and among their prognostications for 2013 are that the number of patient's receiving home care will increase by 40% whereas the number of homes with internet access will reach 95% (Haux et al., 2002). Even though those predications indicate both the need and the technological means for implementing an e-Hospice, we still must proceed with caution. Technology is sometimes thought of as a panacea in health care but stories of system failures are more common than success stories. Part of the problem is obvious, both health care and technology are rapidly changing fields, so it makes sense that there are difficulties aligning one with the other. A further issue is the manner by which technology is incorporated into palliative care. Our vision of an e-Hospice is meant to keep as much as possible the warm and caring environment of a patient's home, while augmenting it with technological services that have traditionally been provided inside hospices. Still, technology cannot be seen as a replacement for patient-physician or patient-family contact but rather another means of delivering and enhancing those relationships. A challenge is that technology must be delivered in palliative care that is both "high tech" and "high touch". DelVecchio-Good et al. point out that biomedical technologies are sometimes perceived as being associated with medical futility or torture (DelVecchio Good et al., 2004) and that gives food for thought about how dying patients or their family will view high-tech palliative care.

Reliability, security and privacy are important non-functional requirements on e-Hospice processes. While backbone Internet technologies have a fairly high availability, end-user connections have a much higher probability of breaking down. Alternative processes of care using other technologies—or physical presents by palliative emergency responsive teams have to be in place as a backup. Many of the security and privacy technologies developed for other business domains such as finance and e-commerce can readily be used for securing the IT infrastructure of an e-Hospice.

One last challenge of technology that certainly will impact our drive towards e-Hospice is a lack of a consensus electronic medical record (EMR). As palliative care expands into the community and patients spend increased time at home or in community care centers, it will become imperative that different institutions be able to share patient records and pharmacy, laboratory and radiology data. An EMR is

needed to facilitate that data sharing. Of course the lack of an EMR is by no means unique to palliative care as all of health care is struggling with that challenge.

### 5.2. Palliative care challenges

One of palliative care's greatest challenge to using IS is that it is not nearly as far advanced in terms of infrastructure to support IS as areas of medicine such as cardiac care. To achieve success in health care IS you require a collaborative nature including partnerships with community care centers, family physicians and pharmacies. Palliative care and the IS supporting it to date are disadvantaged in that many hospices or palliative care centres have come about independently. That requires hospices to start at square one by creating their own database schemas, patient medical records and charting documents.

As shown in the prototype description the exchange of data is crucial to the functioning of e-Hospice and a challenge to exchanging data is reconciling the different means by which palliative data is collected and stored. Such compatibility can be seen in Canada where the variability of palliative care data was shown through a six-centre surveillance study by Gaudette et al. (2002) where they showed that coding of palliative data elements is both variable and incomplete. The study described how Canada has been slow in development of palliative care IS and how that slow development has impeded our ability to plan, develop, implement and evaluate palliative care programs. The *palliative data set* part of the GFE in our prototype has been successful in reconciling heterogeneous data sets and therefore palliative care should pursue the development of consensus data standards and models of palliative practice. Nursing has developed standards of nursing practice such as the Nursing International Reference Model (Goossen et al., 1997) and terminology standards such as the North American Nursing Diagnosis Association (NANDA). Such standards have proven valuable for promoting consistent structure and meaning for nursing processes and terminologies.

As we consider technology in palliative care it is imperative that development of an e-Hospice or other technologies is simply not seen as transferring the care of dying patients to informal caregivers such as family or friends. It is difficult enough for family members in a hospice to watch loved ones dying and that burden will certainly increase if informal caregivers such as family or friends become the primary caregiver for extended periods of time. It has been shown that informal caregivers are overburdened physically, emotionally and financially and in some cases the effects carry over beyond the period of mourning (Rossi Ferrario et al., 2004). As shown through our prototype a fundamental part of e-Hospice is providing support for informal caregivers to help them deal with the stress of providing care.

### 5.3. Government challenges

For e-Hospice to become a reality governments will need to play a significant role. One obvious need from governments is increased funding for palliative care research to overcome the challenges we have identified. Research is needed to develop data

standards, document palliative best practices and the means of both formalizing and disseminating palliative knowledge into the community. Funding is also needed for the infrastructure to set up e-Hospice as webcams and other wireless computer tools and the supporting infrastructure are costly. A challenge is that funding requests will certainly meet with resistance as governments will find it difficult to justify funding expensive IS projects when there are currently bed shortages and waiting lines for medical procedures.

Uncertainties or changes in governments also pose a challenge as the realisation of initiatives such as e-Hospice will take many years before they are fruitful and require ongoing commitment. In, Canada there has been an initiative over the last few years spearheaded by the Canadian Senate to improve palliative care research and delivery. The initiative has identified five priority palliative research areas: Best Practices and Quality Care; Education for Formal Caregivers; Public Information and Awareness; Research and Surveillance and formed working groups for each area. The working groups have proven invaluable in that they have brought together palliative practitioners and researchers and helped bridge the research-practice gap. Recent uncertainties in government have put the working group's future in question. However, the work they have done has been invaluable and it is imperative that such initiatives continue to move forward and build upon the work that has been done to date.

Perhaps the greatest challenge facing the government and other administrative bodies is determining the extent of their involvement. Although the government will have an active role in developing privacy and security legislation a challenge is developing policy that balances the need for access (and concomitantly authorisation) with the needs and rights of the citizen in their various health roles (Scott et al., 2004). Considering that e-Hospice will involve transferring of data across different health regions, provinces or states and potentially across different countries through global e-Hospice, we need to ensure that government policies or legislations do not become so rigid that they become an obstacle to the functioning of e-Hospice. One solution to that challenge is by accommodating e-Hospice (and broader e-health) within the existing administrative and policy infrastructure and, only where necessary, develop new policy and guidelines.

## 6. Opportunities

Despite the three types of challenges described above there are enormous opportunities for e-Hospice to enhance how palliative care is delivered. Because our research has been done with extensive collaboration at a local hospice we believe the e-Hospice prototype offers a cooperative solution between technology and the patient centered world of palliative care. The prototype application described in Section 4 offers the means for managing a patient's symptoms while they remain at home as their illness progresses and also provides access to supportive resources both for the patient and family that may be caring for the patient. We also described how the e-Hospice uses the internet to help a patients maintain their social circle, which will improve a patient's quality of life as their disease progresses.



The literature has described a need for services that can provide access to palliative services such as those proposed by e-Hospice. Evans et al. (2003) describe a need for assistance for primary care practitioners in symptom control and in the management of emotional issues such as bereavement counseling. They also described patients having difficulties accessing specialist services such as hospices, with families reported as having problems in accessing relevant information. e-Hospice can help deliver the requisite information when and where it is needed.

We illustrated in the application scenario in Section 4.1 how e-Hospice could reduce the number of hospice admissions because of complications related to symptoms management. That will save costs for the health care system as well as be more convenient for patients. Although our application scenario uses a specific example of pain management the application and SAMP device could be used to regulate medication doses for any symptom. That allows e-Hospice to monitor chronic symptoms but also have the means of dealing with an acute crisis such as a sudden increase in pain. Further the videoconferencing aspect of e-Hospice provides immediate access to palliative resources should an acute symptom crisis arise.

## **7. Conclusion**

In this paper, we have described the concept of e-Hospice and also shown an initial prototype application. The prototype application allows a patient to manage their pain at home and also provides the means to deliver palliative care resources to ensure the well-being of both the patient and their family. We have also identified three specific barriers to realizing e-Hospice concept and provided solutions to overcoming the barriers. Despite the challenges and work needed to realize e-Hospice we believe it is a worthwhile endeavor.

Consider questions such as where can spouses or non-palliative practitioners turn in the middle of the night to get information on symptoms management? How can a bereaved person get in contact with support groups? Where can a general practitioner get efficient access to palliative educational material so that he can incorporate palliative care into his practice? Our e-Hospice vision would help provide answers to those questions by providing efficient access to palliative services and bringing together all types of people who are involved in or wish to be involved in palliative care. We certainly are not suggesting that an e-Hospice will have all the answers to questions but it is a good starting point to move people in the right direction.

Our aging population will increase the need for palliative care in the forthcoming years. We believe the e-Hospice concept is a viable means to ensure this need can be fulfilled.

## **Acknowledgement**

The authors thank the staff at Victoria Hospice Society for contributing ideas that helped in the writing of this paper.

## References

- Barnes, S.J., 2002. Under the skin: short range embedded wireless technology. *International Journal of Information Management* 22, 165–179.
- Bose, R., 2003. Knowledge management-enabled health care management systems: capabilities, infrastructure, and decision-support. *Expert Systems with Applications* 24 (1), 59–71.
- Davies, J., McVicar, A., 2000. Issues in effective pain control 1: assessment and education. *International Journal of Palliative Nursing* 6 (2).
- DelVecchio Good, M.J., Gadmer, N.M., Ruopp, P., et al., 2004. Narrative nuances on good and bad deaths: internists' tales from high technology work places. *Social Science and Medicine* 58, 939–953.
- Dishman, E., 2004. Inventing wellness systems for aging in place. *Computer* 37 (5), 34–41.
- Dunlop, R.J., Davies, R.J., Hockley, J.M., 1989. Preferred versus actual place of death: a hospital palliative care support team experience. *Palliative Medicine* 3, 197–201.
- Eisenecker, U.W., Czarnecki, K., 2000. *Generative Programming: Methods, Tools, and Applications*. Addison-Wesley, Reading, MA.
- Evans, R., Stone, D., Elwyn, G., 2003. Health services research organizing palliative care for rural populations: a systematic review of the evidence. *Family Practice* 20 (3), 304–310.
- Fainsinger, R.L., 2001. Do we all want to die at home? Editorial Reflections Edmonton Regional Palliative Care Program <<http://www.palliative.org/PC/ClinicalInfo/Editorials/DoWeAllWantToDieAtHome.html>> (accessed 14.12.2004).
- Fainsinger, R.L., Fassbender, K., 2002. The drive for a national palliative care database. Editorial Reflections Edmonton Regional Palliative Care Program <<http://www.palliative.org/PC/ClinicalInfo/Editorials/ClinicalNotes-Editorial-Revised-KF.html>> (accessed 6.12.2004).
- Field, M.J., Cassell, C.K., 1997. *Approaching death: improving care at the end of life*. Institute of Medicine Committee on Care at the End of Life. National Academy Press, Washington, DC.
- Fisher, S., Stewart, T.E., Mehta, S., et al., 2003. Handheld computing in medicine. *Journal of the American Medical Informatics Association* 10, 139–149.
- Gaudette, L.A., Shi, F., Lipskie, T., et al., 2002. Developing palliative care surveillance in Canada: Results of a pilot study. *Journal of Palliative Care* 18 (4), 262–269.
- Goossen, W.T.F., Epping, P.J.M.M., Dassen, T.W.N., 1997. Criteria for nursing information systems as a component of the electronic patient record: an International Delphi study. *Computers in Nursing* 15, 307–315.
- Haux, R., Ammenwerth, E., Herzog, W., Knaup, P., 2002. Health care in the information society. A prognosis for the year 2013. *International Journal of Medical Informatics* 66 (I-3), 3–21.
- Jahnke, J.H., McNair, A., Cockburn, J., de Souza, P., Furber, R.A., Lavender, M., 2005. Component-based engineering of distributed embedded control software. In: Bunse, C. et al. (Eds.), *Embedded Systems Development with Components*. Springer-Verlag, Berlin.
- Kibbe, D.C., 2001. Myths and realities about e-Health. *The Case Manager* 12 (5), 56–61.
- Ross, P.E., 2004. Managing care through the air spectrum. *IEEE* 41 (12), 26–31.
- Rossi Ferrario, S., Cardillo, V., Vicario, F., et al., 2004. Advanced cancer at home: caregiving and bereavement. *Palliative Medicine* 18, 129–136.
- Scott, R.E., Jennett, P., Yeo, M., 2004. Access and authorization in a global e-Health Policy context. *International Journal of Medical Informatics* 73, 259–266.
- Townsend, J., Frank, A.O., Fermont, D., et al., 1990. Terminal cancer care and patients' preference for place of death: a prospective study. *BMJ* 301, 415–417.
- VanDenKerkhof, E.G., Goldstein, D.H., Lane, J., Rimmer, M.J., Van Dijk, J.P., 2003. Using a personal digital assistant enhances gathering of patient data on an acute pain management service: a pilot study. *Canadian Journal of Anesthesia* 50 (4), 368–375.
- Wilkie, D.J., Kay, M., Judge, M., et al., 2003. Usability of a computerized PAINReportIt in the general public with pain and people with cancer pain. *Journal of Pain and Symptoms Management* 25 (3), 213–224.