Proceedings of the First International Workshop on Interactive Systems in Healthcare

Organized by

Gillian R. Hayes, University of California, Irvine

Desney S. Tan, Microsoft Research

Lauren Wilcox, Columbia University

Steering Committee


Gregory Abowd, PhD
Georgia Institute of Technology


Mark Ackerman, PhD
University of Michigan


James Anderson, PhD
Purdue University


Suzanne Bakken, PhD
Columbia University


Jakob Bardram, PhD
IT University of Copenhagen


Karen Cheng, PhD
Charles Drew University


Kay Connelly, PhD
Indiana University


Karen Courtney, RN, PhD
University of Pittsburgh


Don Detmer, MD, MA
American Medical Informatics Association
University of Virginia


Gunther Eysenbach, MD, MPH
University of Toronto


Sheba M. George, PhD
Charles Drew University


Gillian Hayes, PhD
University of California, Irvine


Bill Hersh, MD
Oregon Health & Science University


Holly Brugge Jimison, PhD
Oregon Health & Science University


Bonnie Kaplan, PhD
Yale University


Alex Mihailidis, PhD, PEng
University of Toronto


John "Scooter" Morris, PhD
University of California, San Francisco


Margaret Morris, PhD
Intel Research


Elizabeth Mynatt, PhD
Georgia Institute of Technology


Vimla Patel, PhD, DSc
University of Texas


Philip R.O. Payne, PhD
Ohio State University


Wanda Pratt, PhD
University of Washington


Madhu Reddy, PhD
Pennsylvania State University


Cornie Scheffer, PhD
Stellenbosch University


Chris Seebregts, PhD
South African Medical Research Council


Desney Tan, PhD
Microsoft Research


Gerhard Tröster, PhD
ETH Zurich

Table of Contents

Interactive Healthcare Systems in the Home: Vestibular Rehabilitation

Rikke Aarhus
Department of Computer Science,
Aarhus University.
Aabogade 34
8200 Århus N, Denmark
raa@cs.au.dk

Erik Grönvall
Department of Computer Science,
Aarhus University.
Aabogade 34
8200 Århus N, Denmark
gronvall@cs.au.dk

Simon Bo Larsen
Alexandra Institute
Aabogade 34
8200 Århus N, Denmark
simon.larsen@alexandra.dk

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Abstract

Vestibular dysfunction is a balance disorder, causing dizziness that provokes discomfort and fall situations. This paper discusses early results from a project that aims to develop assistive technologies to support home-based rehabilitation for elderly affected by Vestibular dysfunction.

Keywords

Home-based rehabilitation, interactive systems, participatory design, elderly.

ACM Classification Keywords

J.3 Life and Medical Sciences: Health, Medical Information Systems; H.5.2: Information interfaces and presentation: User Interfaces.

General Terms

Design, Human Factors.

Introduction

In our project, we aim to develop an interactive system to support elderly people affected by Vestibular dysfunction in their home-based rehabilitation program, which they engage in alongside a clinic-based training.

Current trends within the healthcare sector are to reposition care and rehabilitation from the hospital to the home. This process challenges the setting, as a home is not build as a place for care, and also the different actors involved who may experience new tasks and roles. For instance, a hospitalized person needs only to focus on being a patient, while a patient at home often also needs to be e.g. a worker or family member [1]. In this paper, we present preliminary results from a project developing healthcare systems for home-based vestibular rehabilitation (VR).

Vestibular dysfunction and rehabilitation

Vestibular dysfunction causes dizziness and elderly suffering from vestibular dysfunction risk to fall and hence to become isolated, as they fear to move in public. However, it is possible to reduce the symptoms through rehabilitation. The rehabilitation program, at least in our case, includes group-based training twice a week at a specialized clinic supervised by physiotherapists (Figure 1), and daily trainings at home on their own. Patients train two types of exercises; 1) special head and eye movements (see Figure 2) together with balance training (clinic and home), and 2) general workout (clinic).

Figure 1: The clinic at the hospital.

Performing the exercises, safety is of outmost importance due to the risks of falling especially as patients preferably should stand up while doing the exercises. Generally, patients adhere to the training at the clinic while our studies indicate that adherence to the home exercises is low. Some patients do not understand the importance of the home exercises, they are considered difficult to relate to and tiresome, and some of the elderly are not able to do the exercises correctly. Furthermore, little progress is perceived the first 12 weeks of training which affects the motivation. The elderly also lack the randomness in the exercises which is provided at the clinic through the assistance of the physiotherapists. The physiotherapists have expressed a need for a tool to monitor the home exercises to improve adherence.

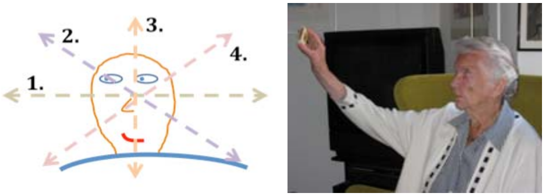


Figure 2: (left) Horizontal, vertical or diagonal eye-movements or all of them combined. (right) An elderly performs the exercises with a matchbox at home.

Design requirements

Through field studies and user-involved activities we have identified several requirements to the design of technology for VR. The technology should support patients in doing the exercises correctly and provide motivational cues. The technology should hence provide an element of surprise and preferably be some kind of gaming activity [3]. It should also offer a way to verify that the user actually carries out the exercises and not only activates the system to make the physiotherapists happy. Designing for the home, the assistive technology should not occupy much space and should blend in with a wide range of different homes and lifestyles. The technology should be easy to setup, use and maintain as the elderly in our project are not experienced technology users and show some degree of reluctance toward having technology in their homes. Finally, the technology for VR should provide a tool for the physiotherapists to bridge the physical distance between clinic and home to improve the outcome of the rehabilitation.

So far, we have developed and tried out numerous ideas trying to incorporate the above outlined requirements. The ideas have been developed and tested together with the elderly and the physiotherapists. The different ideas are described in [3]; here we will only highlight the flower concept that has been developed as a result of the different user-involved activities.

The Flower Concept

The flower concept is composed by an artificial flower (figure 3) and a flowerpot. The flowerpot acts as a docking station for the flower when not in use providing charging and internet connectivity. The flower contains a wireless connection to the ‘flower-pot’, a Led in each petal, accelerometer to measure speed, direction and angle to earth, speaker, special purpose sound chips and a microcontroller. The microcontroller executes the program, or ‘game’, which can be remotely updated by the physiotherapists. The basic activity in the flower concept supports patients if they lie down, sit or stand. The user holds the flower in front of her. A petal lights up indicating a direction similar to a compass. The user now moves the flower in that direction (i.e. doing the exercise), until a new petal (i.e. direction) lights up. The user shall then move the flower in the new direction. This can only be accomplished if the user actually does look at the flower noticing the change of activated petal, and is therefore an indication of correct use in respect to the rehabilitation protocol.

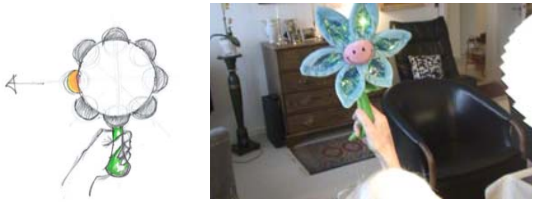


Figure 3: Early drawing and prototype for WOz sessions.

Through the Wizard of Oz (WOz) technique [2], a low-fi version of the flower is currently under evaluation, both in private homes and at the clinic. This version is built around a toy-flower made out of fabric. We have augmented the flower with a Led in each petal. A purpose-made remote controller communicating with the flower wirelessly can control these Leds individually.

Discussion

The early feedback of the flower concept has been broadly positive. The interaction modality can be used by all patients regardless their physical abilities as e.g. the speed can be adjusted to each patient. Our work with the different design concepts and especially the flower concept shows that acceptance or motivational aspects to engage in technology use as part of a home-based care program is important, but complex in nature. The clinic represents a controlled and professional setting where technology acceptance is based mostly on functional requirements. On the other hand, the home is a complex setting with many different and often non-health related activities taking place and other roles for the inhabitant than being a patient. Therefore, technology acceptance in the home is to a wide extent also based on non-functional requirements. Even if the flower is also used at the clinic, it may be perceived differently when used in the home. This was the case with one of our other design concepts, an augmented dart game, which was widely accepted at the clinic but less so in the home due to e.g. fear of breaking decorative items in the home, even if this particular game used soft Velcro-balls.

Introducing technology to the home, we risk giving the elderly a feeling of being sick or hospitalized as the technology either draws attention to the disorder or signals disease which neither of the elderly in our project wish. The flower concept seems not to be perceived in this way. However, further work is needed to better understand the conditions and requirements for applying technology in home-based rehabilitation. In addition, we also need a better understanding of the correlation between the nature of a disorder and the acceptance of healthcare technology to be used in the home. In our case, the elderly do not depend on the exercises to live, as is the case with e.g. a ventilator [4]. How do the degree of dependency and the nature of the disorder affect the acceptance and use of a technology, especially for people who are, as our patients, hesitant technology users?

The flower concept supports the idea of providing a tool for the physiotherapists to understand e.g. individual challenges in the home training. Thereby the connection between home and clinic and the rehabilitation are improved. To establish such connection, or bridging, becomes of great importance due to the current trend to move (parts of) care and rehabilitation to the home from a medical setting. However, a challenge is to provide data that is easily integrated into the work of the physiotherapists. Also, some of the elderly expressed a fear that a clinic-connected system would give them a feeling of being under surveillance in their private homes.

Designing and introducing technology in the home to assist elderly in a rehabilitation program is thus not a straightforward task. It opens for multiple challenges and discussions that deserve further research.

Acknowledgement

We would like to thank the physiotherapists and the elderly who participate in this ongoing project. The project is funded by the Danish Agency for Science, Technology and Innovation.

References

[1] Alonzo, A., Everyday illness behavior: a situational approach to health status deviations. *Soc. Sci. & med.*, 1979. 13(4): p. 397.

[2] Green, P. and Wei-Haas, L. The Rapid Development of User Interfaces: Experience with the Wizard of Oz Method, *Proceedings of the Human Factors Society. 29th Annual Meeting*, 1985. p. 470-4.

[3] Grönvall, E., Aarhus, R., Larsen, S.B. Vestibular rehabilitation in the home: Design challenges. *Proceedings of the 9th Danish Human-Computer Interaction Research Symposium.* 2009: p. 22-25.

[4] Lindahl, B., Sandman, P., Rasmussen, B. Meanings of living at home on a ventilator. Nursing Inquiry. 2003. Vol. 10, no. 1: p. 19–27.

Technologies for Aging Gracefully: A Systematic Design Space

Ronald M. Baecker
Technologies for Aging Gracefully
Lab (TAGlab)
Knowledge Media Design Institute
and Dept. of Computer Science
University of Toronto
40 St. George St., Bahen 7228
Toronto, ON M5S2E4 Canada
rmb@kmdi.toronto.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

We present a design taxonomy of technology for senior citizens, use it to review systematically examples from the research literature and from our laboratory, and suggest how this framework can support imaginative and creative design variations.

Keywords

Senior citizens, aging, cognitive prostheses, mobile devices, multimedia, Alzheimer's disease, stroke.

ACM Classification Keywords

H.5.2. User interfaces; J.3. Life and medical sciences; K.4.2. Social issues.

Introduction

A 2001 U.N. report noted that 10% of the world's population was then over 60, and projected that this would increase to 20% by 2050, and 33% by 2150. Senior citizens have long used prosthetics for mobility such as crutches, for vision such as glasses, and for hearing such as hearing aids. Seniors are now also rapidly adopting information technology; for example, the largest increase in internet use since 2005 has been in the 70-75 year-old age group [6]. This suggests that there are interesting design opportunities for information technology to support graceful aging.

A Design Framework

Design frameworks help researchers and clinicians to understand, compare, and contrast approaches. Ideally, they also suggest novel solutions. The following design space extends previous work [1] with the following six dimensions:

1. What cognitive or social *process* is supported? E.g., memory skills dealing with reminding, orienting, reminiscing, finding, and recognizing; executive functions; or higher-level skills such as communicating and remaining connected with family and friends.
2. For what *population* is one designing? E.g., individuals with amnesia, mild cognitive impairment (MCI), Alzheimer's disease (AD), or stroke survivors, or a population of those "normally aging".
3. What is the *goal*? E.g., *diagnostic*; or *prosthetic*, i.e., compensating for an impaired function; or *rehabilitative*, i.e., restoring some function that is impaired; or *preventative*, e.g., slowing cognitive decline.
4. Who are the *users* and what is the *usage* pattern? E.g, the person with some impairment, caregiver, family, clinician, or some combination of stakeholders? Will the technology be used unaided or with assistance?
5. What *design approach* is used? E.g., *user-centered design* (UCD) — designing *for* users, *participatory design* (PD) — designing *with* users, or *patient-centred design* — design by a clinician for a specific patient.
6. What *technology* is employed? E.g., laptop computers, DVDs, smart cell phones, configurations of tiny "ubiquitous computing" devices, or neural implants. Also, is the technology fixed, or adaptive, or adaptable?

Pioneering Research Projects

For over two decades starting in the mid 80s, Dr. Elliot Cole and associates [3] demonstrated with over one hundred patients that desktop computer technology can significantly and substantially aid individuals with cognitive deficits that result from conditions such as TBI and stroke. Identifying and exploiting what Cole terms "islands of abilities" allows the achievement of specific neurorehabilitation goals.

With the Memory Link program [11] beginning in the late 1980s, Dr. Brian Richards and colleagues applied errorless learning to teach persons with anterograde amnesia to use looseleaf "memory books" with alarm mechanisms to remind them of appointments and medications. Recently, smart phones have been introduced, also for communication and collaboration among amnesics and family members [13].

NeuroPage is a lightweight portable pager that also serves a reminding system. A study [12] of 143 brain-damaged patients' use of NeuroPage showed that more than 80% of patients completing the 16-week trial were significantly more successful with everyday activities such as self-care, taking medication, and keeping appointments. In most cases, improvement was maintained 7 weeks after returning the pager.

The ravages of chronic conditions such as AD, Parkinson's, and stroke are very often also devastating for caregivers. Dr. Elsa Marziali's elegant Caring for Others system [7] uses desktop videoconferencing to provide remote support by social service workers and social connections for 7/24 homebound caregivers of individuals with such conditions.

Current Projects in Our Lab

Elsa and I have developed an effective production process [9] for creating multimedia biographies (digital life histories of entire lifespans) for persons with mid- or early-stage AD or MCI. The biographies stimulate memories, usually bring joy to the AD individual, enable family members to better remember their loved ones as they were before the AD, facilitate family conversation, and are useful for third-party caregivers [4].

Researchers and clinicians at Microsoft Research Cambridge [2] recently reported on the successful use of a novel automatic camera called SenseCam to enable recall of current episodes in the lives of individuals with amnesia or AD. We are carrying out a study comparing raw SenseCam footage to authored narrated slide shows incorporating selected SenseCam stills to memory stimulation with probing questions.

Context-aware cell phones can delivery valuable information for individuals with cognitive deficits. Building on a pilot exploration in which a smart phone suggests who one might encounter in a particular location [5], we are now generalizing this concept to the prediction of words and sentences to support communication by individuals with anomic aphasia.

We are also designing senior citizen gaming web sites for cognitive and social stimulation. One goal is to provide compelling environments that if used regularly might increase cognitive reserve [10] and thus one's resistance to mental aging and to the expression of AD. Another goal is to provide an environment for carrying out randomized controlled trials on the effectiveness of various mental fitness regimens [8].

Design Variations

The six dimensions of each of the eight projects are summarized in Table 1. The design framework should also be a thinking tool suggesting new technologies and new uses for technology. Here are some examples:

Population: As users of a smart phone vary in the degree of cognitive impairment from MCI to mild AD to moderate AD, the inference engine should become progressively more directive and less reliant upon user control of what is displayed.

Goal: As goals for a gaming environment vary from prosthetic to rehabilitative to preventative, the games supported may have to be significantly different.

Users: Digital life histories may vary in production process, content, and usage depending upon the user(s): individuals, couples, small families, or large families dispersed throughout the world.

Technology: Display of names from a social network to aid name recall or of SenseCam images to aid recall of experiences may be done in significantly different ways on a smart phone, a laptop, a desktop or ambient tabletop display, and a wall display.

Acknowledgements

We are grateful to the Technologies for Aging Gracefully Lab (TAGlab): Masashi Crete-Nishihata, Garry Ing, Alex Levy, Mike Massimi, Velian Pandeliev, Deborah Ptak, Nick Shim, Kevin Tonon, Mark Watson, and Mike Wu; to research collaborators Drs. Sandra Black, Adam Brickman, Elsa Marziali, Brian Richards, Elizabeth Rochon, Joshua Steinerman, Yaakov Stern, and Gary Turner; and to sponsors NSERC, MSR, and Google.

References

[1] Baecker, R.M. (2007). A Taxonomy of Technology for Cognition, *Proc. 2nd Int'l. Conference on Technology and Aging*.

[2] Berry, E., et al. (2007). The Use of a Wearable Camera, SenseCam, as a Pictorial Diary to Improve Autobiographical Memory in a Patient with Limbic Encephalitis: A Preliminary Report, *Neuropsychological Rehabilitation, 17*(4/5), 582-601.

[3] Cole, E. (1999). Cognitive Prosthetics: An overview to a method of treatment, *Neurorehabilitation* 12(1), 39-51.

[4] Damianakis, T., Crete-Nishihata, M., Smith, K.L., Baecker, R., and Marziali, E. (2009). The Psychosocial Impacts of Multimedia Biographies on Persons with Cognitive Impairments, *The Gerontologist* doi:10.1093/geront/gnp104.

[5] Fenwick, K., Massimi, M., Baecker, R.M., Black, S., Tonon, K., Munteanu, C., Rochon, E., and Ryan, D. (2009). Cell Phone Software Aiding Name Recall, *Proc. ACM CHI 2009*, 4279-4284.

[6] Jones, S. and Fox, S. (2009). Pew Internet Project Data Memo, Pew Internet & American Life Project.

[7] Marziali, E. & Donahue, P. (2006). Caring for Others: Internet, Video-conferencing Group Intervention for Family Caregivers of Older Adults with Neurodegenerative Disease, *The Gerontologist* 46, 398-403.

[8] http://www.sharpbrains.com/

[9] Smith, K.L., Crete-Nishihata, M., Damianakis, T., Baecker, R.M, and Marziali, E. (2009). Multiimedia Biographies: A Reminiscence and Social Stimulus Tool for Persons with Cognitive Impairment, *Journal of Technology in Human Services* 27, 287-306.

[10] Stern, Y. (2003). The Concept of Cognitive Reserve: A Catalyst for Research. *Journal of Clinical and Experimental Neuropsychology* 25(5), 589-593.

[11] Svoboda, E, and Richards, B. (2009). Compensating for Anterograde Amnesia: a New Training Method that Capitalizes on Emerging Smartphone Technologies, *Journal of the International Neuropsychological Society* 15, 629-638

[12] Wilson, B. A., Emslie, H. C., Quirk, K., & Evans, J. (2001). Reducing Everyday Memory and Planning Problems by Means of a Paging System: A Randomised Control Crossover Study, *Journal of Neurology, Neurosurgery & Psychiatry* 70, 477–482.

[13] Wu, M., Birnholtz, J., Baecker, R., Richards, B., & Massimi, M. (2008). Collaborating to Remember: A Distributed Cognition Account of Families Coping with Memory Impairments, *Proc. ACM CHI 2008*, 825-834.

	Insitute for Cognitive Prosthetics [3]	*Memory Link [11]*	*NeuroPage [12]*	*Caring for Others [7]*	*Multimedia Bios [4,9]*	*SenseCam Research [2]*	*Context-aware Cell Phones [5]*	*Online Gaming Environments [8]*
Cognitive / social process	Communications, organization, … other skills	Reminding re medications & appointments	Reminding re medications & appointments	Social support	Reminiscing	Recall of recent experiences	Recall of words, sentences, and names	Cognitive and social stimulation
Participant population	Primarily individuals with TBI, stroke	Amnesic individuals	Brain-damaged patients	Homebound caregivers	Mid- or early-stage AD or MCI	Mid- or early-stage AD or MCI	People with anomic aphasia	Normally aging seniors
Goal	Rehabilitative	Prosthetic	Prosthetic + rehab.	Prosthetic	Prosthetic + rehab.	Prosthetic + rehab.	Prosthetic + rehab.	Preventative
Users, usage	Individuals	Individuals	Individuals, family "programming"	Individuals	Individuals + families	Individuals + families	Individuals	Individuals + families
Design method	Patient-centred design	UCD (user-centred design)	Not known	UCD	Participatory design + UCD	Participatory design + UCD	Patient-centred design + UCD	UCD
Technology	Desktop PCs+ telerehabilitation	Currently, smart phones	Electronic pagers	Desktop video conferencing	Multimedia on DVDs	Multimedia on PCs	Smart phones	Online games

Who's looking? Invisible problems with interactive medical devices

Ann Blandford
UCLIC
University College London
Gower Street
London WC1E 6BT, U.K.
a.blandford@ucl.ac.uk

Dominic Furniss
UCLIC
University College London
Gower Street
London WC1E 6BT, U.K.
d.furniss@ucl.ac.uk

George Buchanan
Centre for HCI Design
City University
Northampton Square
London EC1V 0HB, U.K.
George.Buchanan.1@city.ac.uk

Harold Thimbleby
Department of Computer Science
Swansea University
Singleton Park
Swansea SA2 8PP, U.K.
H.Thimbleby@swansea.ac.uk

Paul Curzon
School of Electronic Engineering
and Computer Science
Queen Mary, University of London
Mile End Road
London E1 4NS, U.K.
p.curzon@qmul.ac.uk

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Abstract

There is evidence that widely used interactive medical devices such as infusion pumps pose interaction difficulties. Yet this evidence is widely dispersed, and difficulties in programming, interaction and socio-technical design have rarely been a focus for study. Interaction difficulties are effectively invisible. To understand why, it is necessary to study the cultural and organizational contexts within which devices are designed, deployed and used. In this paper, we present examples illustrating interaction difficulties and outline features of the context that keep those difficulties invisible.

Keywords

Medical devices, device design, human error, regulatory framework.

ACM Classification Keywords

D2.10 Design, H5.2 User interfaces.

General Terms

Design, Human Factors.

Introduction

Periodically, an incident in which widely used interactive medical devices are implicated hits the headlines. For example, the report on the death of Denise Melanson [4] highlights the calculation and programming errors that resulted in medication that was intended to be administered over four days being delivered in four hours. In a subsequent user trial replicating the situation as closely as possible, 3 out of 5 participants made programming errors, and all had some difficulty working with the device. Another example is the report on Lisa Norris [8], who also died – in this case, following repeated high doses of radiation therapy due to an operator being unaware of the need to apply a scaling factor in the calculations. Both of these incident reports refer to other "similar" cases for which less information is available.

The role of design in reducing or mitigating errors is becoming more widely recognised. For example, a Panel on Transforming Healthcare report to the US President calls for "research on user-interface hardware and software to promote the development of better solutions to the problem of human computer interaction in healthcare" [7]. Smetzer and Cohen [9] have recognized the issue of misprogramming of drug delivery devices. They note (p.275) that "misuse of infusion pumps and other parenteral device systems is the second most frequent cause of medication errors during drug administration". They discuss the impacts of various factors, including device programming, physical aspects such as tubing, and wider system aspects such as relatives administering patient-controlled analgesia drugs, on medication errors; they advocate Failure Modes and Effects Analysis (FMEA) as a means for assessing system safety. Fairbanks and Wears [2] also highlight the role of design in provoking or mitigating errors, focusing on the design of defibrillators; they argue that design changes "offer the prospect for real and sustained change". However, such reports have as yet had little impact on practice.

It is difficult to get detailed information on incidents that increase system vulnerability but do not result in adverse outcomes. A study by Husch *et al.* [3] highlights how few incidents are reported. They studied infusion pump use in a busy hospital over a 9 hour period, covering 426 instances of intravenous infusions. They identified a total of 389 errors, occurring in 285 of the infusions. In other words, 66.9% of the infusions studied involved one or more errors. Many of these errors would be classed as minor (e.g. no rate on label, which might lead to a more serious error but does not cause direct harm). However, 55 of the errors identified were either rate deviation or incorrect medication. This can be compared with the number of errors in the same categories that were reported through the formal reporting system – namely 48 reports over a 2 year period from the same hospital. On the one hand, this shows that even potentially harmful errors are often not perceived as resulting in harm; on the other hand, the low reporting rate means that errors are effectively invisible, and it is impossible to learn from the "near misses", as happens in other industries [1].

Why are interaction design problems invisible?

In our initial investigations, we have identified several factors that contribute to the invisibility of interaction design problems, and the corresponding human errors. Some relate directly to the visibility of interaction design in procurement, in use and in incident reporting:

1. *Procurement does not have human-factors guidelines*. A recent UK purchasing guide for insulin pumps [6] omits any discussion of interaction design

but notes (p.9) that “Individuals with poor cognitive function should not be responsible for self-management of a pump.” Hospitals buy devices on a range of criteria, including cost and consumables costs; usability and error prevention are not usually central criteria.

2. *The focus of clinicians* is on patient care, and they will do whatever workarounds are necessary to address patient care, rather than considering in what ways the devices they work with could be better designed, or the details of why an interaction went wrong in any way. For example, we have seen ventilators fail and need rebooting mid-operation. If there is no harm, there is nothing to report. Hence serious design issues do not get reported unless they clearly — to the non-technical specialists at the sharp end — lead to patient harm. Because clinicians are not focusing on interaction design, they have limited ability to report on details of the interaction following an incident.

3. *There is minimal questioning of device design*, not just among clinical staff, but across all professions involved in decisions. For example, the incident report on the Lisa Norris case [8] (p.2) notes that “... at no point in the investigation was it deemed necessary to discuss the incident with the suppliers of this equipment since there was no suggestion that these products contributed to the error”, and yet a reading of the report from an HCI perspective suggests that there were clear problems over the integration of software modules, and that the system was unnecessarily difficult to understand and use.

Other factors are organizational, including organizational culture, reporting mechanisms and problem ownership:

4. *The pervasive blame culture* discourages reporting. This culture is widely recognized [5], and it can be an obstacle to investigations, and even to studies. For example, in working with nursing managers to design observational studies of staff using infusion devices, we have to address their concerns that an improved awareness and reporting of interaction errors may result in a perception that performance is getting worse – a perception that would be damaging to patient confidence and to the reputation of the organization.

5. *The lack of high quality data* on interaction errors makes it impossible to ascertain how often interaction errors are a contributory factor in incidents. Barach and Small [1] quote an estimate of 100 000 preventable deaths in US hospitals annually, but few incident reports include details of interactions. Incident reports generally give no indication of what information the clinician was working from, how any calculations were performed, what checks were in place, or how the drug was administered (including details of the devices used or the user interaction with those devices) – details that are essential for designing safer devices and safer systems.

6. *There is a lack of ownership of the problem*. Each country has a different regulatory regime, so it is difficult to generalize. The situation in the UK is summarized by Sujan *et al* [9]. In brief: responsibility for the safe design of interactive medical devices is split across several authorities, with the Medical and Healthcare Regulatory Agency taking responsibility for ensuring that devices perform as designed, the National Patient Safety Agency informing policy on aspects of safety including human error, the National Institute for Health and Clinical Excellence having recently taken over responsibility for informing procurement decisions,

and Licensed Authorities certifying new devices as conforming to relevant legislation such as the Medical Devices Directive [11] which, in turn, includes minimal information on device design. Interaction design of established technologies such as infusion devices is not central to the concerns of any of these bodies.

A research agenda on improving interaction design to reduce patient harm

There are many factors that can contribute to hazardous incidents in healthcare. While there is an extensive literature on the role of broader organisational factors in patient safety (e.g., the "blame culture" [5] and organisational complexity [9]), there is limited discussion or reporting of the role of interaction design in contributing to safety. The contribution of interaction design to medical incidents is substantially underreported. There is a pressing need for much more extensive research on the causal relationships between human behaviour, device design, situations of use and medical incidents. To maximise the impact of such research, it is also essential to extend the dialogue on this topic to accommodate the perspectives of clinicians, manufacturers, policy makers and patients.

Acknowledgements

The CHI+MED project is funded by EPSRC EP/G059063.

References

[1] Barach, P. & Small, S. (2000) Reporting and preventing medical mishaps: lessons from non-medical near miss reporting systems. BMJ. 320. 759-763.

[2] Fairbanks, R. & Wears, R. (2008) Hazards with medical devices: the role of design. Annals of Emergency Medicine. 52. 519-521.

[3] Husch, M., Sullivan, C., Rooney, D., Barnard, C., Fotis, M., Clarke, J. & Noskin, G. (2005). Insights from the sharp end of intravenous medication errors: implications for infusion pump technology. In Quality and Safety in Health Care, 14: 80-86

[4] ISMP Canada (2007) Fluorouracil Incident Root Cause Analysis.

[5] Khatri, N., Brown, G. & Hicks, L. (2009) From a blame culture to a just culture in health care. Health Care Management Review. 34. 312-322.

[6] NHS Purchasing and Supply Agency Buyer's Guide on Insulin Pumps, Feb 2008. From www.pasa.nhs.uk/PASAWeb/NHSprocurement/CEP

[7] President's Information Technology Advisory Committee (2001) Transforming Healthcare Through Information Technology, www.nitrd.gov/pubs/pitac/pitac-hc-9feb01.pdf

[8] Scottish Executive (2006) Unintended overexposure of patient Lisa Norris during radiotherapy tratment at the Beatson Oncology Centre, Glasgow in January 2006.

[9] Smetzer, J.L. & Cohen, M.R. (2006) Preventing Medication errors related to drug delivery devices. In M. R Cohen (Ed.) Medication Errors, 2nd Ed. 275-288.

[10] Sujan, M.A., Harrison, M.D., Steven, A., Pearson, P.H. & Vernon, S.J. (2006) Demonstration of safety in healthcare organisations, In *Proc. SAFECOMP 2006*, LNCS 4166, 219-232.

[11] Council Directive 93/42/EEC concerning medical devices.

Attitudes and Readiness for Adoption of an Electronic Medical Records System: A Preliminary Case Study

Jed R. Brubaker
Department of Informatics
University of California, Irvine
jed.brubaker@uci.edu

Yunan Chen
Department of Informatics
University of California, Irvine
yunanc@ics.uci.edu

Karen Cheng
Department of Psychiatry
Charles Drew University
karencheng@cdrewu.edu

Chris Combs
Department of Informatics
University of California, Irvine
ccombs@uci.edu

Sheba George
Ctr for Biomedical Informatics
Charles Drew University
shebageorge@cdrewu.edu

Sidney Harrison
Department of Informatics
University of California, Irvine
sidneyh@uci.edu

Gillian R. Hayes
Department of Informatics
University of California, Irvine
gillianrh@ics.uci.edu

Sherrie Kaplan
Center for Health Policy Research
University of California, Irvine
skaplan@uci.edu

Abstract

We provide preliminary results from a longitudinal survey study of hospital staff attitudes and perceived readiness during the adoption of an electronic medical records system (EMR). The findings presented here represent baseline data for a survey that will be administered biannually over a three year phased EMR adoption. Data (n=789) address participant-reported comfort with electronic devices, work-use of various technologies, and work-related challenges that may impact the success of the EMR adoption.

Keywords

EMR, Survey, Adoption, Facilitators, Barriers

Introduction

This paper presents preliminary results from a study assessing the impact of EMR adoption on record-keeping, clinical and organizational practices, work efficiency, and patient care at a major academic medical center, referenced here as UniHospital. Findings are based on an initial survey of future EMR users and are informed by observational work conducted in Spring 2008. Our survey was distributed in September 2009 to collect baseline data immediately prior to the deployment of the first phase of an EMR system.

During previous qualitative observational work, we uncovered specific challenges and successes within individual units as well as larger themes across multiple sites. Larger themes include handling of patient and research records; internal and external communication; barriers to adoption and use of technology and

---

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

strategies for overcoming them; and anticipation, management and control of change. Thus, the larger study (of which the work here is a subset) is focused on managing clinical and research data as well as socio-technical challenges of interacting with patients, other medical center workers, and external stakeholders. Results from this survey demonstrate how UniHospital thus far has integrated information technology into existing work practices and staff attitudes about those technologies across both their work and home lives.

Methods and Demographics

Responses were collected via an online survey comprised of 19 questions (some with sub-parts). Our conceptual model (see Figure 1) for facilitators and barriers to implementation and adoption informed by extensive literature on EMR deployments, HIT adoption, and morale and change in hospital settings drove the development of our survey instrument.

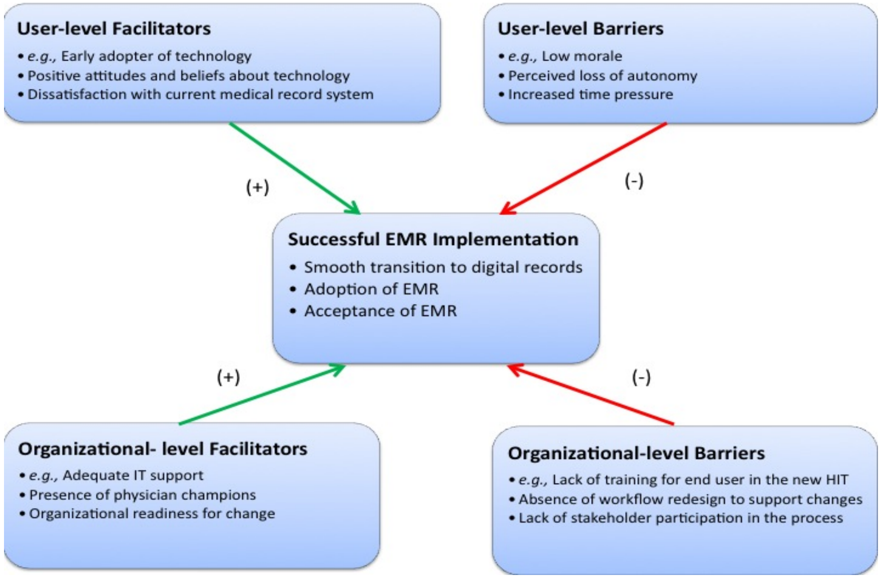


Figure 1: Conceptual model for UniHospital adoption of EMR.

The anonymous survey required approximately 15 minutes to complete. Respondents were recruited from a UniHospital-provided list of approximately 3500 future EMR users, including administrators, records personnel, medical students, clinicians, and staff. Respondents could optionally enter a drawing for a $50 Gift Card (1 in 200 respondents received a gift). The survey was open for the last two weeks of September 2009, and participants were encouraged to complete the questionnaire via emails from hospital administrators and the authors. We received 789 valid responses. Responses were from a wide variety of departments, with no department representing more than 6% of responses. Participants were highly varied in roles, time at UniHospital, and age (~45% were born before 1963, 40% between 1964 and 980, and ~10% after 1980).

Findings

Comfort with Electronic Devices

Overall, participants reported comfort with electronic devices and computational systems, potentially influenced by the use of an online survey. Approximately one-fifth of respondents are “early adopters.” More than half (52%) of respondents noted that they take “only a little time” to learn about new technologies and 38% of participants report that they are eager to try new technologies after a few others report success.

Respondents reported use of a variety of technologies at work. Nearly everyone (84%) reported using email very often. Meanwhile, more than half (67%) reported never using a PDA or SmartPhone at work. A new mobile phone-based paging solution is currently being implemented at UniHospital, which may influence these responses over time.

Current Challenges

In the larger study, we hypothesize that extensive barriers to the completion of current work will increase staff readiness to adopt the new EMR system, particularly where it promises to reduce existing challenges. Thus, it was important in this initial baseline survey to document the challenges users currently experience.

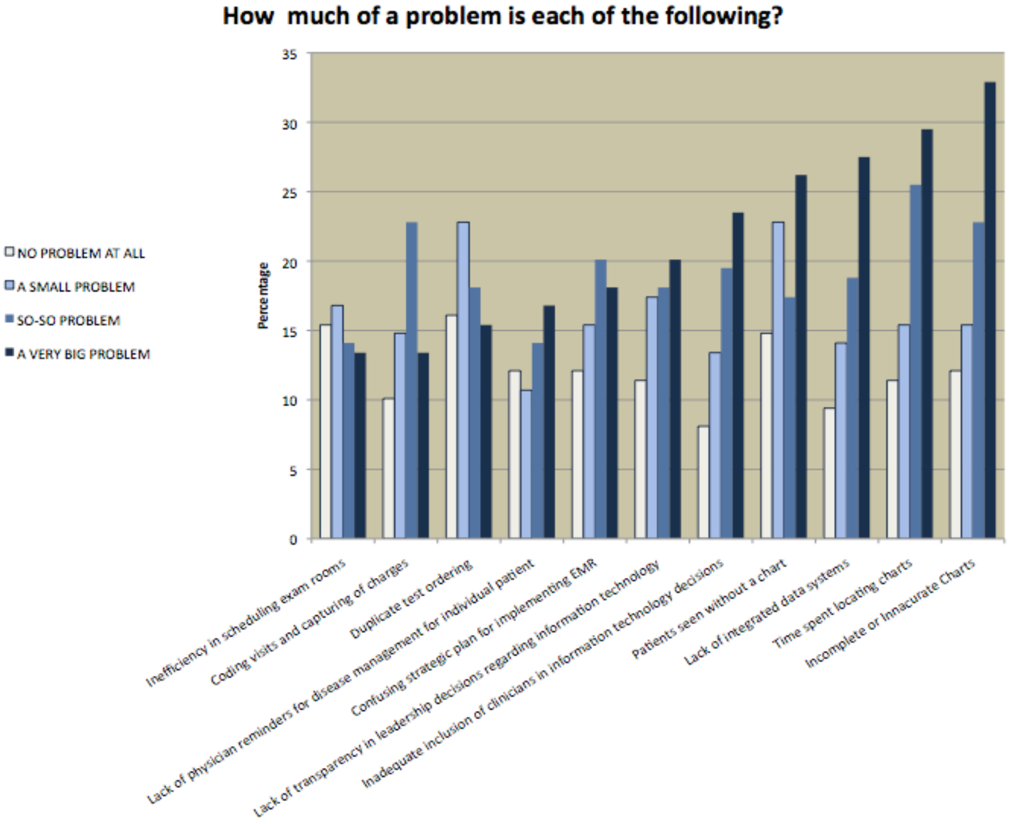


Figure 2: Severity of problems in current work practices and tools.

Respondents generally reported satisfaction with the availability of medical records, time with patients, and the status of the EMR implementation. The three areas with the least satisfaction include the amount of time available for documentation, the amount of time for email or phone visits, and efforts by senior leadership to include providers and staff in decisions about EMR.

The UniHospital EMR project has potential to reduce the time it takes to complete documentation. However, in some EMR implementations, at least in the short term, documentation has taken longer and the follow-up via email and phone has become more difficult [1,2]. Although respondents believe that providers are prepared for the implementation, they want greater involvement in the process. This finding echoes findings from our interview study in 2008, in which participants described concerns about communication between senior leadership and clinicians and staff.

Feelings of being rushed or challenged can be exacerbated by requests to take on new work practices, including use of health information technologies in everyday practice. We detail some of the biggest challenges here (see Figure 2 for complete responses).

Incomplete or Inaccurate Charts: One goal of any EMR implementation is to reduce errors related to incomplete or inaccurate charts. During the transition to a paperless chart, however, UniHospital will use hybrid records, in which records exist in the EMR system, on paper, and in other legacy systems. This situation may actually engender more confusion as clinicians and non-clinical staff work to locate and comprehend all of these disparate data sources. During this time, the importance of adherence to policies around which records should be scanned, which should be printed, and so on must be stressed with all the stakeholders.

Time Spent Locating Charts: During our qualitative study, clinical and non-clinical staff reported a considerable amount of time was spent looking for charts. Survey data echoes this concern. During our fieldwork, we found that the processes for requesting, returning, and archiving records are incredibly complex, and as such we hypothesize that the move to a fully electronic system will greatly reduce these concerns. Of course, as in the previous issue, the interim time of hybrid records may temporarily make this issue even more problematic.

Lack of Integrated Systems: Hospital information technologies tend to grow organically over time. UniHospital's systems are no exception. Over the last few decades, UniHospital has invested in novel and medically important systems. Unfortunately, healthcare technologies are generally fragmented, and few standards for interoperability exist. The strategic plan moving forward includes use of only Eclipsys-based or Eclypsis integrated products unless a clinician or researcher *requires* functionality not available in that system. This plan should greatly improve perceptions about the integration of data systems, but we will carefully attend to perceptions about the quality of individual systems in the event that the trade-off being made here becomes problematic.

Patients Seen Without Charts: As patient charts move to electronic media, they become available in multiple places simultaneously. Thus, it should be less likely that a patient is seen without access to their chart. Likewise, integrated scheduling and records systems should better enable that all patients scheduled for appointments have charts already in the system. When they do not, earlier recognition of this concern allows staff to request this information from either the patients themselves or another medical system and ensures that appropriate information is available to the clinicians at the time of the visit.

CONCLUSION

UniHospital is in the midst of a massive transition. Moving to a fully integrated electronic systems approach to research and clinical records represents a significant advance. Survey data confirms observations that personnel are prepared for and optimistic about this transition. The data reported here represent only one aspect of the overall EMR project. More work will be done to understand the details of situated work practices, in addition to understanding how work practices are described, planned, or imagined to happen.

ACKNOWLEDGMENTS

The authors thank the CIO, CMIO, CMO of UniHospital, the Dean of the Medical School, and study participants.

References

[1] Gadd, C.S. and Penrod, L.E. Assessing physician attitudes regarding use of an outpatient EMR: a longitudinal, multi-practice study. *Proc AMIA 2001*.

[2] Peterson, J. and Whiting, S. Ambulatory electronic medical records for large practices. *Healthcare Quarterly 11*, 1 (2008), 122-12.

Why Understanding the Psychology of User Privacy is Critical to the Success of Interactive Health Systems

Kelly Caine
Indiana University
901 E. 10th St.
Bloomington, IN 47408 USA
caine@indiana.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

Interactive health systems have the potential to dramatically improve quality of life and overall health of users. However, for these benefits to be realized, systems must be accepted and used appropriately. In this paper, I argue that understanding the psychology of user privacy is critical to designing health systems that users trust and accept. I begin by discussing the potential benefits of interactive health systems. Next, I briefly discuss ongoing research that explores the psychology of user privacy and assess how the initial findings relate to emerging interactive health systems. Finally, I conclude by discussing the implications of research on user privacy to multiple communities including practitioners and health researchers who may analyze data generated from interactive health systems.

Keywords

Privacy, psychology, health, healthcare

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous. H.1.2 User/Machine Systems – Human Factors. K.4.1 Public Policy Issues

Introduction

There is widespread agreement among researchers, politicians, and practitioners in the healthcare industry that infusing the health system with technology will improve care, drive down costs, and result in better health outcomes. The evidence supporting such claims continues to mount. For example, electronic medical records may help prevent physicians from making errors when prescribing medicine to patients [2] and mobile applications have been shown to facilitate tracking and self-care in populations where this was previously difficult or impossible [6]. Clearly, interactive systems in healthcare are being designed, implemented, and have the potential to improve the healthcare system.

There are many goals of interactive systems in healthcare. One set of goals that has a special relationship with user privacy are the goals of clinical information data gathering, storage, and sharing (for simplicity, "clinical information sharing"). There are many purported benefits of clinical information sharing. One oft cited benefit is "coordinated care" exemplified in the following scenario: a patient with an allergy to a specific medicine becomes the victim of a car accident. When the paramedics arrive on the scene, the patient's identity is matched to her clinical information and an alternative medicine that the patient is not allergic to is administered. In this case, the clinical information sharing benefits the patient in that she is administered a treatment that is helpful, rather than harmful to her. Another benefit of clinical information sharing is in the interest of public health. Research may benefit the public through improving healthcare for multiple individuals.

Currently, much health research is conducted using a clinical trial methodology. A simplified explanation of this method is as follows: information about a participant's demographics, health status, current medications, etc. are gathered. Next, a participant is randomly assigned to a treatment condition and is monitored throughout treatment. At the conclusion of the treatment course, measurements on the primary variable(s) of interest are compared between the treatment and control groups. Because of time and cost constraints, this method necessarily enrolls and tests relatively few people.

One of the public health benefits of interactive systems in healthcare is that information from vast numbers of patients may be gathered and analyzed outside of clinical trials. The National Center for Vital and Health Statistics describes this idea as follows:

> "Clinically rich information is now more readily available, in a more structured format, and able to be electronically exchanged throughout the health and health care continuum. As a result, the information can be better used for quality improvement, public health, and research, and can significantly contribute to improvements in health and health care for individuals and populations" [5]

The idea is that if personal health information can be collected routinely from large numbers of people, these data may be analyzed and used in research to generate new health information. However, one key assumption in the success of this model remains in question.

A key assumption in the assertion that clinical information sharing will result in "public health research and… improvements in health care for individuals and populations" [5] is that the information that is collected is accurate and complete. If the data that are to be analyzed contain errors and/or omissions the conclusions based on those data may not be valid. Thus, it is more important than ever that data gathered are accurate and complete.

Why Understanding Privacy is Critical

So-called "privacy concerns" are consistently cited as a barrier in the design, implementation, acceptance and use of health IT systems [1]. One risk is that, due to privacy concerns, users will reject technologies they perceive as privacy invasive. However, this is not the only risk associated with privacy. A number of other risks are also present.

When people are concerned about privacy, they engage in a number of everyday privacy behaviors to address their privacy concerns [3]. These behaviors may include:

- Avoiding using a technology
- Hiding
- Being vague
- Censoring themselves
- Lying
- Engaging in selective sharing

While some of these behaviors may be harmless, and even helpful in managing privacy in some contexts, in the context of health information these everyday privacy management behaviors may have negative consequences. For example, a patient is embarrassed about a medical condition ("condition X") he experienced 5 years ago. When he moves to a new town and meets his new doctor, the doctor asks the patient to fill out his history in an Electronic Health Record (EHR). When the patient gets to the section of the EHR asking about the condition he had 5 years ago, the only options that are presented to him on screen are:

Have you ever had condition X:

☐ YES

☐ NO

The system will not let the patient continue filling out the EHR unless he answers this question. Given the choice between revealing information that he feels violates his privacy and answering untruthfully, the patient chooses to answer "NO".

The unintentional result of an EHR that was not designed properly from a user privacy standpoint is that now the system has "bad" or incorrect data about the patient's history. If this information is then electronically exchanged throughout the healthcare continuum and is subsequently included in research about "condition X" it may contribute to an inappropriate conclusion.

Unintentional and unknown consequences

As potentially harmful as incorrect data in an EHR is, there are many other risks if user privacy is not well understood and addressed during the design phase of interactive health systems. For example, avoidance behavior is a commonly reported privacy management strategy in contexts including health disclosure [4]. Extrapolating from this it is possible that people may avoid getting treatment for a condition they feel is particularly embarrassing and do not want to have in their "permanent record". Even today, in e-commerce settings, purchasers are less willing to do business with companies they perceive do not do enough to protect privacy [7]. Following this path even further, it is possible to imagine a future where there is a premium market for medical practitioners who will perform services without those services being included in a patient's health record. Clearly, this hypothetical scenario would not be in line with the goal of using technology to improve the health system.

Citations

[1] Anderson, J. G. Social, ethical and legal barriers to E-health. *International Journal of Medical Informatics.* (2007), 480-483

[2] Bates, D. W., Leape, L. L., Cullen, D. J., Laird, N., Petersen, L. A., Teich, J. M., Burdick, E., Hickey, M., Klleefieeld, S., Shea, B., Vander Vilet, M. and Seger, D. L. Effect of computerized physician order entry and a team intervention on prevention of serious medication errors. *JAMA.* (1998), 1311-1316.

[3] Caine, K. E. Supporting Privacy by Preventing Misclosure. *In EA of the SIGCHI conference on Human Factors in Computing Systems*. (2009)

Implications and Conclusions

The discussion presented here suggests a number of implications for the community of researchers investigating and designing health systems. First, it is clear that more research is needed to understand the psychology of user privacy including everyday privacy behaviors and how these translate to health systems. Second, practitioners need to be made aware of the possible strategies users will engage to manage their privacy when using health systems. Finally, researchers analyzing data should be aware of the kind of system used to collect data and how this system addressed user privacy; if a system did not include appropriate alterative options for managing privacy conclusions based on the data should reflect this shortcoming.

In conclusion, understanding the psychology of user privacy is critical for the development of successful interactive health systems which, if properly designed, have the potential to improve the quality of healthcare for everyone.

[4] Caine, K. E. *Understanding Privacy Behaviors and Misclosures*. Doctoral Dissertation: Georgia Institute of Technology. Atlanta, GA. (2009)

[5] National Center for Vital and Health Statistics. Enhanced protections for uses of health data: A stewardship framework for "secondary uses" of electronically collected and transmitted health data. Available online: http://ncvhs.hhs.gov/071221lt.pdf

[6] Siek, K., Connelly, K. H., Chaudry, B., Lambert, D. and Welch, J. L. Evaluation of two mobile nutrition tracking applications for chronically ill populations with low literacy skills. In *Mobile Health Solutions.*(In press)

[7] Tsai, J., Egelman, S., Cranor, L. and Acquisti, A. The effect of online privacy information on purchasing behavior: An experimental study. WEIS. (2007)

Social and Cultural Barriers to Accepting Mobile Devices for Collection of Health Data in Sub-Saharan Africa

Karen G. Cheng
Charles Drew University of Medicine and Science
Department of Psychiatry and Human Behavior
1731 East 120th Street, Building N
Los Angeles, CA 90059 USA
karencheng@cdrewu.edu

Francisco Ernesto
National Institute for Public Health (INSP-MINSA)
Luanda, Angola
f_ernesto@yahoo.com

Ricardo Ovalle-Bahamón
Charles Drew University of Medicine and Science
Drew Center for AIDS Research, Education, and Services
Luanda, Angola
ovalleri@gmail.com

Khai N. Truong
University of Toronto
Department of Computer Science
Toronto, ON M5S 3G4 Canada
khai@cs.toronto.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

In this paper we describe the findings from focus groups conducted in Angola in southern Africa to assess social and cultural barriers in the use of mobile devices for collection of sensitive health-related data.

Keywords

User study, HIV/AIDS, focus groups, PDA, handheld computers, technology acceptability, developing country.

ACM Classification Keywords

H5.2 [**User Interfaces**] User-centered design; K.4.2 [**Computers and Society**]: Social Issues.

Introduction

Information technology has greatly improved health services, particularly in high-income countries such as the United States and in Western Europe.

However, to date, people in low-resource countries have not received the same benefits from information technology as people in industrialized nations. People in this region do not have the same level of access to technology, due in part to the high cost of the equipment, the lack of equipment and applications that are designed for their context, and unreliable sources of electricity.

Mobile devices may be one solution that can improve the information flow and quality of services provided in low-resource countries [5]. However, the success of using mobile devices in low-resource countries depends on the acceptability of the technology (*i.e.*, user attitude and reaction towards the technology). Understanding a community's motivation for technology is essential given that compliance and accuracy in data recording may be context-specific [3, 4].

The purpose of this study was to identify potential barriers to acceptance of mobile devices for recording of sensitive personal data in a low-resource country, namely Angola in southern Africa. To explore this research question, we conducted focus groups with Angolans from across the social strata. We presented personal digital assistants (PDAs) to them and discussed whether they had any concerns with disclosing HIV/AIDS-related sexual risk behaviors to interviewers using a PDA.

Method

Sampling and recruitment

Participants were men and women, between the ages of 18-55, who live or work in Luanda, Angola. They were recruited via flyers and face-to-face invitations. To gain a broad representation, participants were recruited from varying socioeconomic levels: patrons of *cybercafés* in the Maianga neighborhood, where residents are primarily of higher education and higher income; passers-by of a local youth center in the Bairro Pedelé *neighborhood*, where residents are of moderate education and moderate income; and vendors and clients of the Estalagem *marketplace* in the outskirts of Luanda, most of whom are of low education and low income.

Equipment

The handheld computers used in this study were PalmOne Tungsten E devices. The Tungsten E devices are small 4.5 x 3.1 x 0.48 inch units each powered by a 126MHz ARM processor. Each device has a sharp, high-resolution, 320x320-pixel screen and 32 MB of internal memory and runs Palm OS 5.2.

Focus group procedures

We held a total of six groups – three for men and three for women. Immediately prior to each focus group, participants were individually administered a brief paper survey by a trained, local interviewer to collect demographic information and evaluate participants' experience with technology. In the group discussion, the facilitator introduced the handheld computer and distributed several Palm Tungsten E handhelds to the participants. She or he then probed participants' perceptions of the handheld computer, as well as their thoughts about disclosing intimate sexual behavior to an interviewer using the handheld computer. The sex of the facilitator was the same as the participants in that group. Discussions were held in Portuguese, the official language of Angola, and were audio-taped with participant consent. Each focus group lasted approximately one hour.

Focus group discussions were transcribed and then translated into English for analyses. One focus group – women in the Bairro Pedelé neighborhood – was dropped because of procedural inconsistencies. The original Portuguese transcripts from the remaining five focus groups were combined with the English transcripts, so that raters could compare the text in both languages. The transcripts were then entered into Atlas.ti 5.0 to facilitate coding. Using grounded theory

[2], two raters individually coded the transcripts for comments related to comfort with and willingness to disclose sexual behaviors to an interviewer using a handheld computer. Raters then discussed each coded comment until agreement about the code was reached. Codes were then grouped into themes, and their applicability to the research question was assessed.

Results

In total, there were 49 focus group participants, 30 of whom were men and 19 of whom were women. The average age was 25.5 years, and the average number of completed years of education was 8.9. As expected, the participants from the cybercafés were more educated than participants from the neighborhood, and participants from the neighborhood were, in turn, more educated than participants from the marketplace. Participants from the cybercafés had the most experience with technology: all of them have or had a mobile phone, have used a computer, and have heard of the internet. In contrast, the neighborhood and marketplace participants had lower levels of experience with technology. For example, only half of the participants from the marketplace had ever heard of the internet and none of them had ever used a computer.

Participants described a range of perceptions about handheld computers that could be barriers to acceptance. Since most participants had not used a handheld computer before, they based their perceptions on experience with other technological devices or on their beliefs about technology. The major themes that emerged were

- suspicion of outsiders
- desire to be remembered
- status

Discussion

This study contributes to the literature by providing a more nuanced assessment of technological acceptability in Angola. Using qualitative data, we identified four possible relevant barriers to Angolans accepting the use of mobile devices for HIV/AIDS risk behavior data collection: suspicion of outsiders, desire to be remembered, and status.

An analysis of the historical and social context of Angola can help us understand why these issues might be particularly relevant in Angola. In particular, Angola is recovering from a 27-year civil war during which most of the population was isolated from the rest of the world. A commonly held belief is that foreign intervention is the reason the war continued for so long. The suspicion of outsiders may have continued, from the war until the present. In addition, many Angolans suffer from preventable health conditions because of the poor living conditions and inadequate health care system. The harsh reality of low life expectancy (47 years) [1] may contribute to the desire to be remembered.

There are some practical implications of this study for researchers and practitioners seeking to use mobile devices for health-related data collection in low-resource countries. In particular, we recommend that researchers and practitioners evaluate the following areas before beginning the project:

- What is the historical and social context?
- What is this particular community's relationship with outsiders?
- How do people in this community understand the saving data electronically and the presenting of information electronically?
- What are people's concerns about status? To what degree does access to technology add or take away status?

References

[1] Human Development Report 2008, United Nations Development Programme, New York, NY, 2008.

[2] Corbin, J.M. and Strauss, A. Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology*, *13* (1). 3-21.

[3] Hewett, P.C., Erulkar, A.S. and Mensch, B.S. The feasibility of computer-assisted survey interviewing in Africa: experience from two rural districts in Kenya. *Social Science Computer Review*, *22* (3). 319.

[4] Lane, S.J., Heddle, N.M., Arnold, E. and Walker, I. A review of randomized controlled trials comparing the effectiveness of hand held computers with paper methods for data collection. *BMC Medical Informatics and Decision Making*, *6* (1). 23.

[5] Yu, P., de Courten, M., Pan, E., Galea, G. and Pryor, J. The development and evaluation of a PDA-based method for public health surveillance data collection in developing countries. *International Journal of Medical Informatics*.

Empathy in Health Technologies

Eun Kyoung Choe
The Information School
University of Washington
Seattle, WA, USA
eunky@uw.edu

Marisa E. Duarte
The Information School
University of Washington
Seattle, WA, USA
meduarte@uw.edu

Julie A. Kientz
Human Centered Design & Eng.
and The Information School
University of Washington
Seattle, WA, USA
jkientz@uw.edu

Abstract

A consequence of the movement from paper-based medical record-keeping to digital and online formats is the potential loss of the human element that occurs during face-to-face doctor-patient dialogue. To help reduce the potential for this loss, we have studied how *empathy* may be included in the design of health technologies through interviews with clinicians and patients, followed by ideation for design implications. We identified strategies clinicians use to express empathy when giving a diagnosis, including the recursive process of *understanding* and *communicating* with patients. We discuss how technologies in the consultation room affect doctor-patient interaction. We present design ideas that may support the communication of empathy exemplified by re-thinking the ways clinicians and patients share information and the design of technology use in consultation rooms.

Keywords

Health, communication, empathy, medical informatics, doctor-patient relationship, health informatics

Introduction

Empathy has been considered one of the most important human elements in all forms of helping relationships [5]. In the doctor-patient relationship, empathy is viewed as a prerequisite for successful

---

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

therapeutic outcome [2]. However, despite the current momentum around technologies for health, empathy has not been a major consideration in the process of designing technologies for health. In consequence, the need to support clinicians in expressing empathy in their everyday practice has been largely unfulfilled [6,7]. In the case of the transition from paper charts to electronic medical record systems (EMRS), for example, there exists the potential for removal or displacement of otherwise timely face-to-face expressions of empathy between doctors and patients. Clinicians spend a significant amount of time filling out the forms [4] during or after a consultation with a patient, which could otherwise be used for actively listening to the patient narrative or answering patients' questions. In the absence or the negligence of these human elements of empathy during the process of designing health systems, clinicians and patients may be troubled by unintended consequences of health technologies such as clinicians' workflow interruption or patients having difficulty assimilating information. Tools and technologies that were initially designed for better medical record-keeping purposes may not serve the needs of clinicians and patients if the ways in which clinicians communicate empathy and share information with patients are not considered during the design process. However, if technology can be better designed with empathy in mind, these situations may be avoided.

Our study explores how empathy is expressed and perceived in clinical situations and the kinds of phenomenon surrounding the expression or lack of expression of empathy. We conducted semi-structured, open-ended interviews with clinicians and patients to understand their perceptions of empathy during the diagnosis of severe or chronic conditions. We discuss how the design of health technologies and doctor's workplace settings can create space for the expression of empathy in the clinical scenario in the new era of technology and medicine.

Study Method

We interviewed a total of 14 participants—six clinicians, six patients, and two family members of a patient. The clinicians had completed many in-person medical diagnoses or consultations with patients. The patients had been diagnosed with severe or chronic conditions such as cancer, Parkinson's disease, or diabetes. Our goal was to learn what empathic strategies clinicians employ within the limited resources and time they have, and what patients appreciate. We asked the clinicians to describe how they deliver diagnoses of unexpected findings, such as very serious illness or diseases with poor prognosis. We asked the patients to describe the very moment when they received a diagnosis. Then we incorporated the findings in designing health technologies to best help doctors and patients in various situations.

Results and Discussion

A wide range of themes emerged from the interviews including: definition of empathy, ways in which clinicians understand patients' situation and feelings, tools and artifacts clinicians use when communicating with patients, and attributes of non-empathic communication and its consequences. Due to space constraints, we will limit the discussion to two main themes uncovered by this research —1) strategies clinicians use to express empathy, and 2) tools and technologies in a consultation room which impact doctor-patient interaction. At the end of each section, we discuss technology design ideas that support clinicians' empathic care.

Strategies Clinicians Use to Express Empathy
Experienced clinicians are well aware of the intrinsic value of empathic dialogue: the recursive process of understanding and communicating with patients in varying mindsets and physical and emotional situations over time. Empathy is hardly ever communicated without the clinician's understanding and acknowledgment of the patient's background. For example, the clinician may need to know where patients are coming from, where they are in their feelings, their level of understanding of the disease and options, their relationships, and the nature of their work and home life. One clinician said that the personality of a patient is a key characteristic to differentiate one patient from another, but the medical record is literally "a record of medical process," so there is little room to contain personal information. Furthermore, the clinician's understanding of a patient's situation and emotional state means little unless the clinician is able to skillfully communicate that understanding. Understanding and communicating happen simultaneously as clinicians consciously and continuously reassess the patient's situation and modify their method of delivering unexpected news based on the patient's feedback and life story.

Design Ideas: The interface that records health information may be designed to contain personal characteristics and narratives that help clinicians to better remember each patient in order to treat them more like "a human being," rather than "as a number" or "an illness." Patients' distinct characteristics include personality, previous key events, background, relationships, family or guardian information, and the nature of their work and home lives. Visual cues, such as photos or past conversations, can help clinicians quickly recall the patient, even if they meet with the patient only once or twice a year. An interface showing a "quick view" or a summary of the patient's medical and personal information may help clinicians mentally prepare before going into the consultation room.

As part of empathic communication, clinicians acknowledge the patient's physical and emotional discomfort. Health information technologies may also be designed as a learning tool for clinicians to know where patients are in their feelings. Kubler-Ross's five stages of grief model [3], for example, can be used as a basis for a design of bar type menu in a chart, which allows clinicians to mark the patient's emotional state. It would allow clinicians to always be mindful of the patient's emotional state, and when clinicians recognize a patient going through a deep depression, they may provide patients with further emotional support.

Tool and Technologies in Consultation Room
EMRS or a combination of EMRS and handwritten paper charts are commonly used before, during, or after the consultation. Before meeting with patients, clinicians review charts to remind themselves of the patient and his/her condition. During the meeting, clinicians write notes either in the EMRS, on the paper chart, or on a notepad. Some clinicians reported that they draw a diagram or sketch out organs on a piece of paper while explaining diagnoses and give it to patients or family members afterwards. However, it is confusing to keep the record of handwritten notes, especially when EMRS and a paper chart are used together. To show the lab test or a graph on the monitor, they may turn the

monitor screen toward patients. Although clinicians prefer sitting side-by-side or perpendicular to the patient for easier data sharing and building a closer relationship, the sitting positions of the clinicians and patients are restricted by workplace setting—the way the desk, chairs, computer, and monitor are arranged. Some clinicians try to face patients by sitting on a swivel chair, using a notepad or a laptop, and being detached from a desk or monitor. Despite the merits of EMRS, both clinicians and patients expressed concern over widespread practice of using a computer during patient consultation due to the intrusiveness affecting the fluidity of conversation, and the inefficiency of filling out forms. Patients were especially frustrated when clinicians did not spend enough time with them. When the bad news was not communicated properly, patients had hard time assimilating the information, and were not being able to remember what was said during the visit.

Design Ideas: Because handwritten notes are easy to lose and difficult to archive, providing a place to sketch a drawing in the medical record system with a tablet PC or digital pen and paper may help both clinicians and patients to share information without losing it or making copies. The drawings or a transcription service can be provided for the patient who has difficulty assimilating the information on-site, who does not bring other family members to the meeting, or who is not in an emotional state to receive the news during the visit. Those can be sent to patient's email with the summary of what has been discussed during the visit. A desktop computer, keyboard, large monitor, and desk that are not oriented toward a patient introduce intrusiveness affecting the fluidity of conversation. Thus, the facilities and technologies used in the consultation room should be carefully designed in a way to encourage the clinician and patient to face each other or sit side-by-side when they need to share data and look at charts.

Conclusion and Future Work

The goal of this work is to reduce the discomforts of patients and some of the negative consequences of poor doctor-patient communication by designing technologies that can support the human communication of empathy. This was exemplified by re-thinking the design of health information technologies. We claim that empathy is an important consideration in the process of designing technologies for health. As our next steps in this research, we will focus on elaborating the designs of empathic interfaces for patients and doctors in the context of treating specific conditions, such as in the case of Alzheimer's disease or post traumatic stress disorder (PTSD).

References

[1] Heath, C. and Luff, P. (2000) Technology in Action. Cambridge: *University Press.*

[2] Ickes, W. (1997) Empathic accuracy. New York: *The Guilford Press.*

[3] Kubler-Ross, E. (2005) On grief and grieving: Finding the meaning of grief through the five stages of loss. New York: *Scribner.*

[4] Poissant, L. *et al*. (2005) The impact of electronic health records on time efficiency of physicians and nurses. *JAMIA,* 12(5):505-516.

[5] Reynolds, W.J., *et al*. (1999) Empathy: A crucial component of the helping relationship. *J. of Psychiatric & Mental Health Nursing*, 6(5):363-370.

[6] Siegler, E.L. and Adelman, R. (2009) Copy and paste: A remediable hazard of electronic health records. *AJM,* 122(6):495-496.

[7] Walsh, S. (2004) The clinician's perspective on electronic health records and how they can affect patient care. *BMJ.* 328(7449):1184–1187.

Interdisciplinary Computerized Common Patient Goals Tool

Sarah Collins, RN, PhD
Department of Biomedical Informatics
Columbia University
622 West 168th Street VC5
New York, NY 10032
Sarah.collins@dbmi.columbia.edu

Suzanne Bakken, RN, DNSc
School of Nursing and Department of Biomedical Informatics
Columbia University
630 W. 168th Street
New York, NY 10032
sbh22@columbia.edu

David Vawdrey, PhD
Department of Biomedical Informatics
Columbia University
622 West 168th Street VC5
New York, NY 10032
dkv2101@columbia.edu

Enrico Coiera, MBBS, PhD
Centre for Health Informatics
Room 103 Level 1 AGSM
University of New South Wales
Sydney, NSW, Australia 2052
e.coiera@unsw.edu.au

Leanne Currie, RN, DNSc
School of Nursing
Columbia University
630 W. 168th Street
New York, NY 10032
lmc2007@columbia.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

We developed a prototype of an interdisciplinary computerized common patient goals tool that integrates a discussion board feature and tested its usability with ICU clinicians (n=16). Positive feedback supports the future development of a functional system and testing of its impact and use in laboratory and clinical settings.

Keywords

Interdisciplinary collaboration, electronic documentation, ICU

ACM Classification Keywords

J.3 Life and Medical Sciences **---** Medical information systems

Introduction

Active and consistent communication between nurses and physicians is essential to achieve high quality and timely evidence-based care, yet, interdisciplinary collaboration is often lacking in the clinical environment [7]. Within the intensive care unit (ICU) multiple clinicians must coordinate care for critically ill patients who are subject to frequent and extreme status changes. Paper-based daily ‘patient goals’ tools [6, 4] allow for clinicians to share in the daily identification of patient goals and for all members of the team to be aware of these goals throughout the day. However, the paper-based daily tools are not efficient for conveying frequent updates to a group. Computer-based ‘goals tools’ within an electronic health record (EHR) can be continuously updated and viewed by many. According to Coiera, concrete, routine activities are easily computerized, and the distributed cognition theory posits that providing a central repository of information for all team members to access will decrease cognitive burden [3, 1]. Therefore, the aims of this study were to: 1) Develop a common patient goals tool prototype that might be used within an EHR; 2) Evaluate nurses’ and physicians’ perceptions of the common patient goals tool prototype in a laboratory setting.

Methods

Prototype Development

Based on literature and preliminary data, we developed a prototype of an interdisciplinary computerized common goals tool. The prototype was developed using Microsoft Office PowerPoint 2007® (Microsoft Corporation, WA) and demonstrated the user interface and examples of the prototype functionality through a series of PowerPoint slides. After an initial development phase, one physician tested the prototype and revisions were made prior to additional usability testing by ICU nurses, physicians, and nurse practitioners.

Prototype Usability Evaluation

Usability testing was conducted with ICU nurses, physicians and nurse practitioners at a large teaching hospital in New York City. The testing took place in a laboratory setting, in which the investigator sat in a room with the participant and a computer. Morae™ Version 3.1 (TechSmith, MI) software, which captures a simultaneous audio and visual recording of the participant’s voice and computer screen, was used. During each usability session the participant was provided with four patient goals (typical for an ICU patient) and four tasks to complete and was instructed to think-aloud. The four patient goals were: 1) Weaning mechanical ventilation; 2) Maintaining fluid balance; 3) Preventing a pressure ulcer; and 4) Preventing a deep vein thrombosis. The four tasks were: 1) Changing goal information; 2) Entering information into the discussion board; 3) Adding information to the *To-Do* list; and 4) Entering a new goal. Thematic analysis was performed on the think-aloud data. Institutional Review Board approval was obtained for the study.

Results

Each usability testing session lasted between 15 and 20 minutes. After initial testing with an ICU physician, the common goals tool prototype was refined and the discussion board feature named *online rounds* was added. Nine critical care staff nurses, 4 critical care residents, and 3 critical care nurse practitioners were recruited for the usability testing of the refined prototype. A sample size of 15 users has been shown to detect 97% of usability problem areas [2]. Figure 1 shows the revised prototype and the thematic analysis of the participants’ feedback during the testing.

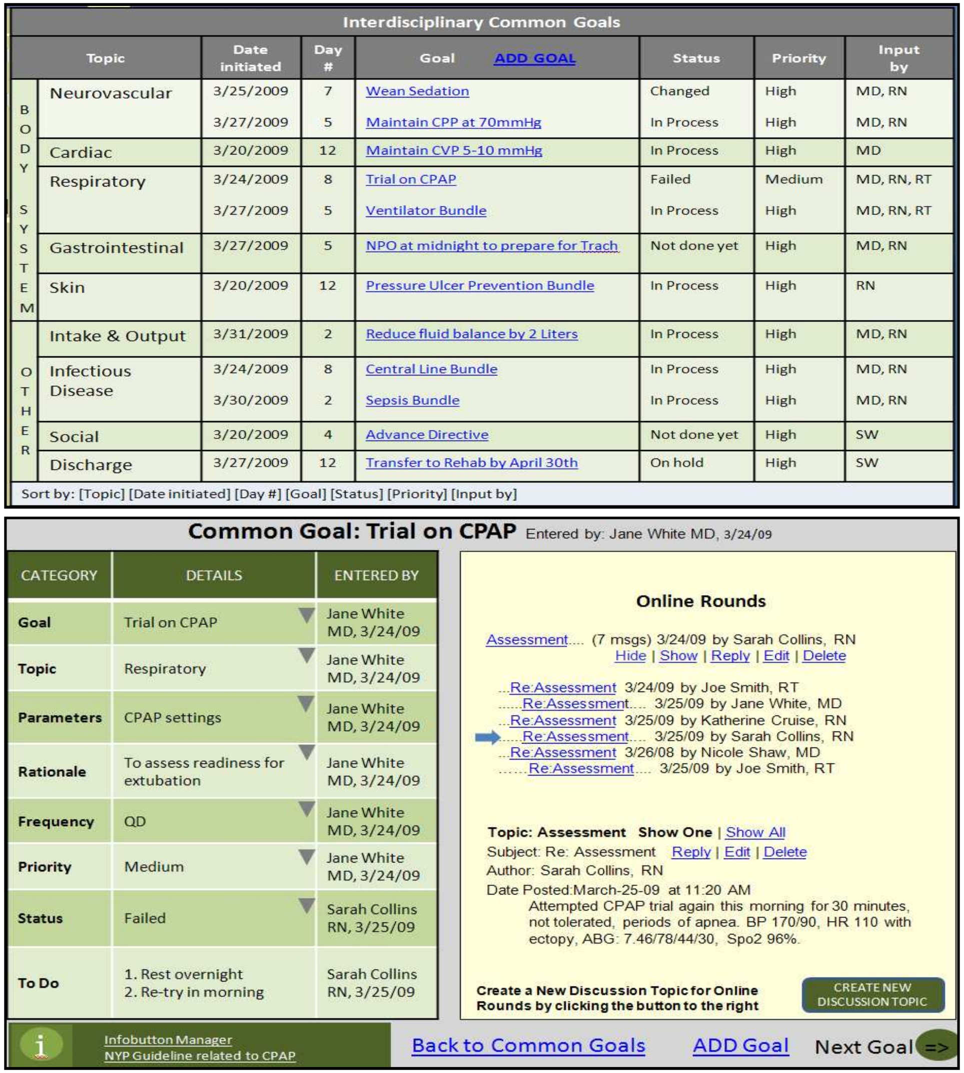
The *Common Goals Overview Page* provides an overview of all of the patient’s common goals organized by *body system* or *other* clinical topic and includes *dates*, *status*, *priority level*, and the *clinicians* that have entered information. There is a *Goal Details Page* for each common goal (e.g., *Trial on CPAP* in Figure 1) that contains structured documentation categories on the left side of the screen and an *online rounds* discussion board on the right side of the screen.

Thematic analysis of ICU Nurses', Physicians', and Nurse Practitioners' Usability think aloud feedback:

Overall:
- The tool may be useful to ensure that verbal information exchange does not result in a loss of information during hand-off

Positive features:
- Interdisciplinary
- Integrated into EHR
- Explicit goals that reflect patient care activities
- Goal rationale
- Goal To-do list
- One screen that would not require scrolling

Missing features:
- Intervention category linked to the CPOE system
- Billing diagnoses
- Patient contact information



Interdisciplinary Common Goals

	Topic	Date initiated	Day #	Goal ADD GOAL	Status	Priority	Input by
BODY SYSTEM	Neurovascular	3/25/2009	7	Wean Sedation	Changed	High	MD, RN
		3/27/2009	5	Maintain CPP at 70mmHg	In Process	High	MD, RN
	Cardiac	3/20/2009	12	Maintain CVP 5-10 mmHg	In Process	High	MD
	Respiratory	3/24/2009	8	Trial on CPAP	Failed	Medium	MD, RN, RT
		3/27/2009	5	Ventilator Bundle	In Process	High	MD, RN, RT
	Gastrointestinal	3/27/2009	5	NPO at midnight to prepare for Trach	Not done yet	High	MD, RN
	Skin	3/20/2009	12	Pressure Ulcer Prevention Bundle	In Process	High	RN
OTHER	Intake & Output	3/31/2009	2	Reduce fluid balance by 2 Liters	In Process	High	MD, RN
	Infectious Disease	3/24/2009	8	Central Line Bundle	In Process	High	MD, RN
		3/30/2009	2	Sepsis Bundle	In Process	High	MD, RN
	Social	3/20/2009	4	Advance Directive	Not done yet	High	SW
	Discharge	3/27/2009	12	Transfer to Rehab by April 30th	On hold	High	SW

Sort by: [Topic] [Date initiated] [Day #] [Goal] [Status] [Priority] [Input by]

Common Goal: Trial on CPAP Entered by: Jane White MD, 3/24/09

CATEGORY	DETAILS	ENTERED BY
Goal	Trial on CPAP	Jane White MD, 3/24/09
Topic	Respiratory	Jane White MD, 3/24/09
Parameters	CPAP settings	Jane White MD, 3/24/09
Rationale	To assess readiness for extubation	Jane White MD, 3/24/09
Frequency	QD	Jane White MD, 3/24/09
Priority	Medium	Jane White MD, 3/24/09
Status	Failed	Sarah Collins RN, 3/25/09
To Do	1. Rest overnight 2. Re-try in morning	Sarah Collins RN, 3/25/09

Online Rounds

Assessment.... (7 msgs) 3/24/09 by Sarah Collins, RN
Hide | Show | Reply | Edit | Delete

...Re:Assessment 3/24/09 by Joe Smith, RT
......Re:Assessment.... 3/25/09 by Jane White, MD
...Re:Assessment 3/25/09 by Katherine Cruise, RN
......Re:Assessment.... 3/25/09 by Sarah Collins, RN
...Re:Assessment 3/26/08 by Nicole Shaw, MD
.......Re:Assessment.... 3/25/09 by Joe Smith, RT

Topic: Assessment Show One | Show All
Subject: Re: Assessment Reply | Edit | Delete
Author: Sarah Collins, RN
Date Posted:March-25-09 at 11:20 AM
Attempted CPAP trial again this morning for 30 minutes, not tolerated, periods of apnea. BP 170/90, HR 110 with ectopy, ABG: 7.46/78/44/30, Spo2 96%.

Create a New Discussion Topic for Online Rounds by clicking the button to the right

Figure 1. Common Patient Goals Tool Prototype. Top: Common Patient Goals Overview page. Bottom: Patient Goal Details Page including Online Rounds Discussion Board

Specific feedback about potential usefulness of *Online rounds* discussion board feature:
- May be useful in facilitating intra- and interdisciplinary information exchange of patient updates
- May be easier than tracking down notes in the current EHR system

Clinician Concerns:
- Double documentation
- Responsibility to document on the *online rounds* discussion board may fall solely to the nurses

Clinician Questions:
- Is the *online rounds* discussion board part of the official patient record?
- Will this tool replace current documentation?

Discussion

This prototype contains both information tools (e.g., the structured fields on the overview page and on the detail page for each goal) and communication tools (e.g. the discussion board) [1]. Discussion boards are popular tools to facilitate online communication about a particular topic [5], yet an extensive search in PubMed, CINAHL, and Google Scholar for the use of discussion boards in clinical documentation retrieved no results. However, in education discussion boards have been shown to facilitate critical thinking and promote individual and distributed cognition by forcing individuals to reflect and elaborate on their thoughts in order to successfully convey meaning [5].

Concerns regarding shared responsibility of documenting are inherent in any patient-centered, as opposed to discipline-centered, documentation system, and in most clinical settings, would likely be a new method of documentation. Pronovost et al. dealt with this issue by mandating documentation on the daily goals sheet [6]. Further studies should be conducted to understand how clinicians would use a discussion board in clinical practice and its impact on workflow.

The limitations of this study included the small sample size, the limited setting from which the clinicians were selected and the fact that usability testing was conducted with a prototype tool based in a laboratory setting as opposed to a real patient-care environment.

Conclusion

The common goals tool prototype received positive feedback from the sixteen clinicians who participated in the final usability testing. The innovative use of the *online rounds* discussion board that is linked to each common goal has potential to be a new patient-centered interactive method of interdisciplinary computerized documentation. However, clinicians' use of a discussion board, its role as part of the official medical record, and its impact on clinical workflow has not been evaluated. Future work should build a functional system based on the prototype presented in this study to further explore and evaluate these issues in the laboratory and clinical settings.

Acknowledgements

This project was supported by National Institute for Nursing Research T32NR007969. Dr. Collins is supported by T15 LM 007079.

References

[1] Coiera, E., *When conversation is better than computation*, J Am Med Inform Assoc, 7 (2000), pp. 277-86.
[2] Faulkner, L., *Beyond the five-user assumption: benefits of increased sample sizes in usability testing*, Behav Res Methods Instrum Comput, 35 (2003), pp. 379-83.
[3] Hutchins, E., *Cognition in the Wild*, MIT Press, Cambridge, MA, 1995.
[4] Narasimhan, M., Eisen, L. A., Mahoney, C. D., Acerra, F. L. and Rosen, M. J., *Improving nurse-physician communication and satisfaction in the intensive care unit with a daily goals worksheet*, Am J Crit Care, 15 (2006), pp. 217-22.
[5] Pena-Shaff, J. B. and Nicholls, C., *Analyzing student interactions and meaning construction in computer bulletin board discussions*, Computers & Education, 42 (2004), pp. 243-265.
[6] Pronovost, P., Berenholtz, S., Dorman, T., Lipsett, P. A., Simmonds, T. and Haraden, C., *Improving communication in the ICU using daily goals*, J Crit Care, 18 (2003), pp. 71-5.
[7] Pronovost, P., Wu, A. and Sexton, J., *Acute decompensation after removing a central line: practical approaches to increasing safety in the intensive care unit*, Ann Intern Med, 140 (2004), pp. 1025-33.

Engaging with mental health: a global challenge

David Coyle
The Computer Laboratory
University of Cambridge
William Gates Building
15 JJ Thomson Avenue
Cambridge CB3 0FD, UK
coyledt@tcd.ie

Gavin Doherty
School of Computer Science
and Statistics
Trinity College Dublin
College Green
Dublin 2, Ireland
gavin.doherty@cs.tcd.ie

Mark Matthews
Student Counselling Service
Trinity College Dublin
College Green
Dublin 2, Ireland
mark.matthews@cs.tcd.ie

John Sharry
Child and Adolescent Psychiatry
Mater Misericordiae Hospital
Metropolitan Building
James Joyce Street
Dublin 1, Ireland
jsharry@mater.ie

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Abstract

Using the metrics of the World Health Organisation, the Global Burden of Disease Study has found that mental health difficulties are currently the leading cause of disability in developed countries [1]. Projections also indicate that the global burden of mental health difficulties will continue to rise in the coming decades. The human and economic costs of this trend will be substantial. In this paper we discuss how effectively designed interactive systems, developed through collaborative, interdisciplinary efforts, can play a significant role in helping to address this challenge. Our discussion is grounded in a description of four exploratory systems, each of which has undergone initial clinical evaluations. Directions for future research on mental health technologies are also identified.

Keywords

Mental health, collaborative design, interactive systems

ACM Classification Keywords

H.5.m [Information Interfaces and Presentation]: Miscellaneous – interdisciplinary design, mental health

Introduction

Mental disorders are health conditions defined by the experiencing of severe and distressing psychological symptoms, to the extent that normal functioning is seriously impaired, and some form of help is usually needed for recovery. The US Surgeon General's first report on mental health concluded that (1) the efficacy of mental health treatments is well documented and (2) a range of effective treatments exist for most mental disorders [2]. Unfortunately international studies also conclude that the majority of people experiencing difficulties do not receive appropriate specialist treatment [2, 3]. Research concludes that in the UK mental health has now overtaken unemployment as the nation's most expensive social problem [4].

An interdisciplinary challenge

Addressing the challenges of providing more effective mental healthcare (MHC) services will require the concerted efforts of professionals across a range of disciplines. It is likely – indeed necessary – that technology will play a significant role in future service delivery. Coyle et al [5] identifies two broad challenges which interactive systems can help in addressing [5]:

1. Access/capacity constraints: traditional mental health intervention strategies, particularly talk-based strategies, are time and resource intensive. As a result existing services often do not have sufficient capacity to meet the needs of people requiring professional help.
2. Engagement: research suggests that, even when professional help is available, many clients find it difficult to successfully engage with traditional treatment. The level to which clients engage with their treatment, and draw on their own personal resources, is a major factor in the success of interventions.

With several notable exceptions, early research on the use of technology was generally justified on the basis of increased access - e.g. electronic contact as a natural extension of face-to-face dialogue and the computerisation of self-help materials. Increased engagement and actual improvements in the effectiveness of treatment have received less attention [5]. Collaboration between HCI and MHC professionals can help in maximising the effectiveness of new technologies. While MHC professionals have the necessary domain expertise, HCI researchers are experienced in design methodologies and are likely to have a broader knowledge of the potential uses of new technologies. For example the experience of HCI researchers is important given the high cost of systems failures in sensitive interventions. Other ongoing areas of HCI research, such as designing for personal reflection and behaviour change, can play a valuable role in future research on mental health technologies.

Examples of exploratory systems

We have primarily focused on the design of technology to support talk-based, psychological approaches to mental health treatment, e.g. psychotherapy. Reviews of previous research on technology in this area are available in [5, 6]. Over the past 7 years we have developed several exploratory systems.

Personal Investigator

Personal Investigator (PI) is a 3D computer game designed to support adolescent mental health interventions. It incorporates Solution Focused Therapy, a goal oriented, strengths based intervention approach. PI is used in clinical sessions involving one therapist and one adolescent. It aims to ease the difficulties many adolescents experience in engaging with face-to-face treatments. Two clinical evaluations of PI have been conducted, the first with 4 adolescents, the second with 22 [7]. Results indicate that PI can have a beneficial impact on interventions, supporting improved client-therapist relationships and improved client engagement.

PlayWrite
PlayWrite extended the ideas developed with PI. Rather than providing a fixed game, it provides a flexible game template and enables end users – MHC professionals - to create and adapt the content delivered through this template. Using PlayWrite MHC professionals have created 10 games, implementing different theoretical approaches to MHC and targeting a range of difficulties including depression, anxiety and anger management. For example, gNatenborough's Island supports a six week cognitive behavioural therapy (CBT) intervention for depression. Evaluations of this game began in April 2009 and will run until May 2010.

Mobile Mood Diary
Therapists, particularly those practicing CBT, often ask clients to complete paper based mood charts, but adherence can be low and they can provide unreliable information. Mobile Mood Diary, a mobile phone and computer based mood chart system, was developed to make recording moods more convenient and reliable. A controlled school study was run studying compliance variation between a paper-based chart and the Mobile Mood Diary [8]. An initial clinical evaluation with 10 adolescent clients has also been completed. Results showed a high level of adherence amongst participating adolescents over a sustained period.

Mobile My Story
My Mobile Story makes use of the multimedia capabilities of mobile phones. It allows adolescents to record inter-session thoughts, ideas and feelings in the form of sounds, pictures, videos and text. This content can then be accessed on a computer to construct therapeutically meaningful stories. Existing paper-based therapeutic exercises can be incorporated into the system as 'therapeutic plans', thereby supporting a range of existing approaches. A pilot clinical evaluation with 5 adolescents has been completed, with further evaluations ongoing. Initial feedback suggests that My Mobile Story can help to increase client engagement between sessions and, according to one therapist, can help to *"personalise the content for therapy sessions"*.

Design challenges and future directions

Theories for design and evaluation
Mental health technologies remain a relatively unexplored design space. Alongside exploring the potential of a wider range of technologies, there is a need for more detailed investigation of theories, from both MHC and HCI, that can help in generating ideas and support us in reasoning about designs. For example mental health frameworks such as the Skilled Helped Model provide a structured overview of a helping intervention. Behaviour change models such as the Trans-Theoretical Model many also prove useful, as could activity theory which has previously been applied to a range of healthcare settings. Applying models for complex medical evaluations may also prove beneficial.

Strategies for collaborative design
While collaboration with domain experts and end users is important is many design areas, it has a particular significance in MHC areas. The ethical requirements and stigma associated with mental health mean that designers often face severe restrictions on access to people experiencing difficulties and to situations in which interactive systems will be used [5]. Faced with such constraints HCI practitioners may have to rely on the expertise and insights of MHC professionals. However research in related healthcare areas has

shown that the success of interdisciplinary teams is not something that can be taken for granted. We have discussed initial strategies for collaborative design decision making in [9]. Providing a deeper understanding of collaborative design strategies, and of the techniques which support effective interdisciplinary teams, is an important objective for future research.

Adaptable systems
Therapists often work with clients from different socio-cultural backgrounds, experiencing a range of disorders, of varying severities. Furthermore, teams of therapists often have different theoretical backgrounds and adopt a variety of eclectic approaches to working with clients. In such situations fixed systems offer limited benefits. Systems where the core capabilities are re-usable across a range of situations, and which can adapted to the needs of end users have been identified as a important future requirement [5]. PlayWrite represents an example of such a system. In this case MHC professionals play an active role in adapting the system. This approach can also help to support collaboration.

Support for resource allocation strategies
Targeting of resources and needs based service provision have become important trend in mental health service delivery. Models such as Stepped Care encapsulate this notion, with distinct steps - intensities of treatment - ranging from inpatient treatment, through primary care teams dealing with issues such as mild depression, to General Practitioners supporting initial contact and diagnosis. Designing interactive systems to support these different levels of care, and transitions between them, represents a major challenge for research in this area.

Citations

[1] World Health Organisation, (2004) The Global Burden of Disease: 2004 update. WHO Press: Geneva.

[2] Surgeon General, (1999) Mental Health: A Report of the Surgeon General - Executive Summary. Department of Health and Human Services: Washington, DC.

[3] WHO World Mental Health Survey Consortium, (2004) Prevalence, severity, and unmet need for treatment of mental disorders in the World Health Organization World Mental Health Surveys. Journal of the American Medical Association, 291(21).

[4] Layard, R., (2006) The case for psychological treatment centres. British Medical Journal, 332: p.1030–2.

[5] Coyle, D., Doherty, G., Matthews, M., & Sharry, J., (2007) Computers in Talk-Based Mental Health Interventions. Interacting with Computers, 19(4): p.545-562.

[6] Marks, I.M., Cavanagh, K., & Gega, L., (2007) Hands-on Help: Computer-aided Psychotherapy. 1st ed. Maudsley Monographs, Psychology Press Ltd.

[7] Coyle, D., Doherty, G., & Sharry, J., (2009) An Evaluation of a Solution Focused Computer Game in Adolescent Interventions. Clinical Child Psychology and Psychiatry, 14(3): p. 345-360.

[8] Matthews, M., Doherty, G., Sharry, J., & Fitzpatrick, C., (2008) Mobile Phone Mood Charting for Adolescents. British Journal of Guidance and Counselling. 36(2): p. 113-129

[9] Coyle, D. & Doherty, G. (2009) Clinical evaluations and collaborative design: developing new technologies for mental healthcare interventions. ACM CHI’09. p.2051-2060, Boston, USA.

Salient Summaries: Increasing Awareness of Cognitive Decline

Anind K. Dey
HCI Institute
Carnegie Mellon University
Pittsburgh, PA 15213 USA
anind@cs.cmu.edu

Matthew L. Lee
HCI Institute
Carnegie Mellon University
Pittsburgh, PA 15213 USA
matthew.lee@cs.cmu.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

Keeping track of the fluctuations in functional abilities that elders experience is important for early detection of cognitive decline and maintaining independence. We describe our research in understanding how to design ubiquitous home sensor systems that can monitor how well individuals carry out everyday activities important for independence. These systems collect an overwhelmingly large amount of data and thus only the most salient details need to be presented. In this paper, we identify the information needs of stakeholders to inform the design of salient summaries of the data for elders, their family caregivers, their doctors, and their therapists to become more aware of changes in functional abilities.

Keywords

Embedded assessment, eldercare

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

General Terms

Design, human factors

Introduction

Many elders experience cognitive decline as they get older. They may forget particular steps in a multi-step task or may have difficulty concentrating on a task. Occasional lapses in memory, attention, or decision-making are a normal part of aging, but consistent cognitive problems may be the first signs of progressive neurological conditions such as Alzheimer's disease or its precursor, Mild Cognitive Impairment.

Cognitive decline usually manifests itself first as changes in an individual's *functional* ability, that is, the ability to carry out everyday activities. In particular, Instrumental Activities of Daily Living (IADLs) such as preparing a meal, taking medication, using the telephone, and doing housework are important for maintaining independence and require a relatively high level of cognitive ability to be performed. Assessments of how well individuals perform IADLs can provide early indicators for decline and allow for earlier interventions to prevent accidents and delay institutionalization [1]. Maintaining awareness of changes in functional abilities and adapting to them is key for successful aging.

However, many elders [7] and even their family caregivers [4] often are not aware of the subtle changes in their functional abilities that may be early signs of progressive cognitive decline. Even performance-based psychometric testing is not always reliable due to their infrequency, lack of objectivity, and reliance on simulated, often contrived tasks.

Ubiquitous sensing technologies situated in people's homes can collect and provide information about *how often* an individual engages in various activities, *e.g.*, [9,10]. However, an even earlier indicator for decline is *how well* people perform IADLs [8]. This kind of embedded assessment [6] technology that can track the individual steps involved in performing a task and can detect the amount of time/effort spent or the number of errors committed prior to task completion can provide objective, timely, and ecologically-valid information. This information enables elders and their caregivers to maintain their awareness of early changes in abilities and for clinicians such as primary care physicians and occupational therapists to make earlier and more accurate diagnoses of decline.

Yet, embedded assessment sensing systems can produce an overwhelmingly large amount of lifelog data. Based on our past work with people with Alzheimer's disease, where we examined how to use salient summaries of recent experiences to improve recall of the experiences and confidence in memory [5], we believe that we can similarly create salient summaries of the sensor data. The challenge is thus to identify the most meaningful aspects of these data and create *salient summaries* that are usable and useful for elders, caregivers, and clinicians to support their health goals.

In our work, our goal is to address the following research questions through formative fieldwork, design of novel sensing systems, field deployment to collect real data, and evaluations with real users:

1. Is embedded assessment of how well people perform everyday activities useful for stakeholders (elders, their caregivers, and their doctors and therapists) for reaching their goals?
2. What are the information needs of each group of stakeholders, and how should meaningful salient summaries of lifelog data be produced?

3. How can embedded assessment data actually enable stakeholders to reach their goals and what information should future sensing systems collect?

Initial Fieldwork

To identify, at an early stage, the potential impact and usefulness of embedded assessment on elders, family caregivers, and clinicians, we conducted concept validation sessions in which we presented scenarios of sensing systems that were capable of monitoring how well an elder performs everyday activities such as taking medications, preparing a meal, and using the telephone. We also presented stakeholders with hypothetical data that these systems would have collected over the course of a year and asked how these data would be helpful to the various stakeholders to achieve their respective goals, for example, gaining awareness of changing abilities, diagnosing medical conditions, or applying solutions to fix problems. Addressing research question #1, the results of the concept validation were positive with stakeholders expressing that the data from an embedded assessment system was helpful. Elders expressed that the data would help them keep track of changes and make the changes necessary to maintain independence. Family caregivers said monitoring these “mundane” tasks gave them a new window into the daily functioning of their loved one. Doctors said that the sensor data provided them with more detailed information they can normally obtain from short interviews with patients during an office visit. Occupational therapists found the low-level details helpful for identifying the particular deficit and applying the right adaptation to maintain task adequacy. Clinicians also found it helpful for tracking the effect of a change in medication or new functional adaptation.

Current and Proposed Research

After this initial validation of the value of our proposed sensing system, we are currently designing and building an embedded assessment sensing system that will be deployed to collect real long-term IADL performance data from independently-living elders. With this personalized data we can further identify the information needs that each stakeholder finds useful for support their goals. Based on these information needs, We will create salient summaries of this personalized data to highlight the most important features, events, or trends for each stakeholder.

We are currently integrating various existing sensor technologies with a wireless infrastructure to wirelessly sense the individual steps of particular IADLs. We are developing sensing systems for three particular IADLs (medication taking, breakfast preparation, and telephone use) because these are important tasks for independence, common among elders, reasonably easy to sense, and most importantly, are already used in existing scales [2,3,8] of functional abilities.

We will continue to refine the design of the sensors through a combination of field and laboratory pilot testing to ensure accuracy and robustness for detecting the individual steps of the task. We will then deploy the sensors into the homes of ten elders who live on their own who may be already experiencing some declines in functional abilities. Throughout the deployment, the sensors will be validated by comparing their data with expert assessors and standard psychometric tests for cognitive and physical decline. After a baseline period of 1-3 months, a subset of the participants will receive feedback about their functional abilities in the form of an interactive display in their home. Their interactions with these displays will be logged as well as their comments about whether it provides insight into their own abilities. After six months of data, we will present these data to family caregivers and clinicians and ask them whether the data is useful or interesting to them. We will begin by showing them visualizations of the data very close to the sensor data and apply different summarization techniques to highlight trends. To address research question #2, we will use iterative design to develop visualizations that highlight the most salient information from the sensor data that each stakeholder wants. In contrast to the initial concept validation fieldwork, engaging stakeholders with real data will enable us to address research question #3 by observing how the data actually impacts the practices of stakeholders, rather than having stakeholders only imagine what they would do.

Contributions

This research provides technical, HCI, and clinical contributions. From a technical standpoint, we will develop new sensing technology that can sense the adequacy—instead of merely frequency—of task performance. From a HCI standpoint, we will investigate the information needs of stakeholders of embedded assessment technology through evaluations before, during, and after a long-term deployment. From these data, we will generate and evaluate design guidelines for making salient summaries and visualizations for long-term performance data of functional abilities. This research will also have practical clinical contributions in the form of novel, objective, ecologically-valid, timely, and salient measures of functional abilities that can help clinicians make more accurate diagnoses of physical, cognitive, or functional decline. This research can also help elders and their caregivers become more aware of changes in their abilities as they age. These sensors and summarization techniques can influence the design of future commercial home monitoring for elders, children, and smart home residents.

Citations

[1] Barberger-Gateau, P., Fabrigoule, C., Helmer, C., Rouch, I. and Dartigues, J. Functional impairment in IADLs: an early clinical sign of dementia? *J Am Geriatr Soc.* 47, 4 (1999): 456-462.

[2] Diehl, M., Marsiske, M., Horgas, A., Rosenberg, A., Saczynski, J. and Willis, S. The revised observed tasks of daily living: A performance-based assessment of everyday problem solving in older adults. *Journal of Applied Gerontology* 24, 3 (2005): 211-211.

[3] Holm, M. and Rogers, J. (1999). Performance Assessment of Self-Care Skills. *Assessment in occupational therapy mental health.* B. Hemphill-Pearson. Thorofare, NJ, Slack Inc: 117–24.

[4] Kemp, N., Brodaty, H., Pond, D. and Luscombe, G. Diagnosing Dementia in Primary Care: The Accuracy of Informant Reports. *Alzheimer Disease & Associated Disorders*. 16, 3 (2002): 171-176.

[5] Lee, M.L. & Dey, A.K. Lifelogging Memory Appliance for People with Episodic Memory Impairment. *Ubicomp 2008*: 44-53.

[6] Morris, M., Intille, S. and Beaudin, J. Embedded Assessment: Overcoming Barriers to Early Detection with Pervasive Computing. *Pervasive* (2005): 333-346.

[7] Okonkwo, O., Griffith, R., Vance, D., Marson, D., Ball, K. and Wadley, V. Awareness of Functional Difficulties in Mild Cognitive Impairment. *J Am Geriatr Soc.* 57, 6 (2009): 978-978.

[8] Owsley, C., Sloane, M., McGwin Jr, G. and Ball, K. TIADL: Relationship to cognitive function and everyday performance assessments in older adults. *Gerontology* 48, (2002): 254-265.

[9] Philipose, M., Fishkin, K., Perkowitz, M., Patterson, D., Fox, D., Kautz, H. and Hahnel, D. Inferring Activities from Interactions with Objects. *IEEE Pervasive Computing* 3, 4 (2004): 50-57.

[10] Tapia, E., Intille, S. and Larson, K. Activity recognition in the home using simple and ubiquitous sensors. *Pervasive 200*: 158-175.

Stepping Outside the Classroom: Fitness Video Games For K-12 Settings

Elsa Eiriksdottir
School of Psychology
Georgia Institute of Technology
Atlanta, GA 30332 USA
elsa@gatech.edu

Yan Xu
College of Computing
Georgia Institute of Technology
Atlanta, GA 30308 USA
yxu7@gatech.edu

Dan Kestranek
College of Computing
Georgia Institute of Technology
Atlanta, GA 30308 USA
dan.kestranek@gatech.edu

Richard Catrambone
School of Psychology
Georgia Institute of Technology
Atlanta, GA 30332 USA
rc7@prism.gatech.edu

Andrew Miller
College of Computing
Georgia Institute of Technology
Atlanta, GA 30308 USA
andrew.miler@gatech.edu

Elizabeth Mynatt
College of Computing
Georgia Institute of Technology
Atlanta, GA 30308 USA
mynatt@gatech.edu

Erika S. Poole
College of Computing
Georgia Institute of Technology
Atlanta, GA 30308 USA
erika@gatech.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

We discuss the development and ongoing evaluation of The American Horsepower Challenge, a pedometer-based fitness game for middle school students that is being used in over 60 schools across the United States.

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

In this paper, we describe our ongoing study of a nationwide deployment of a pedometer-based fitness program for middle school students called *The American Horsepower Challenge (AHPC)*. Developed by Humana Games For Health and sponsored by The Humana Foundation, the philanthropic arm of Humana Inc.[1], AHPC is a game that turns everyday walking activity into a team sport.

Through a combination of wireless pedometers and a Web-based game, AHPC tracks students' steps and turns them into points in an online school vs. school 'horserace.' Our research team has been following the participants in this competition over two school years by collecting step data, surveying stakeholders in the game, conducting focus groups and individual interviews with students, and conducting interviews with some

---

[1] "One of the nation's leading health benefits companies"

parents and teachers. We are investigating whether this game changes the participants' attitudes and everyday physical activity levels.

The American Horsepower Challenge addresses two trends: a decrease in youth physical activity levels and an increase in online and computer-based social play. Adolescents and teens have adopted increasingly sedentary lifestyles. As of 2004, 17 percent of adolescents aged 12-19 were overweight, compared to just under 6 percent in 1980. Most disturbingly, studies have shown that overweight adolescents have a 70 percent chance of becoming overweight adults. [1] Additionally, youth are spending increasing amounts of their social leisure time online. As of 2007, 93 percent of American teens reported regularly using the Internet, 64 percent of whom reported actively engaging in social and collaborative activities online. Videogames are similarly universal: as of 2008, 97 percent of American teens reported playing video games, and 76 percent of them play games with others. [2]

AHPC attempts to leverage youth online activity as a way to encourage everyday physical activity. Instead of encouraging physical activity on the individual level, AHPC introduces competition between different schools and collaboration between teammates in the same school, providing other initiatives for the children to have more physical activity.


Fig. 1. Illustration of a shoe with a pedometer

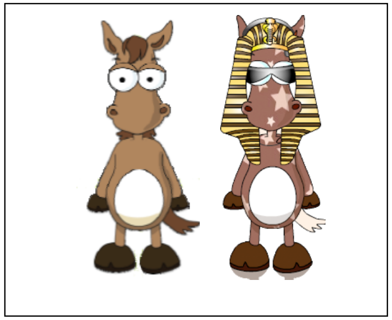


Fig. 2. A horse before and after customization


Fig. 3. School busses on the racetrack (AHPC version 1)

Design and Deployment

AHPC takes real-world fitness data and feeds it into a virtual environment: a road race in which schools (each represented by a cartoon school bus) compete for grants from The Humana Foundation that support onsite wellness activities or services. Each participating student at a given school is represented by a horse avatar that sits inside their school's bus, and the relative position of the school buses on the racetrack correlates with the aggregate step-counts of students in each school.

To input step-count data, each student wears a foot-mounted pedometer that wirelessly syncs with a base station set up in a high-traffic area in their school. Students' step counts are uploaded to AHPC servers each time they pass within range of the base station. Students can log onto the game website to check their steps, see their school's standing against other schools, and purchase outfits or 'skins' for their horse avatars as a function of the number of steps the student has taken. Students can also update their 'status' and view other students' updates in a Twitter-like activity stream.

The competition takes place over a four-week 'heat.' Thus far, there have been three heats: spring 2009, fall 2009, and spring 2010. With a few exceptions, the same students have been enrolled in all three heats. During a heat, students' steps are counted by the system and their results are updated continuously. At the end of the competition, the school that has the most number of steps wins the competition. The program began with 78 schools across the United States selected by The Humana Foundation based on participation in the National School Lunch Program, a federally assisted meal program. Sixty-one schools have continued in AHPC across all three heats of the game.

Related Work

AHPC incorporates features of two related research agendas within the CHI community: games for health and pedometer-based fitness interventions.

AHPC takes cues from ubiquitous computing systems that track and display fitness activity in order to integrate activity awareness into users' everyday social lives. *Fish'n'Steps*, for example, displays users' physical activity levels as fish in a publicly viewable fishbowl [6], while *Chick Clique* allows small groups of friends to share instantly updated step-count leaderboards. [7]

Games for health motivate players to complete desired actions by making use of video game reward structures. Players are often rewarded for the achievement of a particular in-application goal. For example, in the influential diabetes video game *Packy & Marlon* [3] for the Super Nintendo system, players were rewarded when they managed their character's blood glucose throughout a level. Players reported taking more ownership of their food intake and insulin measurement as a result.

Other health games focus on the desired physical activity itself, what Florian Mueller has termed 'exertion interfaces.' This category includes commercial products such as Nintendo's Wii Sports and Wii Fit series, as well as research prototypes like Mueller's 'Breakout for Two' in which two non-collocated players compete in a soccer-kicking game via a pair of impact-sensitive video-walls. [4] By encouraging people to have physical exercises together, this kind of exertion interface increases social bonding. In AHPC, we also find emerging social interactions between peers and student-parents, but we focus more on long-term and sustainable behavioral and attitudinal change.

Research

In order to study the effectiveness of AHPC and to understand the ways in which it affects students, parents, and teachers, we have been following participants since the first heat in the spring of 2009 and plan to complete our observation at the end of this spring's heat. We have invited each student and parent to complete an online survey before the start of each heat and have conducted site visits during which we interviewed students and teachers, both in focus groups and individual interviews.

In our survey design and interview protocols, we have focused on several issues we believe to be central to a successful intervention for this age group. We are looking for any effects the intervention may have had on students' overall activity levels, but we are also interested in any changes in their attitudes toward exercise and physical activities. We are also interested in AHPC as a decentralized team activity and ways in which asynchronous team play have affected students and parents (e.g., taking walks together). Finally, we are interested in the ways in which socio-structural factors associated with the program's school-based intervention have affected its differing success in varied school environments. Through these activities, we have begun to collect a series of preliminary impressions under the broad themes of *family communication, social media platforms for health,* and i*ntegration into school environment*.

Family Communication

Our preliminary results suggest that like similar studies of 'games for health', there are second-order social effects on intra-family communication. [3] In our visits to schools across the country, children have spoken about AHPC, despite being a school-based program, being a way to connect to busy, working parents who otherwise are too exhausted to provide the attention the children desire. The program provides a legitimate reason for children to talk with their parents a bit more than they might otherwise, and AHPC may serve as a springboard for health or fitness discussions between parents and children.

Social Media Platforms for Health

The student participants we have interviewed, who are primarily in sixth and seventh grade, self-report as avid users of social network sites, especially Facebook, and they have expressed a desire to integrate their AHPC data into other social streams. As videogames become more social, and as social media become more integrated into children's everyday lives, integration with social media platforms will be key to the future success of programs like AHPC. However, one should expect that children will access these resources outside of the school itself, as the schools we visited had filtering software that in some cases prevented access to popular social media sites.

Integration into School Environment

When deploying a fitness gaming program within a school, it is important to understand the characteristics of the school itself. For example, our preliminary results suggest school size impacts how students view AHPC; some schools are small enough that nearly every student is given the opportunity to be on a sports team. Because one of the advantages of AHPC is that it extends some benefits of ‘being on a team’ to its participants, its effectiveness in small schools (where it is much easier to ‘make the cut’ at sports) may be reduced, at least as currently designed, relative to larger schools.

Additionally, the subject taught by the teacher promoting the game matters for a number of reasons. Does the teacher have a dedicated classroom (e.g. a history teacher?) or is the teacher in PE and moving around the campus a lot? Are the children all meeting in one class or are they spread across classes? Additionally, classes with fewer strict curriculum requirements (e.g. science, history) allowed for AHPC activities to be integrated into the children's school activities. When teachers had AHPC children in more structured classes (especially math) there may be little room for the teachers to have the creativity/time to integrate AHPC into the school day.

References

[1] MacKay AP, Duran C. Adolescent Health in the United States, 2007.

[2] Lenhart, A et al. Teens and Social Media. Pew Internet & American Life Project (Dec 18, 2007).

[3] Brown, S. J, Lieberman, D. A, Gemeny, B. A, Fan, Y. C, Wilson, D. M, and Pasta, D. J. Educational video game for juvenile diabetes: results of a controlled trial. Informatics for Health and Social Care, 22, 1 (Jan 1, 1997), 77-89.

[4] Mueller, F., Agamanolis, S., and Picard, R. 2003. Exertion interfaces: sports over a distance for social bonding and fun. CHI '03.

[5] Lin, J.J., et al. “Fish‘n’Steps: Encouraging Physical Activity with an Interactive Computer Game,” *Proceedings of UbiComp ’06*, (Sep 2006), 261-78.

[6] Toscos, T., Faber, A., An, S., & Gandhi, M.P. “Chick Clique: Persuasive Technology to Motivate Teenage Girls to Exercise.” In *CHI ’06 Ext Abstracts* (2006), 1873-8.

MobileCARE: An Interactive Mobile Platform for Tele-Supported Trauma Care and Education

Xin Feng
University of Miami
Miller School of Medicine
1800 NW 10th Ave
Miami, FL 33136 USA
xfeng@med.miami.edu

Antonio Marttos
University of Miami
Miller School of Medicine
1800 NW 10th Ave
Miami, FL 33136 USA
amarttos@med.miami.edu

Carl I. Schulman
University of Miami
Miller School of Medicine
1800 NW 10th Ave
Miami, FL 33136 USA
cschulman@med.miami.edu

Jeffrey S. Augenstein
University of Miami
Miller School of Medicine
1800 NW 10th Ave
Miami, FL 33136 USA
jaugenstein@med.miami.edu

Jill Graygo
University of Miami
Miller School of Medicine
1800 NW 10th Ave
Miami, FL 33136 USA
jgraygo@med.miami.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

This paper presents the design and implementation of an interactive platform for trauma care and education that aims to address the challenge for more accessible clinical information and resources. This platform, called MobileCARE, allows clinicians to access patient information through mobile devices such as smartphones. It integrates multimedia education videos on trauma care and procedures, as well as supports features such as teleconferencing and other innovative human technology interfaces. Preliminary results are presented with a special focus on initial user feedback.

Keywords

Electronic medical record (EMR), mobile computing, user interface, clinical education, telemedicine

ACM Classification Keywords

H5.2. User Interfaces: User-centered design

General Terms

Design, Documentation, Human Factors

Introduction

For the past decade, the electronic medical record (EMR) has gradually been accepted as one of the most viable approaches to improving patient care [1], reducing medical error [2, 3], and lowering healthcare costs [3]. Despite these promising advantages, the adoption rate of EMRs, although showing some recent increases, remains relatively low at about 20-25% [4].

Perhaps one of the greatest obstacles to adoption is the need for better tools, which integrate a user-centered design approach, to provide clinicians with a more intuitive user interface to access clinical information and resources in a timely fashion [5]. This need has been particularly magnified in trauma care, where clinicians often work simultaneously on multiple complex tasks in a highly dynamic environment under severe time constraints, which subsequently puts much higher demands on the usability (e.g. efficiency, ease of use, tolerance of error) of medical technology [6].

The rapid growth of Electronic and Information Technology (E&IT) in the past decade can be a pillar to address this challenge [7]. As a key example, mobile technologies, including personal digital assistants (PDAs) and smartphones, which have become ubiquitous today, are generally portable, lightweight computers with features such as multimodal user interface, high-speed wireless connectivity, and enhanced processing power. Such personal devices have the potential to provide an optimized interface to access clinical information anywhere, anytime [7].

This paper presents the implementation of a user-centered, ubiquitous computing application for trauma care and education: an interactive platform termed MobileCARE, which has been developed at the Ryder Trauma Center, allows clinicians to access patient information in real-time by wireless mobile devices. A suite of multimedia education videos on trauma and critical care has been developed and deployed on these mobile devices as decision-support tools. The teleconferencing capability has been implemented to allow physicians at remote sites to provide tele-consultation and/or tele-mentoring. Particular attention has been paid to the ease-of-use of the system, with the example of using innovative user interfaces (e.g. voice interface) to interact with the system and input non-structured descriptions. Preliminary results are presented, with a special focus on the initial user feedback on the various components of MobileCARE.

Methodology

This section presents the implementation details for the MobileCARE platform, including the trauma care and education components, as well as the various user interface technologies implemented in MobileCARE.

MobileCARE client and patient information

A suite of mobile devices (e.g. smartphones, PocketPCs) running Windows Mobile platform have been supported as the MobileCARE client, on which clinicians can get access to patient information in real-time through the MobileCARE data interface layer to other large scale EMRs deployed at the Ryder Trauma Center. The patient information available on the MobileCARE client includes demographic information, laboratory results (e.g. pathology, radiology), and other treatment history reports (e.g. operating room history reports) that occurred in the trauma care unit within the last three days. The MobileCARE client also enables clinicians to document a patient’s status at different stages by various types of notes (e.g. admission notes, progress notes) through structured prompts, which is complemented by open form dictation. MobileCARE is developed by Microsoft .NET and the MobileFrame development tool kit.

Multimedia education on trauma and critical care
As shown in Fig.1, a suite of multimedia lectures (e.g. shock management) on trauma and critical care, as well as a number of procedural animations (e.g. central line placement) which demonstrate the process for performing medical procedures using high quality anatomic animation, have been developed based on a learning curriculum defined by the steering committee at the Ryder Trauma Center and refined according to the feedback of clinicians.

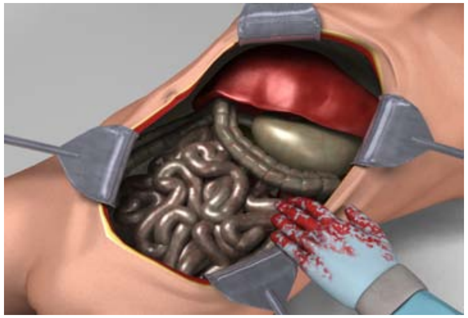


Fig. 1 Example anatomic view during procedural animation

These multimedia education materials have been integrated into MobileCARE and can be presented to clinicians within the right context as a decision-support tool. These education materials are also available for residents for their initial learning as well as for maintenance of their knowledge and skills.

Innovative interfaces to facilitate human computer interaction
HTC HD2, a smartphone running on Microsoft Windows Mobile 6.5, is being used as the current Windows Mobile client device. It comes with a 4.3 inch capacity touch screen. It supports a tactile interface which allows the user to use fingers to interact with MobileCARE. MobileCARE is capable of presenting information in various forms (e.g. text, graph); furthermore, it has the potential to actively alert clinicians by sending tactile cues (e.g. “new patient report arrived”).

Voice interface is also supported on the MobileCARE client device to select menu choices, to navigate through screens, as well as to input non-structured descriptions to a transcription service and receive the completed transcription back through the system in a timely manner.

HTC HD2 also comes with a 5 mega pixel camera. This camera, together with a third-party product called iVisit, has been integrated in MobileCARE to support teleconferencing for up to four MobileCARE clients. This communication includes audio, video and still images, which remote physicians can use to potentially make timely assessments of patients, interact with local physicians, as well as provide tele-consultation and/or tele-mentoring.

Results and Discussion

A number of IRB-approved studies have been completed to evaluate the user acceptability on the clinical education and telemedicine components of MobileCARE. As an example of these studies, a 5-point Likert scale (e.g. 1-strongly disagree, 3-neutral, 5-strongly agree) survey on multimedia trauma education videos was used to gather usability data from 17 army training team members rotating through the Ryder Trauma Center. Sample results are shown in Table 1.

Question	**% Agree or Strongly Agree**
The procedural animations were clear and easy to understand.	94%
The audio was clear and crisp.	88%
I was able to understand the audio content.	94%
The graphics in the animation were clear and crisp.	94%
I was able to understand the graphics in the procedural animation.	83%
The animations were relevant to trauma and critical care.	83%
The procedural animations would be a useful reference during patient care.	88%

Table 1 Sample results from usability survey on multimedia trauma care education videos

A heuristic evaluation of the MobileCARE platform has also been completed, the recommendations from which have been used to improve the ease-of-use of MobileCARE.

Conclusion

In summary, an interactive, mobile platform for trauma care and education has been implemented, which enables clinicians to access patient information using mobile devices. It integrates multimedia trauma education and supports features such as teleconferencing and innovative human technology interfaces. Preliminary studies have shown positive feedback on the user acceptability of different components of the system. A larger usability study in a real-life clinical setting is still needed to generalize these results.

Acknowledgements

This work has been sponsored by Department of Defense (DOD) Telemedicine & Advanced Technology Research Center (TATRC) grant "Innovative approaches to combat trauma education". All opinions expressed here are those of the authors.

References

[1] Deckelbaum, D. L., Feinstein, A. J., Schulman, C. I., Augenstein, J. S., Murtha, M. F., Livingstone A. S., & McKenney, M. G. Electronic medical records and mortality in trauma patients. *J Trauma*, 67, 3 (2009), 634-636.

[2] Bates, D.W., and Gawande, A. A. Improving safety with Information Technology. *N Eng J Med.*, 348 (2003), 2526-34.

[3] Roeder, J.A. The electronic medical record in the surgical setting. *AORN J.* 90, 4(2009), 502-504.

[4] Jha, A.K., Ferris, T.G., Donelan, K., et al. How common are electronic health records in the United States? A summary of the evidence. *Health Affairs*, 25, 6(2006), w496–507.

[5] Xiao, Y., Hunter, A., Mackenzie, C.F., Jefferies, N.J. Task complexity in emergency medical care and its implications for team coordination. *Human Factors*, 38, 4(1996), 636-645.

[6] Pronovost, P. J., Angus, D. C., Dorman, T., Robinson, K. A., Dremsizov, T. T., Young, T. L. Physician staffing patterns and clinical outcomes in critically ill patients: a systematic review. *JAMA*, 288, 17 (2002), 2151-62.

[7] Feng, X., and Winters, J.M. Emerging Personalized Home Rehabilitation: Integrating Service with Interface. in Winters, J.M. and Story, M.F. eds. *Medical Instrumentation: Accessibility and Usability Considerations*, CRC Press, Boca Raton, FL, 2006, 355-372.

Designing for Rehabilitation at Home

Geraldine Fitzpatrick
Vienna University of Technology
Vienna, 1040, Austria
geraldine.fitzpatrick@tuwien.ac.at

Madeline Balaam, Lesley Axelrod, Eric Harris, Graham McAllister
Interact Lab, Uni of Sussex
Brighton, BN1 9 UK
{madela,L.Axelrod,erich,
G.McAllister} @sussex.ac.uk

Ann-Marie Hughes, Jane Burridge
School of Health Sciences
University of Southampton
Southampton, SO17 1BJ, UK
{A.Hughes, J.H.Burridge}
@soton.ac.uk

Thomas Nind, Ian Ricketts
School of Computing, University of
Dundee, Dundee, DD1 4HN UK
{rickets,tnind}@computing.dundee.ac.uk

Anna Wilkinson, Sue Mawson
Centre for Health and Social Care
Research, Sheffield Hallam Uni
Sheffield, S10 2BP, UK
{A.J.Wilkinson,
S.J.Mawson}@shu.ac.uk

Stefan Rennick Egglestone, Tom Rodden
MRL, Nottingham University
Nottingham, NG8 1BB, UK
{sre,tar}@nott.ac.uk

Penny Probert Smith, Nour Shublaq
Engineering Science
University of Oxford
Oxford, OX1 UK
{penny.smith,
nour.shublaq}@eng.ox.ac.uk

Zoe Robertson
Assistive Tech Clinical Specialist.
Barnsley District General Hospital,
Barnsley S75 2EP
zoe.robertson@nhs.net

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Abstract

New technologies open up possibilities for designing interactive experiences that can engage and motivate post-stroke survivors to undertake what would otherwise be boring repetitive movements. In this paper we outline a few of the challenges we met as part of the cross-disciplinary Motivating Mobility project. These are: the extended 'user'; autonomy and motivation; and early prototype studies.

Keywords

Rehabilitation technologies, stroke, user centred design

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

New wireless and sensor based technologies are increasingly making their way into patients' homes, e.g. as self-care and assistive technology packages. The drivers for this shift are indisputable when most developed countries are dealing with an aging population and rising healthcare costs. Apart from shifting costs and the burden of care, it can also enable people to take greater control of their health, including the management of chronic diseases. The particular concern of our Motivating Mobility project is with home-based rehabilitation of upper arm movement for people recovering from a stroke. The focus of this position paper is to provide a general overview of the project and to highlight some particular design challenges we have faced as a cross-disciplinary project team.

Motivating Mobility Project

Strokes are one of the leading causes of severe adult disability, limiting physical activity and affecting independence and quality of life. There is growing evidence that post-stroke rehabilitation exercises can reduce disability [4] and increase independence. Effective home-based regimes require repetitive movements, done regularly and correctly as prescribed by physiotherapists. However, these exercises may be practiced incorrectly, and patients can find them monotonous and frustrating. New sensing technologies open up possibilities for interactive applications to help motivate and support rehabilitation in the home.

The Motivating Mobility project is comprised of physiotherapists, interaction designers, user experience researchers, software engineers and electronics engineers. The overall aim is to prototype devices where patients can undertake repetitive movements without necessarily thinking of them as exercises – think here of being asked to swing your arm 500 times compared to being asked to play a virtual game of tennis where the arm swings are embedded into an enjoyable experience. We aim to realise this through a personalisable "plug and play" rehabilitation toolkit that would facilitate the continuation of rehabilitation in the home and where a physiotherapist, patient or carer can match appropriate input devices that facilitate desired movements, with motivating content.

To inform the overall approach we spent considerable time understanding the experience of stroke patients, their family/carers and their health professionals. We interviewed people in their homes and in community-based stroke clubs. We gave participants a range of probes to complete to access the more intangible aspects of stroke recovery. We also created a clinical functional matrix mapping levels of ability against class of activity (e.g., elbow/shoulder, grasp and release) and the specific movements that a physiotherapist might prescribe for a patient. The user case studies and matrix were brought together into personas, prototype storyboards and prototypes/toolkit components, which we took to workshops with patients, carers and therapists. We are currently working with four stroke patients, developing specifically tailored applications they can use at home [2]. We have deployed three of these to date.

Discussion

Elsewhere we have talked about the issues in designing technologies to fit into the everyday spaces of the homes of patients [1] as well as more general design considerations [3]. Here, we wish to identify a few of the challenges we faced in trying to support post-stoke rehabilitation in the home.

The extended 'user' network:

Many discussions of healthcare applications implicitly work with a model of 'a patient'. Because stroke patients live with disabilities that often require support to meet even basic functional needs, their carers and/or family members also become core participants and indeed key enablers. The partners will often be the ones who have to set up and manage any technology we put into the home on a day-to-day basis, and for specific exercise sessions. If the patient has communication impairments from the stroke then their partners will also need to assist with this.

Addressing the concerns and needs of this extended notion of a ‘user’ to include the carer as core partner is not without challenge. Interviews with carers/partners indicated that they too went through significant lifestyle changes as a result of their loved one’s stroke. Many found this a difficult adjustment to make and all were, naturally, keen to see their loved ones improve. Carers were active partners in decision making concerning rehabilitation practice. For example in one case, a young mother, who had a stroke following surgery for a brain tumour, was closely supported by her mother and the mother was proactive in encouraging her daughter to participate in our study. Another two of our female participants were senior citizens with supportive husbands. These men had to take on household and other responsibilities that they had not ever undertaken before the stroke. Stroke recovery, like bereavement may be an incomplete and lengthy process with stages of anger, denial and so on for both the person with stroke and their carers. Wanting things to return as they were is a natural desire but may be unrealistic and views and attitudes vary over the course of rehabilitation. It is a challenge then to recognise and manage the agendas and concerns of all the participants, while ensuring that the stroke patient’s own wishes are respected.

The challenge of autonomy and motivation

Another key issue, and one that differentiates this type of application from a rehabilitation system in a clinical setting, is that of autonomy: this is the patient’s home and they have the autonomy, and indeed the right, to do as they want. In contrast it is common to hear language such as ‘patient compliance’, which implies that the clinician knows best and that the patient should do what they are told. The motivations for this are well-intentioned and easy to understand, e.g., when there is evidence that post-stroke function can be recovered with repetitive exercise [3]. However, the functional pay-off of repetitive exercise can take some time. The patient can often be more motivated to do the ‘wrong’ movement if it means a more immediate ‘good’ outcome, e.g., if they can get the cup of tea to their mouth even if it means incorrectly lifting their shoulder to do so. The issue of autonomy then also requires us to re-think the role of the clinician, in this case the physiotherapist, to be more of a partner and expert facilitator. Growing interest in techniques such as motivational interviewing suggest that this move is already starting to happen.

Autonomy for the patient here is ‘dependent autonomy’ in reality. While the person with stroke has an impairment that causes disability, the carer can be key to how much of a handicap this is. The degree of autonomy they experience then will be influenced by the carer and this dependent relationship. As autonomy is also recognised as an important component for motivation, it is worth considering how our design solutions engage and impact this relationship.

While a compliance ‘stick’ approach does not work in the home setting, understanding how best to motivate unique autonomous individuals through interactive technology is non-trivial. The evidence for this becomes all the more obvious when we are trying, on the one hand, to develop a tool-kit approach that can be scalable and flexible, and on the other hand trying to develop applications for specific people. Even in our four patients, we found huge diversity and resulting in prototypes ranging from a book reader to a play toy that can be used in collaboration with a child, to a tangible chess game. Identifying the key functional therapy movements and some candidate technology components is only the beginning. The real challenge is to design interactive content that engages, that will evolve as the patient's function returns or boredom levels grow, and that can provide feedback in very specific ways appropriate to the patient's personality and interests as well as clinical needs. Even ownership of the feedback is an issue as therapists feel ownership of information about exercises they provide; carers feel responsibility for exercises carried out; and we see the person with stroke as the primary stakeholder.

From concept to prototype... and what next?
A final challenge, just touched upon here, is the tension inherent in working with real patients who have real needs, yet also working with very early technology prototypes and at a pre-clinical technology-trial stage. We had frequent discussions in our project team arising from our different disciplinary perspectives. The interaction/HCI designers were thinking of the project as a proof of technology concept that if successful might go on to a pilot trial. Here success was more about understanding what types of technologies might have the potential to work in this setting. The clinicians were more used to working with developed or at least relatively stable technologies, even if at trial stage, where real clinical trials can be undertaken and clinical outcome measures matter. Negotiating these different research stages and approaches is another challenge for collaborative working. Similarly there are different approaches to data collection and evaluation.

Finally is the question of what do we leave the patient with at the end? We are not conducting a full clinical trial and can only look for indicative measures that the approach will work so the expectations of the patients and carers need to be very carefully managed. If we want to leave the technology with the patient after the prototype study has been completed, there is then the matter of how the maintenance and repair of early prototypes are managed in the absence of continuing resources. On the other hand taking the technology away, having left it with the patient for three months and having said it may help, is also very difficult to do. Patients also expressed a frustration about helping out with research and then not hearing about outcomes after their involvement is finished. For many, their study involvement is not just about being a participant e.g., for a simple usability test. They want to be part of making a difference for other stroke survivors. Designing for rehabilitation at home is a complex multi-stakeholder process.

Acknowledgements

Many thanks to our participants. This work was funded by the UK EPSRC: Grant EP/F00382X/1.

References

[1] Axelrod, L., Fitzpatrick, G., et al. The reality of homes fit for heroes: design challenges for rehabilitation technology at home, Journal of Assistive Technologies, Vol 3: 2, 35-43, 2009.

[2] Balaam, M. et al, Rehabilitation Centred Design, to appear in EA CHI2010, ACM Press.

[3] Eggleston, S. Axelrod, L., et al. A framework for a home-based stroke rehabilitation system. In Proc 3rd Int Conf on Pervasive Computing Technologies for Healthcare 2009.

[4] Schreiber, J., Stern, P. A review of the literature on evidence-based practice in physical therapy. *The Internet Journal of Allied Health Sciences and Practice*. 3, 4, (2005).

Shared Visualization of Patient Information

Oscar Frykholm
Human-Computer Interaction
School of Computer Science
Royal Institute of Technology
Lindstedtsvägen 5
100 44, Stockholm, Sweden
frykholm@kth.se

Kristina Groth
Human-Computer Interaction
School of Computer Science
Royal Institute of Technology
Lindstedtsvägen 5
100 44, Stockholm, Sweden
kicki@kth.se

Abstract

Based on field studies of work at the surgical department of a university hospital, we propose ideas for enhancing the visualization of, and collaboration on, patient information. As several specialized physicians are connected to a case for a time period of several weeks or months, we have identified the need for physicians to quickly visualize only the relevant information on a case, as well as to add and high-light the information based on their specialization. During distributed multi-disciplinary team meetings we find advantages of introducing a shared workspace displaying relevant patient information and interactive tools to support for instance visualization, annotation and search.

Keywords

CSCW, electronic patient record, multi-disciplinary team meeting

ACM Classification Keywords

J.3 Medical information systems.

General Terms

Design

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Introduction

Highly specialized medical care in Sweden has been centralized to the regional university hospitals, a rationale introduced to increase medical care, efficiency in treatment and to improve the possibilities for research and education. Patients suffering from severe diseases, and in need of specialized examinations and treatment, are referred from the local to the university hospital. As much as possible, patients are treated at the local hospital and during the specialized care at the university hospital the local physician is still involved in the case. Physicians at the university hospital treat patients during a shorter period of time, when conducting examinations, diagnosis and treatment. Therefore, one physician does not have sole responsibility for a patient, rather, all physicians more or less need to be able to discuss any patient. An important activity in specialized care is the multi-disciplinary team meetings (MDTM), where physicians discuss cases and decide on diagnosis and treatment. It has been reported that MDTMs for instance improve clinical decision-making and communication between specialties [7].

A main challenge is to present patient information in a way which facilitates for physicians to quickly get an overview of a case. Previous research projects include for instance Lifelines2 [8], Persival [6] and CAREVIEW [5], which explore the presentation of patient information using a bird's-eye view and ways of interacting with patient information.

Another challenge is to introduce collaborative tools in MDTMs to facilitate case discussions, and sharing and annotation of information. Kane & Luz have conducted studies of MDTMs, stating for instance that new knowledge is generated during MDTMs, and that current patient records do not meet users' needs on interacting with and keeping patient information. They suggest tools for annotation and pointing, and large shared interactive displays, both for personal and collaborative interaction [2, 3]. Lu & Lajoie have investigated interactive, shared displays and found that they enhanced group decision-making, visualization of patient information and communicative interactions [4].

The setting

The specialized medical care of patients suffering from severe diseases of the liver, pancreas, and esophagus has been centralized to the department of upper abdominal surgery, called Gastro, at a university hospital in Sweden. Approximately 25 surgeons work at Gastro and it has, due to the complexity of the diseases, a close collaboration with other departments. Patients referred to Gastro follow a process, a clinical pathway, consisting of four main steps:

- *Coordination* Upon referral, patient information is reviewed and, if necessary, complemented with new examinations. This step is to assure that available information is sufficient for the MDTM in the next step.
- *MDTM: Consensus meeting and Pre-operative planning* At the consensus meeting all relevant patient information is discussed and consensus is reached on a diagnosis and treatment. If surgery is decided, the case is reviewed at a surgical planning meeting.
- *Surgery* Before, during and after surgery, surgeons access patient information in order to plan the surgery and write post-surgical notes.
- *Post-operative meeting* A few months after surgery, patient outcome is discussed during a MDTM, in order to present feedback on the treatment.

Patient information is continuously accessed and complemented during the clinical pathway, usually by different physicians and at different occasions. In the end, they have produced a full description of the case, including relevant examinations, diagnosis, treatment and outcome.

Multi-disciplinary team meetings at Gastro

We have in more detail studied MDTMs at Gastro, specifically on information structure and time-related aspects [1]. A consensus meeting usually lasts 60-90 minutes, handles ten cases and is attended by five to twenty physicians (differences are due to level of complexity of the diseases). As all physicians are not located in the same hospital building, or even the same city, video-conferencing and screen sharing is used.

figure 1. *Consensus meeting* Two projectors show radiology images, controlled by the radiologists in the foreground. The screen on the top left shows participants from other hospitals.

The different roles of the participants, the work-flow of the meeting and the way information is presented, make it possible to follow a clear structure [1]. The chair (a senior surgeon) makes sure they follow the meeting structure and reach a decision. Each case discussion begins with the presenter (a younger surgeon or the referring physician) giving a short introduction of relevant patient information. The radiologist then presents a radiological diagnosis by showing images and pointing out specific areas. After the two presentations, prepared in advance, the chair leads the discussion. Questions can be directed to a specialist, or any participant can state his/her opinion directly. At the end of each discussion, a decision on diagnosis and treatment must be made, and the presenter later dictates the decision on the patient record.

The meetings use advanced technology, such as radiology software and screen sharing, but when it comes to presenting and searching for patient information, physicians rely on their own memory of the cases. The presenter and the referring physician are best updated on the patient, but they are not always able to answer specific questions, which make MDTMs vulnerable as to whom is present and what they remember.

A clinical information workspace

Our research project has a close collaboration with physicians at Gastro and we have conducted initial studies during the last three years. Field studies of their work and MDTMs have led us to propose ideas on collaborative tools to be used throughout the clinical pathway.

We suggest a shared, interactive workspace to be used by all physicians connected to the work at Gastro, i.e. both physicians at the university and local hospitals. The workspace would be able to present information from any patient record or medical database, but only the most relevant information for a case is kept in the workspace, such as a set of radiology images, a description of the patient's general condition or a plan on how to perform the surgery. Early in the clinical pathway there might not be much presented in the workspace, but as physicians start highlighting information, adding images etc., the description of the case evolves. Along the clinical pathway, physicians get an overview of what has been decided and what is important for the case, and can add new information which is relevant at that time. In the end, a complete description of relevant information for the case, from referral to sign-off and outcome, is presented. A time-line-based visualization ([8]) would be a natural basis for presenting both all the current patients at Gastro, as well as information regarding one patient.

The ideas have been refined in workshops and discussions with physicians and the department director. They identified opportunities to tackle challenges in their current processes, such as information hand-over between physicians, feedback loops during the clinical pathway and access to relevant information. The ideas will be realized together with the physicians, focusing on implementing the shared workspace and collaborative tools in MDTMs. As the MDTM is an activity where a lot of information is presented, asked for and created, easy-to-use visualization and collaboration tools would really be beneficial.

Some of the ideas are based on software design, such as time-line visualization of patients, case-based presentation of patients, annotation tools etc. Other ideas will be more hard-ware-based, for instance interactive screens and pointing devices. In all, the tools will enhance collaboration between all physicians during both synchronous and asynchronous communication, as well as co-located and distributed meetings.

References

[1] Groth, K., Frykholm, O., Segersvärd, R., Isaksson, I. & Permert, P. Efficiency in Treatment Discussions: A Field Study of Time Related Aspects in Multi-Disciplinary Team Meetings. In *Proc. of CBMS*, IEEE (2009).

[2] Kane, B. & Luz, S. Information Sharing at Multidisciplinary Medical Team Meetings. *Group Decision and Negotiation* (2009)

[3] Kane, B. & Luz, S. 2009. Achieving Diagnosis by Consensus. *Comput. Supported Coop. Work* 18, 4 (2009), 357-392.

[4] Lu, J. & Lajoie, S.P. Supporting medical decision making with argumentation tools. In *Contemporary Educational Psychology 33* (2008), 425–442.

[5] Mamykina, L., Goose, S., Hedqvist, D. & Beard, D. V. CareView: analyzing nursing narratives for temporal trends. In *CHI '04 Extended Abstracts* (2004), 1147-1150.

[6] McKeown, K. R., Chang, S., Cimino, J., Feiner, S., Friedman, C., Gravano, L., Hatzivassiloglou, V., Johnson, S., Jordan, D. A., Klavans, J. L., Kushniruk, A., Patel, V. & Teufel, S. PERSIVAL, a system for personalized search and summarization over multimedia healthcare information. In *Proc. of JCDL'01*, ACM (2001), 331-340.

[7] Ruhstaller, T., Roe, H., Thurlimann, B. & Nicoll, J. The multidisciplinary meeting: An indispensable aid to communication between different specialities. *European Journal of Cancer 42*, 15 (2006), 2459-2462.

[8] Wang, T. D., Plaisant, C., Quinn, A. J., Stanchak, R., Murphy, S. & Shneiderman, B. Aligning temporal data by sentinel events: discovering patterns in electronic health records. In *Proc. of CHI '08*, ACM (2008), 457-466.

Resilience in Emergency Medical Dispatch: Big R and little r

Dominic Furniss
UCLIC
University College London
Gower Street
London, WC1E 6BT, UK
d.furniss@ucl.ac.uk

Jonathan Back
UCLIC
University College London
Gower Street
London, WC1E 6BT, UK
j.back@ucl.ac.uk

Ann Blandford
UCLIC
University College London
Gower Street
London, WC1E 6BT, UK
a.blandford@ucl.ac.uk

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Abstract

Emergency medical dispatch (EMD) is integral to emergency health care provision. It involves interaction between humans and computers and needs to be resilient to fluctuating demands. Here we investigate resilience in the London Ambulance Service control room. We find it useful to distinguish between Big R and little r, the former relating to strategy creation and the latter strategy sharing and reuse. Systems can be designed to allow for Big R responses to the unexpected. Little r can facilitate the efficiency, effectiveness and safety of more mundane tasks. This distinction can help research studies in resilience for other health care contexts.

Keywords

Emergency medical dispatch, resilience

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

Emergency medical dispatch (EMD) is on the front-line of emergency health care provision. Its effectiveness has direct consequences on patient outcome and quality of care. Emergency resources have to be directed to incidents in a timely fashion, but these resources are finite and demand for them can fluctuate greatly. This is especially pertinent for the London Ambulance Service (LAS) control room which handles approximately 3,800 calls on a normal day [1]. In this paper we investigate the importance of different forms of resilience in the LAS control room.

Background

Resilience Engineering is a relatively recent area of study which is contrasted with traditional approaches to safety [2]. The rhetoric suggests that resilience looks at building capacity to deal with the unexpected, whereas traditional safety looks to make the system robust and error free against predicted threats. Resilience is commonly associated with coping with beyond design-basis events, i.e. rare and extreme events that systems are not designed to handle. A common example is the 9/11 attack on New York which required a response to something that had never been experienced before. However, it has also been associated with more mundane interactions, error avoidance, mitigation and recovery [3].

We subscribe to the view that unexpected errors can occur even for mundane interaction, and there is a constant risk of making these sorts of slips and lapses, particularly where processes, tools and artefacts are designed poorly. People will often reuse strategies and work-arounds to compensate for these poor designs and circumstances, which we define as resilience at the little r level. This contrasts with the Big R level which involves the 'creation' of novel strategies to respond to a vulnerability or threat. So the crux of this distinction is on the scale of innovation rather than the scale or frequency of the threat. In the following analysis of the LAS control room we see that both are relevant, and extra clarity can be gained by keeping these two types of resilience distinct.

Resilience in the LAS control room

To investigate resilience in the LAS control room this analysis builds on prior work [3, 4, 5]. The novelty in this analysis is its focus on resilience and the distinction we use between Big R and little r.

Distinguishing between Big R and little r

This distinction concerns the leap from established strategies and actions. Big R is to do with the creation of a strategy, whereas little r is in the propagation and reuse of a strategy. For example, in a overly busy Emergency Department Big R resilience might involve creatively thinking of using the corridor to extend the department's capacity to accept patients [6]. However, Big R would be limited to that first creative step. In contrast, little r might involve the reuse of this strategy to increase capacity to cope with other peaks in demand; it might also involve sharing this strategy with other hospitals that might find it useful too.

Big R in the LAS control room

There are different modes of control in the LAS control room: (I) normal routine work, (II) transition to a major incident, and (III) where a major incident is declared [4]. These three levels signify an increase in seriousness and scale of the incident. For example, a terrorist attack, such as the 7th July bombings in London in 2005, would entail reconfiguring to (III) where a major incident is declared. This most extreme mode means that the team that was dealing with the escalating incident is moved to a separate room whilst another team takes over their normal duties. This frees the team's cognitive resources to focus on the incident, rather than juggling many different incidents. This team also has special communication and command lines which makes it more tightly integrated with the other emergency service' responses e.g. the fire-brigade and police. These reconfigurations in structure and resource allows the incident to be handled flexibly and resiliently, which is required as the incident is likely to be unexpected in type, detail and scale. This fits the observation that "you may not be able to design for the unexpected, but you can design to allow the unexpected" [7].

Big R relates to big innovation and these can also occur to address smaller needs, e.g. thinking of more efficient or less error prone ways of working. To facilitate this process a staff suggestion scheme was planned to be introduced to the LAS between 2000 and 2004.

Little r in the LAS control room
In [3] we described resilient markers that were evident in the LAS control room. These markers are at the little r level because they are part of ongoing activities, and strategy reuse, that dampen error and facilitate improved interaction. These work within and around the more formal design of the system; they are identified in five models [3]:

(1) the physical model concerns itself with the layout of the control room; an example of resilience was the physical co-location of individuals which allowed colleagues an augmented awareness to prepare for oncoming demand and better joint working;

(2) the information flow model concerns itself with the structure of the task and its progress; an example of resilience was 'buffering' because the LAS staff were observed to hold on to information before passing it on to colleagues so they were not overloaded or unnecessarily interrupted;

(3) the artefact model concerns itself with the design and use of equipment; an example of resilience was redundancy because a computer system and a paper based system ran side-by-side in case the technology failed;

(4) the social model concerns itself with the social structure in the system; an example of resilience was the social hierarchy because staff with more responsibility had greater experience through successive promotion so they could better anticipate and control what was going on and even fill in for others where needed; and

(5) the evolutionary model concerns itself with the development of the socio-technical system over time; an example of resilience was that new technological opportunities were exploited to better cope with increasing demand from the environment.

Little r relates to little innovation and so will include the sharing of best practice and reuse of past strategies that had not been entirely thought of or prescribed by designers. For example, control room staff used their initiative to preempt the needs of serious incidents and send more resource straight away even though this did not fit the automated system or procedure. One example of this included a report of a construction worker falling from a great height. The worker could not be seen so his condition was classed as 'unknown' by the automated system, and procedure advised one vehicle to first attend to assess the situation. However, the dispatcher foresaw that one ambulance would not be adequate and sent more resource immediately.

Discussion

Resilience is a useful concept for understanding the performance in the LAS control room. Past performance measures have included shortening times to the most serious calls, reducing excessive utilisation of front-line ambulances, harnessing available technology, and making people more effective. Some of these very grounded measures demonstrate resilience e.g. having spare capacity in front-line ambulance use to absorb spikes in demand; however, resilience does not seem to be referred to explicitly. This may only be a issue when trade-offs are being made in services, especially where there is pressure on the service to be more efficient and effective as this can conflict with being more resilient, i.e. spare capacity to absorb peaks in demand may be reduced for efficiency gains.

A distinction between Big R and little r further refines a resilience view. The Big R involves innovation: reconfiguring to allow for responses to the unexpected and having processes to encourage new strategies to be heard and assessed. The little r involves reuse and sharing of strategies: to help to dampen error and provide a balance between working efficiently, effectively and safely.

Implications

The distinction between Big R and little r may be useful for other areas of research in health care. For example, we are planning a series of studies of resilient interaction with medical devices. These will be focused on the design of the devices, the vulnerabilities of the device coupled with the work context, and the positive strategies that clinicians have developed to work efficiently, effectively and safely with devices i.e. strategies that compensate for poor designs and poor circumstances. Big R will involve looking at how these strategies are created, and little r will involve how these strategies are shared and reused.

Acknowledgements

We thank Michael Hildebrandt, Björn Johansson, Jonas Lundberg, and Erik Prytz for their engaging discussion at the resilience workshop, Pukeberg, Sweden, which contributed to ideas in this paper.

References

1. London Ambulance Service Annual Report 2008-9.
2. Hollnagel, E. (2004). *Barriers and Accident Prevention*. Ashgate.
3. Back, J. Furniss, D. Hildebrandt, M. & Blandford, A. (2008). Resilience Markers for Safer Systems and Organisations. *Proc. of SafeComp* 2008.
4. Blandford, A. & Wong, W. (2004) Situation Awareness in Emergency Medical Dispatch. *International Journal of Human-Computer Studies.* 61(4). 421-452.
5. Furniss, D. & Blandford, A. (2006). Understanding Emergency Medical Dispatch in terms of Distributed Cognition: a case study. *Ergonomics.* 49 (12 & 13). 1174 – 1203.
6. Wears, B., Perry, S. & McFauls, A. (2006). “Free Fall” – A Case Study of Resilience, Its Degradation, and Recovery in an Emergency Department. *2nd Symposium on Resilience Engineering.*
7. Dix, A. (2007). Designing for Appropriation. *British-HCI Conference*. 28-30.

Urban Underserved African American & Latino Views about Telemedicine

Sheba M. George, PhD
Charles Drew University of Medicine and Science
2594 Industry Way
Lynwood, CA, 90262
shebageorge@cdrewu.edu

Alison Hamilton
University of California, Los Angeles
1640 S. Sepulveda Blvd., Suite 200
Los Angeles, CA 90025
alisonh@ucla.edu

Richard S. Baker
Charles Drew University of Medicine and Science
1731 East 120th Street
Los Angeles, CA 90059 USA
richardbaker@cdrewu.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

This study explores perceptions about telemedicine among urban underserved African American and Latino populations. Telemedicine has been advanced as a vehicle to increase access to specialty care among the urban underserved, yet little is known about its acceptability among these populations. We conducted 10 focus groups with African American and Latino participants (n = 87) in urban Los Angeles in order to explore perceptions about this novel type of care. We found that African Americans tended to identify more concerns and fewer advantages whereas Latinos had the opposite tendency. These findings have implications for important issues such as adoption of telemedicine, doctor–patient interaction and patient satisfaction. It will be critical to consider perceptions of this healthcare innovation among urban, underserved African American and Latino populations in the development of strategies to market and implement telemedicine.

Keywords

User study, telemedicine, focus groups, technology acceptability.

ACM Classification Keywords

K.4.2 [**Computers and Society**]: Social Issues.

Introduction

Telemedicine involves using computer, information, and telecommunications technologies to provide healthcare when the provider and care recipient are in separate geographic locations. It has been advanced as a vehicle to increase access to specialty care among the urban underserved [1-2] yet little is known about its acceptability among minority populations. The objective of this study was to explore perceptions regarding telemedicine among African Americans and Latinos in South Central Los Angeles, who make up the largest proportion of the minority populations who experience the most severe and concentrated types of health disparities [3]. Much of this disparity in health is thought to be due to lack of timely access to appropriate healthcare [4].

Telemedicine has been promoted as an innovative approach to bridging the healthcare delivery gap suffered by medically underserved communities. The role of telemedicine in facilitating increased access to care has traditionally been framed in terms of its ability to mitigate geographic barriers. Accordingly, remote rural communities have been the primary beneficiaries of telemedicine implementation [5]. However, limited access to appropriate medical care, particularly specialty care, is a major challenge for inner city communities as well. Although telemedicine has the potential to redress the healthcare delivery problems of the inner city, there is little in the existing literature on telemedicine or healthcare in general that sheds light on perceptions about telemedicine among the general population and more specifically, urban underserved populations. [6]. Given that the Institute of Medicine’s report on the quality of health care has already identified illiteracy and distrust of technology as potential barriers to the delivery of telemedicine in urban underserved settings, it is important to assess community perceptions of this technology [7]. In this study, we examined perceptions of African Americans and Latinos who have not yet experienced telemedicine to assess their willingness to try this technology. In addition to our focus on these two racial/ethnic groups, we examined differences between elders in these groups (over 65 years and younger adults (parents of school-aged children), since these are the two groups that currently receive reimbursement for the use of telemedicine services from Medicare and Medicaid.

Methods

We used community-based recruiting efforts, namely, the distribution of flyers in English and Spanish in community centers and public housing sites, to invite African Americans and Latinos interested in sharing their thoughts about “a new type of high tech medical clinic” to contact us. When 8–10 individuals from the priority populations (African American and Latino parents of school-aged children and seniors) responded to these efforts, 10 focus groups were assembled in local community-based settings such as senior centers and community-based public housing sites. Of these, 5 were African American and 5 Latino groups and 6 were exclusively parents of school aged children whereas 4 were seniors only groups. In total, 49% of participants (n = 43) were African American, and 51% (n = 44) were Latino.

After informed consent was obtained from all participants, they were asked what the word “telemedicine” meant to them to see what sorts of initial associations participants had with the word. After a 5-minute discussion, a brief video presentation—a dramatization of an actor, playing the part of a patient, receiving care for ear pain at a local telemedicine clinic—was shown to focus group participants. The five Latino groups were shown a Spanish version of the same video. In the video, the actor arrived at the clinic with ear pain that was assessed by a physician's assistant who then contacted an ear, nose, and throat (ENT) specialist using a videoconferencing link. This ENT specialist was depicted as being several miles away from the clinic, and he was able to examine the patient without being physically present in the room by using a video otoscope that transmitted images of the patient's inner ear via the Internet to the specialist. The viewing of the video presentation was followed by the focus group interview, which concentrated on the participants' reactions to and perceptions about receiving medical care through telemedicine.

All interviews were transcribed, and all Spanish-language transcripts were translated into English by a professional transcription and translation agency. Transcripts were reviewed for accuracy and then analyzed using qualitative data analysis software (Atlas.ti). Through an iterative process of immersion in the data and refining the categories, key themes and theoretical insights were identified and interpreted collaboratively by the authors.

Results

While African Americans and Latinos, for the most part, perceived similar advantages of telemedicine, there were notable differences in the types of concerns they had about it . Most of the advantages revolved around the following: (1) reduced waiting time, (2) immediate feedback as to diagnosis and course of action, (3) increased access to specialists, and (4) increased access to multiple medical opinions. While African Americans and Latinos, for the most part, discussed similar advantages of telemedicine, there was greater variation in their discussion about concerns regarding telemedicine. African Americans in general expressed concerns about three issues: (1) the physical absence of the physician specialist; (2) the ability to monitor the specialist's qualifications with telemedicine; and (3) and privacy/confidentiality issues related to the use of technology. While the Latino participants were substantially less concerned about these issues and in some cases felt very differently about them, they did express concerns about whether telemedicine would be made accessible to the uninsured. Both groups also expressed concerns about the adequacy of the scopes to accurately diagnose their medical condition. There were no noteworthy differences between the seniors and the young parents.

Discussion

The advantages of any healthcare innovation are usually assessed by potential users relative to their current experiences of receiving care. This was true regarding telemedicine for the focus group participant of our study. Given their underserved inner city location the study participants overwhelmingly identified timely access to care as one of the greatest relative advantages of telemedicine. For these minority groups, the larger socioeconomic context presents several barriers in terms of access to and utilization of healthcare. In the face of such conditions, telemedicine appears to provide some relatively instant solutions to issues such as the challenge of transportation to get to specialist care, lack of timely access to specialists, lack of timely diagnoses and feedback, and lack of multiple opinions in a specialist-scarce zone. While participants in both groups perceived telemedicine as having similar relative advantages as compared to their current mode of care, they had distinctly different types and levels of concern about telemedicine. African Americans tended to identify more concerns and fewer advantages whereas Latinos had the opposite tendency.

The qualitative racial/ethnic differences in attitudes about telemedicine-based health care among Latinos and African Americans point to differences in their lived experiences and values. While the point of reference for many African Americans is the history of racism and medical experimentation and abuse they collectively have experienced in the United States, immigrant Latinos encounter the U.S. medical system without this particular historical backdrop and their point of reference maybe less than optimal healthcare in their home countries, along with a generally positive perception of the American healthcare and medical education systems. For many of the immigrant Latinos, access to American health care and especially telemedicine-based care that is perceived as scientifically and technologically cutting-edge also seems to be seen as a positive improvement.

Based on the preliminary findings presented here, it is clear that such differences require tailored approaches to the introduction and implementation of telemedicine among these different groups. It is critical to gather this group-specific information before the extensive introduction of telemedicine clinics in the community for at least three reasons. First, this information can be important for determining the best manner in which to introduce and market telemedicine among these two groups. Second, this information can be important in selecting the best ways in which to implement new telemedicine clinics. Third, these data will also serve as a baseline point of comparison for studies that will examine changes in patient perceptions over time. Studies with larger samples and mixed methods will be necessary for a more comprehensive understanding of the issues touched upon in this exploratory study.

References

[1]. Shea S, Starren J, Weinstock R, et al. Columbia University's Informatics for Diabetes Education and Telemedicine (IDEATel) Project: Rationale and design. *JAMIA* 2002; 9:49–60.

[2]. Chang BL, Bakken S, Brown SS, et al. Bridging the digital divide: Reaching vulnerable populations. *JAMIA* 2004; 11:448–457.

[3]. *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, DC: Institute of Medicine, 2002.

[4]. Baker RS, Watkins NL, Wilson MR, Bazargan M, Flowers CW Jr. Demographic and clinical characteristics of patients with diabetes presenting to an urban public hospital ophthalmology clinic. *Ophthalmology* 1998; 105:1373–1379.

[5]. Puskin DS. Opportunities and challenges to telemedicine in rural America. *J Med Syst* 1995; 19:59–67.

[6]. *Telemedicine for the Medicare population: Update*. Rockville, MD: Agency for Healthcare Research and Quality, 2006.

[7]. *Crossing the quality chasm: A new health system for the 21st century.* Washington, DC: Institute of Medicine, National Academy Press, 2001.

Designing a Remote-Control Slit Lamp Microscope for Teleophthalmology

Kentaro Go
Interdisciplinary Graduate School
of Medicine and Engineering
University of Yamanashi
4-3-11 Takeda, Kofu 400-8511
Japan
go@yamanashi.ac.jp

Kenji Kashiwagi
Faculty of Medicine
University of Yamanashi
Chuo 409-3898 Japan
kenjik@yamanashi.ac.jp

Naohiko Tanabe
Faculty of Medicine
University of Yamanashi
Chuo 409-3898 Japan
tanabe@yamanashi.ac.jp

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

This paper reports a design project for a remote-control slit lamp microscope system to support telemedicine. The system realizes real-time teleophthalmology by remote control of a slit lamp microscope from a remote site. The project is an attempt to address regional problems related to local shortages of medical doctors. It is also a case study of the development and deployment of a telemedicine system through human-centered design approaches.

Keywords

Telemedicine, ophthalmology, slit lamp microscope, human-centered design

ACM Classification Keywords

H5.2. Information interfaces and presentation (e.g., HCI): User Interfaces.

General Terms

Design, Human factors

Introduction

Regional shortages of medical doctors have become an important social issue in Japan. Reportedly, Tokyo has 4.6 times more medical doctors per capita than Ibaraki prefecture, which has the fewest per capita among all 47 prefectures [1]. Particularly specialized physicians––and especially ophthalmology specialists––are becoming scarce in remote island and mountain areas. Teleophthalmology, an application domain of telemedicine for ophthalmology, has been studied; it is useful to ameliorate the situation [2].

Using early teleophthalmology systems, an expert remote presenter who is trained in the use of the ophthalmic peripherals, hardware, and software can capture still and moving images of the eyes and transmit them to ophthalmologists [2]. Therefore, the current status of teleophthalmology applications remains limited to specific purposes such as doctor-to-doctor consultation, research, and clinical trial collaboration, in addition to distance learning for medical professionals. Furthermore, the indirect operation of a slit lamp microscope, a fundamental diagnostic device for the eye, makes it difficult for ophthalmologists to conduct fine appropriate diagnoses rapidly over long distances. In asynchronous store-and-forward setting, opportunities to find serious eye problems might be missed.

As described in this paper, we report our tele-ophthalmology project for designing EyeViewRobo: a remote-control slit lamp microscope system, which is used for a real-time telemedicine [3]. We introduce the system, discuss its requirements, and show the current project status.

EyeViewRobo: A Remote-Control Slit Lamp Microscope System

For ophthalmologic examination, a slit lamp microscope is generally used as a fundamental diagnostic device (figure 1). The microscope comprises a slit lamp unit and a microscope unit. An eye specialist adjusts the microscope-unit position using a joystick. Using the slit lamp microscope, the eye specialist's basic tasks include adjustment of the microscope position using the joystick to find a focal position and to switch slit types using the knobs on the slit lamp unit to set an appropriate diagnostic condition. The eye specialist might use a fronting lens and a blue filter together with the microscope to conduct additional examinations. Coordinated use of these special devices requires great skill and experience for microscope control in addition to knowledge of clinical medicine.

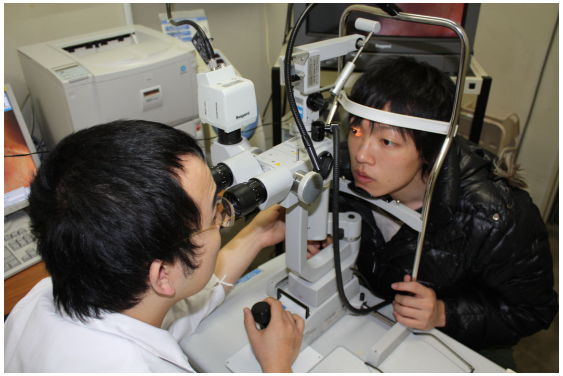


figure 1. Slit lamp microscope in use.

To resolve this shortcoming, we adapt a slit lamp microscope for a remote control device. An eye specialist can operate the remote-control slit lamp microscope from a geographically remote site and conduct a diagnosis.

Figure 2 presents an overview of EyeViewRobo: a remote-control slit lamp microscope system. The system has an input and output (I/O) device at the specialist's site and a clinical robot at the patient's site.

The specialist's site is assumed to be a central hospital of a region, such as a university hospital; the patient's site is a clinic in a remote area. That clinic is assumed to have a medical doctor who is not an eye specialist, or perhaps a nurse who would support the specialist's microscope operation and assist the patient.

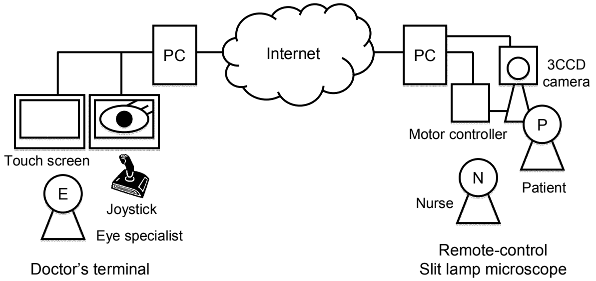


figure 2. Schematic overview of the EyeViewRobo.

The eye specialist operates the I/O device and inputs the microscope position and slit light parameters. The I/O device transmits the parameters to the microscope and the microscope changes its appropriate function levels. It has a 3CCD video camera to capture still and moving images. It transmits images over the internet to the I/O device at the specialist's site using a Digital Video Transport System (DVTS) [4]. The DVTS provides standard definition non-compressed video at 30 frames per second and requires 30 Mbps bandwidth. The eye specialist examines the received images using the I/O device and performs a diagnosis.

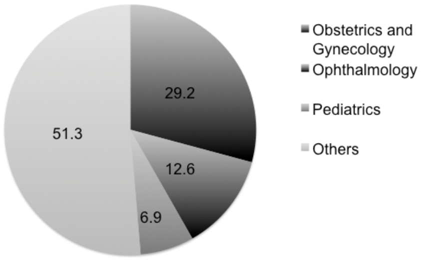


figure 3. Percentages of patients visiting the university hospital for emergency services in FY2005 (total: 6,314 patients).

Motivation: Regional Requirements

Yamanashi prefecture, with a population of about 873 thousand people, is located in central Japan. Although bordered on the east by Tokyo, it is the smallest prefecture among all eight metropolitan prefectures. Most of the land (78%) is mountainous covered by forests.

Yamanashi prefecture has 60 hospitals and 1,081 clinics, including dental clinics (FY2008). Specifically, ophthalmology services are provided at 18 hospitals and 34 clinics. However, most hospitals and clinics are located in urban areas in the prefecture. Moreover, nighttime emergency services for ophthalmology are provided at the University of Yamanashi Hospital only, meaning that only one eye specialist works the graveyard shift in the prefecture. In FY2005, 6,314 patients visited the university hospital for nighttime emergency services. As figure 3 shows, ophthalmology visits are the second most frequent. Because patients have no alternative in Yamanashi prefecture, all patients with eye problems must visit the university hospital at nighttime, with the associated travelling time and cost. Therefore, teleophthalmology applications can provide cost-effective services to potential patients in the prefecture's mountain areas.

Project Status

We have been working on iterative design of the EyeViewRobo system with human-centered design approaches [5]. The first version demonstrated how the system is used in the form of a paper-based prototype. The second version was designed as a rapid working version of the prototype by modifying current technologies such as a standard slit lamp microscope. The third version is a refined version of the prototype intended for field tests. The current version of the system is at the fourth iteration stage. It was implemented for clinical tests at a university hospital and at a regional emergency medical service center.

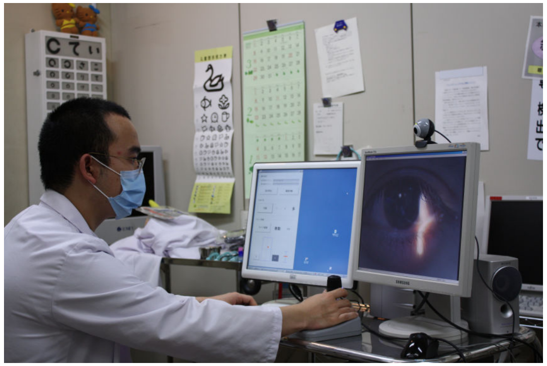


figure 4. Doctor's terminal for the current version of EyeViewRobo.

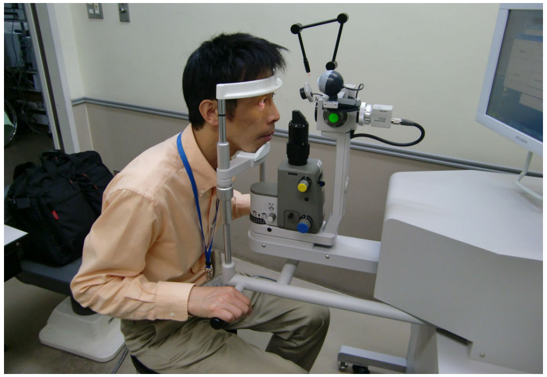


figure 5. Remote-control slit lamp microscope for the current version of EyeViewRobo.

Conclusion

This paper presented a remote-control slit lamp microscope system to support real-time tele-ophthalmology. Our project addresses regional problems of a shortage of medical doctors. We are developing clinical tests both at the university hospital and at a regional emergency medical service center.

Acknowledgements

We wish to thank Takagi Seiko, Corp., Actron, Corp., and Fits Design, Corp. for developing the remote-control slit lamp microscopes. This project is partially supported by the Grant-in-Aid for Scientific Research from the Ministry of Education, Culture, Sports, Science and Technology, and by the Strategic Information and Communications R&D Promotion Programme, 2008, in the Ministry of Internal Affairs and Communications.

References

[1] Kyodo Tsushin News, Shortage of rural doctors worsens, April 21, 2009 (translated in English by Shukan ST, May 1, 2009).

[2] Li, H. Telemedicine and ophthalmology, Survey of ophthalmology, Vol. 44, 61-72, 1999.

[3] Go, K., Ito, Y., and Kashiwagi, K. Interaction Design of a Remote Clinical Robot for Ophthalmology, LNCS 4557, Springer-Verlag (2007), 840-849.

[4] DVTS Consortium, http://www.dvts.jp/en/ (Last accessed: Jan 12, 2010).

[5] Go, K., Kashiwagi, K., Tanabe, N., Horiuchi, K., and Koike, N. Iterative Design of Teleoperative Slit Lamp Microscopes for Telemedicine, Proc. 4th Int'l Conf. on Pervasive Computing Technologies for Healthcare 2010 (accepted for publication).

Health Systems for Local Communities

Andrea Grimes
Georgia Institute of Technology
85 5th St. NW
Atlanta, GA 30308
agrimes@cc.gatech.edu

Abstract

I describe the value of designing health systems for members of geographically defined communities. First, I discuss my design and evaluation of two such systems, EatWell and Community Mosaic. I then highlight the implications of helping users produce and consume content in these community-focused applications. I present this work to spur future research on creating systems that promote healthy behaviors in the community context.

Keywords

Health, community, nutrition.

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Introduction

HCI researchers have explored the implications of applications that promote wellness in the context of social units such as friends [2] and coworkers [5]. Other research has looked at how online health communities can provide social support for people coping with illness over geographic distances [1]. In my ongoing work I have designed and evaluated systems that address wellness in yet another social context: the local community. I define *community* geographically, whereby members are people who live in, work in or frequent the same general geographic area. In particular, my research has focused on African Americans in low-income neighborhoods in Southwest Atlanta, GA, USA because of the extreme diet-related health disparities that exist in this context (e.g. diabetes disproportionately affects this population) [4].

In this abstract, I first overview two systems that I have designed to promote healthy eating habits in the local community context: EatWell and Community Mosaic. I will then briefly describe how through the evaluation of these systems I am exploring the implications of helping end-users produce and consume content in such community-focused health applications. I offer these reflections as a starting point for discussion on how researchers can create future applications that promote health in the community context.

EatWell and Community Mosaic

I have designed two community-focused systems, EatWell and Community Mosaic that help people gain strategies for how to eat healthfully in their local neighborhoods. EatWell is a mobile phone application that allows users to create short audio stories describing how they have tried to eat healthfully locally (e.g. at fast food restaurants or when cooking at home) and listen to the stories that others in their community have created. My three-week field study of EatWell showed the value of using technology to raise awareness about the different ways in which it is possible to eat healthfully within one's local context [3].

I am currently in the final stages of designing the Community Mosaic (CM) system. CM differs from EatWell in that it 1) leverages the mediums of photography and text to allow people to capture and convey their experiences with trying to eat healthfully, 2) makes these experiences more publicly visible and 3) provides mechanisms for people to visualize and react to the content that the community creates. With CM, people will use their existing cell phones to create messages documenting how they are trying to eat healthfully (e.g. by visiting the farmers' market). These messages will consist of a photograph and/or a text description. Once the user sends the message to the CM system phone number, CM will create a visualization of this content on a large, public touch-screen monitor. This monitor will be installed in the lobby of a community center and thus anyone who walks by the display will be able to view the shared content, share their reactions and view the reactions of others.

In the upcoming months, I will conduct a longitudinal mixed-method empirical study at a community center in Atlanta, GA. Through this evaluation I will analyze how people's eating habits are actually impacted by gaining increased access to the experiential knowledge of others in the local community. Health behavior theories indicate that the availability of resources for engaging in healthy behaviors are tied to one's ability to engage in positive behaviors [7]. Thus, applications that make these resources more visible have the opportunity to be critically useful. Through my evaluation of this application, I will gain insight into the relative benefits and drawbacks of my two technological approaches and subsequently derive implications for future work. In particular, I will compare the impact of audio (EatWell), photography and text (Community Mosaic) as mediums for conveying information about health resources. I will also examine the impact of making this information accessible on a public display (Community Mosaic) versus a mobile device (EatWell).

Thus far, I have described how EatWell and Community Mosaic facilitate the sharing and visualization of health information. In the following sections, I focus on the *producers* and *consumers* of that content, and discuss the importance of 1) considering how to empower users to share (produce) their experiences and 2) examining how consuming the shared content affects their health-related attitudes.

Empowering Lay Health Advisors

To enable the increased awareness of community resources, my approach has been to encourage community members to share their experiences with others. My approach is similar to the Lay Health Advisor (LHA) method that is often used in the field of public health [6]. With this approach, everyday people are given support to advise others in their community of how to live healthfully. LHAs are typically encouraged to interact in-person with community members; in contrast my research explores the benefits and drawbacks of a technologically mediated approach. One potential benefit of taking such an approach is that technology has the potential to expand the scope with which people can share their experiences and their thoughts on how to engage in healthy behaviors.

My approach further differs from the classical LHA model because CM and EatWell do not provide the formal training that LHAs typically have for helping others to live healthfully. Instead, the scaffolding for what to share and say happens through the social norms that arise in the community of users, much like what often occurs in online health communities. However, while online health communities typically bring together users from diverse geographic contexts, my systems support people in sharing experiences with those in their local communities. Indeed, in my EatWell user study I found that facilitating the sharing of experiences in a local community setting is a uniquely valuable approach. For example, I found that by using EatWell, many participants felt a sense of community empowerment [3]. They indicated that the stories that participants shared inspired a feeling of hope in the face of the extreme health disparities that exist in their neighborhoods. This hope was facilitated as individuals became aware that there were other people, like them, in their local community who were concerned about eating healthfully, and who cared enough about improving the state of African American health to share their personal experiences with trying to eat healthfully.

I will further explore the impact of helping people share health-related experiences in the community setting through my upcoming evaluation of CM. In particular, I will more closely analyze to what extent people feel that they can and are improving the health of their community by sharing their thoughts on nutrition, and how such attitudes affect their contributions to the system.

Like any virtual community dependent upon user generated content, one challenge that I am addressing in the design of CM is how to help users feel a sense of confidence that they are qualified to share their experiences. As CM publicly displays visualizations of the content that users share, in my evaluation of CM, I will examine to what extent these visualizations help content creators feel a sense of pride in their nutrition-related knowledge and experiences, and to what extent the visualizations affect their desire to share information. Through my work, I will derive implications for how future research can use technology to facilitate lay health advising in local communities, and the ways in which users adopt and react to such applications.

Affecting Perceptions of the Community

In addition to designing systems that empower community members to share their healthy eating strategies, I am also examining how using these systems affects the ways in which people conceive of their community. In particular, with my upcoming CM user study, I will study to what extent seeing other community members’ strategies affects how possible users feel it is to make healthy eating decisions within their community. Furthermore, I will also examine how confident they feel that they can eat healthfully themselves. These are particularly important concerns within my target population, as I am studying a low-income community in which people can face increased challenges with trying to eat healthfully. However, beyond my own research, I argue that it is critical that future work consider how to best address these concerns because health behavior theories indicate that believing that it is feasible to eat healthfully in one's environment is an important indicator of whether or not one will actually engage in healthy behaviors [7].

Conclusion

Community-focused health interventions are common within medical fields such as public health [6]. While many of those interventions are programmatic (e.g. educational workshops), I argue that future research should explore how technology can be leveraged to promote healthy living in the community context. In this abstract I described two examples of such systems, and the initial success that I have shown through my evaluation of EatWell [3] suggests that this is an approach with much potential for positive impact. In addition, I have suggested two ways in which future health systems can promote healthy behaviors in the community context: by empowering individuals to feel confident sharing their experiences for the benefit of others, and affecting perceptions of how possible it is to engage in healthy behaviors in one's community. My goal is that this abstract will help spur discussion and future work on designing technologies that promote healthy behaviors in the community context. I believe that the resonance of this research with the community-based approaches used in healthcare fields, together with the growing interest in HCI to develop health applications for everyday people, will allow my work be of interest to the diverse attendees of the WISH workshop.

Acknowledgements

I thank Beki Grinter, Vasudhara Kantroo, Mansi Sharma, Heerin Lee and Blanche Payne. I also thank the NSF, Microsoft Research, Yahoo! Research and Humana for their support of this research.

References

[1] Barak, A., Boniel-Nissim, M. and Suler, J., "Fostering empowerment in online support groups," *Computers in Human Behavior* 24, 5 (2008), 1867-1883.

[2] Consolvo, S., Everitt, K., Landay, J.A., "Design Requirements for Technologies that Encourage Physical Activity," *CHI'06* (2006), 457-466.

[3] Grimes, A., Bednar, M., Bolter, J.D. and Grinter, R.E., "EatWell: Sharing nutrition-related memories in a low-income community," *CSCW'08* (2008), 87-96.

[4] Hargreaves, M.K., Schlundt, D.G., Buchowski, M.S., "Contextual factors influencing the eating behaviours of African American women: a focus group investigation.," *Ethnicity & Health* 7, 3 (2002), 133-147.

[5] Lin, J.J., Mamykina, L., Lindtner, S., Delajoux, G. and Strub, H.B., "Fish'n'Steps: Encouraging Physical Activity with an Interactive Computer Game," *Ubicomp'06* (2006), 261-278.

[6] Plescia, M., Groblewski, M. and Chavis, L., "A Lay Health Advisor Program to Promote Community Capacity and Change Among Change Agents," *Health Promotion Practic*e 9, 4 (2008), 434-439.

[7] Stokols, D., "Translating Social Ecological Theory into Guidelines for Health Promotion," *American Journal of Health Promotion* 10, 4 (1996), 282-298.

FitBaby: Using Observations of Daily Living to Improve the Health of Preterm Infants and Their Caregivers

Gillian R. Hayes
Department of Informatics
University of California, Irvine
gillianrh@ics.uci.edu

Karen Cheng
Department of Psychiatry
Charles Drew University
karencheng@cdrewu.edu

Sen Hirano
Department of Informatics
University of California, Irvine
shirano@ics.uci.edu

Sunyoung Park
Department of Informatics
University of California, Irvine
sunyp1@uci.edu

Dana Gravem
School of Medicine
University of California, Irvine
dgravem@uci.edu

Julia Rich
UCI Medical Center
University of California, Irvine
jkrich@uci.edu

Dan Cooper
Institute for Clinical &
Translational Science
University of California, Irvine
dcooper@uci.edu

Abstract

Capture and access technologies to collect and report Observations of Daily Living (ODLs) can strengthen support of caregivers at home. We present a mobile capture and access application for parents of newborns conducting in-home assisted exercise routines: FitBaby. This system enables parents to log ODLs through input forms on SmartPhones and automatic collection of sensor-based data. The system allows for real-time prompting and feedback to caregivers. This paper describes the challenges to caring for preterm infants and how ODLs, specifically those collected by FitBaby, can support these activities and improve health outcomes.

Keywords

FitBaby, Preterm Infants, Capture and Access

ACM Classification Keywords

J.3 Computer Applications.Life and Medical Sciences; H.5.2 Information Systems.Information Interfaces and Presentation

Introduction

Over the past two decades, the incidence of preterm births (born at less than 37 weeks of gestation) has increased dramatically and in 2002 accounted for 12% of live births in the US [8]. Premature birth is associated with long term health impairments including neurological and cognitive deficiencies, chronic lung disease, and altered growth patterns of lean, fat, and bone tissues [6]. Furthermore, in Hack et al's study, 64% of low birth weight (LBW) children at age eight demonstrated one or more limitations, including conditions such as asthma, impaired vision, and

---

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

cognitive disabilities [7]. Other studies suggest that an improvement in care for these LBW infants in the early months is likely to reduce the incidences and burdens of their chronic conditions over the lifespan [14, 15].

A primary barrier to care to LBW children is ensuring the continuity of care from hospital to the home. Upon discharge, standard procedures are to educate caregivers about how to care for their LBW infant and then to discontinue all support and care from NICU providers to the caregiver and the infant. Responsibilities for clinical care are transferred to the child's pediatrician, who will often request a visit within the first three weeks after discharge. In addition, county regional centers have responsibility for monitoring the progress of these at-risk children after discharge, but it is common for regional centers to take up to six weeks to initiate contact with families.

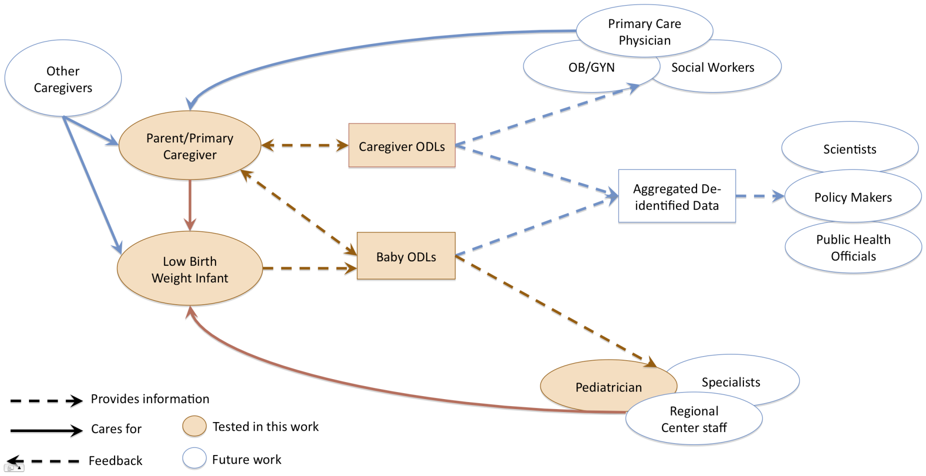


fig 1: information transfer model for ODLs for LBW infants and their caregivers

The transition to home can be very stressful for caregivers (called parents from here on). They suffer from greater sleep deprivation than caregivers of non-LBW babies, because LBW babies have particularly challenging feeding schedules and needs [16] and sleep for shorter durations at a time [4]. The physical demands of caring for an LBW baby is compounded by the stress of not knowing whether they are properly caring for their baby. Caregivers are also more likely to experience depression and isolation from their social support networks, at least in the short term [5]. The lowered emotional well-being of parents may impact their ability to give quality care to the baby.

Related Work

Mobile and ubiquitous computing solutions for healthcare have become prevalent in both research and commercial efforts. These systems and applications have the potential to improve patient care in a variety of locations for a variety of ailments, improving the level of care offered and the efficiency with which it is delivered. In response to this growing concern about chronic health, major research efforts have focused on "smart home" technologies.

The increased prevalence of chronic health conditions, however, is not just at the older end of the lifespan. As survival rates from acute events in very young children rise, chronic health conditions in children have also increased. Thus, researchers have begun to examine particular issues surrounding chronic health conditions for children. Of particular interest to this work are projects related to enabling families to cope better with the chronic illness of a child (e.g., [9]) and to documenting early milestones for child development (e.g., [12]). Findings indicate that families who are educated about a condition and involved with the management of it can better cope [3]. In part, this education may decrease stress and anxiety for the

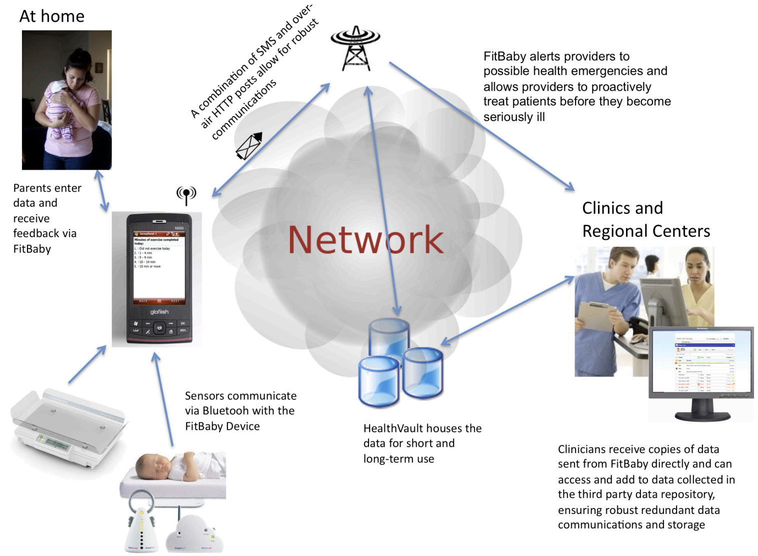


fig 2: (above) technical architecture for FitBaby system (below) sample screen of a log entry.

Minutes of exercise completed today:

1. ○Did not exercise today
2. ○1 - 4 min
3. ○5 - 9 min
4. ○10 - 14 min
5. ○15 min or more

caregivers as they become more expert and involved in the care [10]. These findings also indicate that greater education and involvement in care correlates to higher rates of compliance with treatment regimens [3]. These results mirror findings with adult chronic diabetes patients who showed increased locus of control and increased compliance when better educated and able to test data about their health themselves [13]. They also further support our interest in developing recording and analysis technologies that will directly involve parents and their families in understanding and treating the conditions of pediatric patients.

FitBaby

FitBaby is a mobile system for collecting observations of daily living (ODLs) for premature infants and their caregivers after release from the hospital. ODL data is collected by both manual (diary entries, photos and videos recorded using the mobile phone) and automatic means (wireless sensors, including scales and crib monitors connected to the phone). These data are recorded both on the phone and over the network to enable clinicians to view data at a distance.

FitBaby supports collection of ODLs in several ways. The system generates an alert if a log has not been completed by a prescribed time. This feature was found to be very useful during an initial pilot study of FitBaby and improved the frequency of parents completing the logs. We are currently developing new features that will reflect the exercise data back to the caregiver through simple visualizations. These interfaces will include glanceable displays [2] on the mobile phones as well as the ability to "drill down" into the data on a more traditional desktop platform. Reflecting this kind of information back to them can enable greater feelings of self-efficacy and influence on the health of their babies [13].

This combination of automatically and manually collected data will enable us to record a significant amount of information about infant progress without substantial burden on the families. Furthermore, our innovative visualizations and reporting to the parents and clinicians will enable both overview and detailed reporting on infant progress and development.

Conclusions and Future Work

This work provides multiple significant contributions, both in terms of research results and the software systems themselves. First, through interviews and fieldwork, we have begun to understand the design requirements for supporting preterm and typical infant care at home. Second, the FitBaby system itself serves as a potential model for enabling other computing researchers to design and develop new related systems for the chronic care of children. Our current and future work focuses on the refinement and iterative design of the FitBaby system and its evaluation *in situ* through deployment to families and clinicians of LBW infants.

Acknowledgements

We are grateful to the nurses in the Neonatal Intensive Care Unit at UCI MC, whose work with an earlier prototype has proven invaluable to our new designs. We thank the participants in the various studies that have led to this work. This work was supported by an NSF CAREER grant #0846063. We thank Sheba George and Khai Truong for comments on earlier versions of this paper.

Citations

[1] Eliakim A and Nemet D. 2005 Osteopenia of prematurity - the role of exercise in prevention and treatment. Pediatr Endocrinol Rev 2: 675-682.

[2] Consolvo, S., McDonald, D. W., Toscos, T., Chen, M. Y., Froehlich, J., Harrison, B., Klasnja, P., LaMarca, A., LeGrand, L., Libby, R., Smith, I., and Landay, J. A. 2008. Activity sensing in the wild: a field trial of ubifit garden. *Proc. CHI '08.* 1797-1806.

[3] Deaves, D. 1993 An assessment of the value of health education in the prevention of childhood asthma. *Journal of Advanced Nursing*. 18, 354-363.

[4] FamilyDoctor.org, Caring for Your Premature Baby, http://familydoctor.org/online/famdocen/home/children/parents/infants/283.html. Accessed May 2009.

[5] Gennaro S. 1988 Postpartal anxiety and depression in mothers of term and preterm infants *Nursing Research*, 37(2): 82-85.

[6] Greer FR. 2007 Long-term adverse outcomes of low birth weight, increased somatic growth rates, and alterations of body composition in the premature infant: review of the evidence. J Pediatr Gastroenterol Nutr 45 Suppl 3: S147-S151.

[7] Hack, M., Taylor, H.G., Drotar, D., Schulchter, M., Cartar, L., Andreias, K., Wilson-Costello, D., and Klein, N. 2005 Chronic Conditions, Functional Limitations, and Special Health Care Needs of School-aged Children Born with Extremely Low-Birth-Weight in the 1990s *Journal of the American Medical Association.* 294(3), 318-325

[8] Hamilton BE, Martin JA and Sutton PD 2003 Births: Preliminary data for 2002. *National Vital Statistics Repository.* 51, 1-20.

[9] Jeong, H., Park, S., and Zimmerman, J. 2008. Opportunities to support parents in managing their children's health. In *CHI '08 Extended Abstracts.* 3225-3230.

[10] Jerrett, M. and Costello, E. 1996. Gaining control: Parent's experiences of accommodating children's asthma. *Clinical Nursing Research*. 5(3), 294-308.

[11] Kaushik P, Intille S, Larson K. Observations from a Case Study on User Adaptive Reminders for Medication Adherence. Proc. PervasiveHealth. 2008; 250-253.

[12] Kientz, J. A., Arriaga, R. I., Chetty, M., Hayes, G. R., Richardson, J., Patel, S. N., and Abowd, G. D. 2007 Grow and know: understanding record-keeping needs for tracking the development of young children. In *Proc. CHI’07.* 1351-1360.

[13] Mamykina L, Mynatt ED and Kaufman DR. 2006 Investigating health management practices of individuals with diabetes. *Proc. CHI’06* ACM, New York, NY, 927-936.

[14] Olds D. 2006 Progress in improving the development of low birth weight newborns. Pediatrics. Mar;117(3):771-80.

[15] Ramey CT, Bryant DM, Wasik BH, Sparling JJ, Fendt KH, LaVange LM. 1992 Infant Health and Development Program for low birth weight, premature infants: program elements, family participation, and child intelligence. Pediatrics. Mar;89(3):454-65.

[16] Samour PQ and Helm KK. 2005 Handbook of pediatric nutrition, Edition Three. Jones & Bartlett Publishers.

HCI Research Direction for Mediating Communication in Healthcare

Hee Young Jeong
School of Interactive Computing
Georgia Institute of Technology
Atlanta, GA 30332 USA
hyj@gatech.edu

Rosa I. Arriaga
School of Interactive Computing
Georgia Institute of Technology
Atlanta, GA 30332 USA
arriaga@cc.gatech.edu

Tae Jung Yun
School of Interactive Computing
Georgia Institute of Technology
Atlanta, GA 30332 USA
tjyun@gatech.edu

Gregory D. Abowd
School of Interactive Computing
Georgia Institute of Technology
Atlanta, GA 30332 USA
abowd@gatech.edu

Adebola Osuntogun
School of Computer Science
Georgia Institute of Technology
Atlanta, GA 30332 USA
bola@gatech.edu

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Abstract

There is an increasing need for Human Computer Interaction (HCI) research in Healthcare Information Technologies (HIT). In this workshop, we present HCI research opportunities for mediating communication between healthcare professionals and their patients based on our conceptual diagram of HIT. To present the opportunities clearly, we provide four ongoing research projects on pediatric asthma management.

Keywords

HCI Research, Healthcare communication, Pediatric asthma

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

Healthcare Information Technology (HIT) is rapidly growing for improving the quality of public health. It plays an important role in recording, transferring, and providing appropriate healthcare information. Particularly for transferring healthcare information between medical professionals and their patients, all relevant stakeholders such as doctors, nurses, medical sociologists, and technology developers need to better understand the human and social aspect of the healthcare ecosystem. Thus, HCI researchers should pay attention to interactive systems for mediating healthcare communication. HCI research can contribute to engage medical professionals with their patients for facilitating healthcare communication in effective ways.

In this workshop paper, we present a conceptual diagram about the role of HIT between medical professionals and patients since medial professionals' goals are to improve their patients' health status. Based on the diagram, we suggest HCI research direction including opportunity examples for developing HIT as communication mediators. In order to present our idea concretely, we use four ongoing research examples from pediatric asthma. This domain presents a good test bed for HIT because asthma is one of the most common chronic diseases, and children's healthcare issues are deeply involved with their family's ability to communicate with their physicians..

Concept

Within healthcare communication contexts, a basic conceptual diagram shows major roles of HIT focused on two stakeholders, medical professionals and patients (Figure 1). This diagram aims to explore HCI research opportunities and future direction in healthcare.

Representative examples of HIT are Electronic Medical Records (EMR) for medical professionals and Personal Health Records (PHR) for patients. To collect accurate healthcare information in EMR and PHR, HIT also needs to support healthcare communication systems. Collaborative healthcare systems are necessary for mediating communication between medical professionals and patients and are especially important in chronic illness management, Therefore, it is critical for HIT researchers and their collaborators to understand each stakeholder's need and consider human factors and social aspects [1].

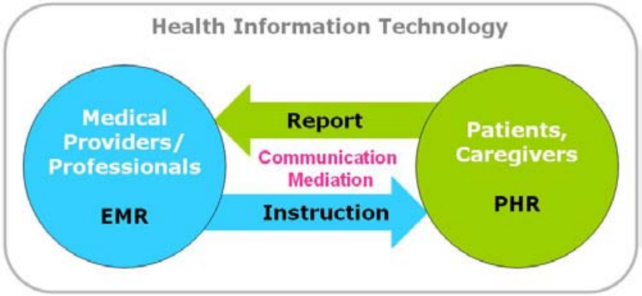


Figure 1. A conceptual diagram about the roles of Health Information Technology

In terms of communication mediation, there are two different information transfer flows. One is from patients to medical professionals, and the other one is from medical professionals to patients. From the patients' perspective, reporting their current health status is key in communicating with medical professionals. HIT for patients' health report can support medical professionals' decision making process for accurate diagnosis and appropriate treatment strategies. On the other hand, after medical professionals diagnose patients' health status, they usually provide lots of treatment information in a short time. The patient now has to manage information given by the physician regarding medication prescription(s), home medical supplies, and daily health monitoring strategies. Thus, HIT can play an important role in providing instructions to patients and educating them with detailed information.

Results: Ongoing Research

The HIT diagram reflects our four ongoing research projects in pediatric asthma management.

In-depth interviews and technology probes for "PHR"

In order to understand each stakeholder's need and develop easy access health systems based on the need, ethnographic research is necessary. Although asthma assessment research in medical field is active [6], looking for HIT opportunities from HCI perspective is still our assignment since the human and social aspect of HIT are critical. From patients' views, what kinds of technologies are easy to use for asthmatic children' in their everyday lives and why? Thus, we conducted in-depth interviews with nine families and technology probes study for four weeks with three families who have asthmatic children. Finally, in-depth interviews gave us three implications in developing HIT; managing asthma triggers by capturing experience, sensing activities for self management, and inducing collective efforts to increase asthma awareness. In the probes study, we found that the level of technological support should change based on the patient's disease severity.

Shadowing of healthcare specialists for "EMR"

To understand medical professionals' needs, we shadowed them at a local pediatric pulmonology practice. Since this group of healthcare providers sees the children with severe asthma, the communication between parents and physician is especially significant. Results from the observation indicate the potential for improving asthma care by leveraging available technology (EMR) to support physician monitoring of patients by the introduction of alert systems, the clinic initiated communication with patients and providing opportunities for physician reflection on patient status.

Short Message Service (SMS) system for "Report" by increasing symptom awareness and disease knowledge

By using mobile technologies, patients can report their health status to medical professionals anytime and anywhere. For example, SMS is useful in monitoring asthma patients' health status [2]. We are currently conducting a SMS system study that aims to investigate whether increased symptom awareness enhances asthma management in patients and physicians. During a four to six month period, twenty children with moderate to severe asthma will receive asthma symptom related questions and educational content through SMS from their cell-phones. Based on their responses to the questions, physicians can monitor children's asthma status and take proper actions. This is the first study that investigates the effect that communication between scheduled medical visits has on both patients and physician management strategies.

Sustainable interactive game for "Instruction"

The goal of giving treatment instructions to patients is to encourage them to effectively manage their health. Specifically for asthmatic children, interactive multimedia games are promising technologies in educating self-management [3]. However, most internet-based health educational games are too instructional and boring for children. Thus, we are developing a sustainable interactive game with asthma educators at a non-profit partnership. Our game reflects asthmatic children's real life environment for educating about asthma triggers and medical devices. Scalability and customization are major consideration factors in developing the sustainable game since it is flexible enough that the educational content could be changed to address other health issues, e.g., diabetes.

Implications for the Interdisciplinary Community

From our ongoing research experience, it turns out that collaboration with interdisciplinary communities is extremely important. These are our three implications for future HCI research direction in healthcare.

- Collaborative formative study: Patient centered approach is primary in healthcare communication for chronic illness management [5]. To understand patients' need, collaborative formative studies with medical professionals are one of the best ways for efficient time management and the quality of the study. Medical professionals can provide basic healthcare knowledge that HCI researchers need to know, and HCI researchers give them new technological tools that can provide insights on ways to better understand patients.
- Tele-monitoring for bridging a communication gap: Proper usage of tele-monitoring and tele-health is a major key for effective healthcare communication [4]. Particularly for bridging a communication gap based on the human and social aspect. Nurses play a pivotal role because they are, often times, communication facilitators between patients and physicians. Data collected via tele-monitoring/health studies can also provide important insights for the informatics community and suggest efficient ways of transferring healthcare information between relevant stakeholders.
- Persuasive technology for enhancing self-management: Persuasive technology is significant in enhancing patient's self-management skills. For example, healthcare educators including school nurses, teachers, and coaches can collaborate with HCI researchers and instructional designers in providing useful education methods at the children's level. In addition, it is helpful for developing sustainable persuasive technology to work with medical sociologists and social workers because they know how to enhance social interaction between all stakeholders.

Future work

During the WISH program, we will empower the research network to improve HCI research in the medical arena by sharing our research results.

Reference

[1] Alpay, L., Toussaint, P., and Zwetsloot-Schonk, B. Supporting healthcare communication enabled by Information and Communication Technology: can HCI and related cognitive aspects help?. *In Proc. Dutch directions in HCI 2004*, ACM Press (2004), 12

[2] Anhøj, J. and Møldrup, C. Feasibility of Collecting Diary Data from Asthma Patients through Mobile Phones and SMS (Short Message Service): Response Rate Analysis and Focus Group Evaluation from a Pilot Study. *Journal of Medical Internet Research 6*, 4 (2004), e42

[3] Lieberman, D.A. *The researcher's role in the design of children's media and technology, The design of children's technology.* Morgan Kaufmann Publishers, San Francisco, CA, USA, 1998.

[4] Robinson, T.N., Patrick, L., Eng, T.R., and Gustafson, D. An Evidence-Based Approach to Interactive Health Communication. *JAMA 280*, 14 (1998), 1264-1269

[5] Thorne, S.E., Harris, S.R., Mahoney, K., Cona, A., and McGuinness, L. The context of health care communication in chronic illness. *Patient Education and Counseling 54*, 3 (2004), 299-306

[6] Valerio, M., Cabana, M.D., White, D.F., Heidmann, D.M., Brown R.W., and Bratton, S.L. Understanding of Asthma Management, Medicaid Parents' Perspectives. *CHEST 129*, 3 (2005), 594-601

Sensor-Integrated Geometric Blocks:

Towards Interactive Play-Based Assessment of Young Children

Donghwa Jeong
Department of Mechanical and Aerospace
Engineering
Case Western Reserve University
10900 Euclid Avenue
Cleveland, OH 44106 USA
donghwa.jeong@case.edu

Endri Kerci
Department of Mechanical and Aerospace
Engineering
Case Western Reserve University
10900 Euclid Avenue
Cleveland, OH 44106 USA
endri.kerci@case.edu

Kiju Lee
Department of Mechanical and Aerospace
Engineering
Case Western Reserve University
10900 Euclid Avenue
Cleveland, OH 44106 USA
kiju.lee@case.edu (Corresponding Author)

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

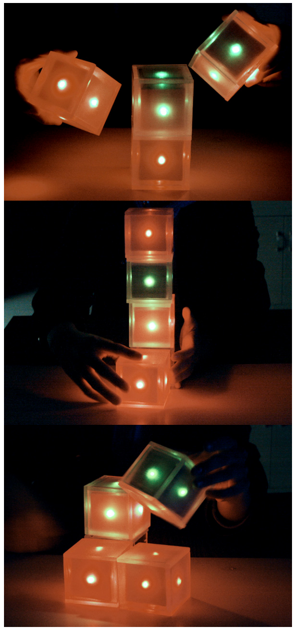


figure 1. Conceptual design of SIG-Blocks consisting of four interactive cubes

Abstract

In this paper, we present a conceptual framework and a physical prototype of sensor-integrated geometric blocks (SIG-Blocks) for automated play-based assessment of cognitive and fine-motor skills. SIG-Blocks enable remote and real-time monitoring of a person's behavior and performance during play through integrated sensors and wireless communication established between the blocks and a host computer. This paper first describes the conceptual and design framework and then presents the prototype of SIG-Blocks with an interactive graphical user interface (GUI). In addition, to provide a computational method for analyzing complexity associated with play, a quantitative measure of play complexity given a set of geometric blocks is presented based on an information-theoretic approach.

Keywords

Play-based assessment, remote monitoring, geometric blocks, tangible interface, child development

ACM Classification Keywords

H.5.2 Information interfaces and presentation: User Interfaces

General Terms

Design, Experimentation, Theory

Introduction

Children make significant progress in cognitive, social, and emotional capabilities as they grow physically. These early years of a person's life are crucial for learning how to perceive and interact with his or her external environment [1]. During the infancy and preschool periods, children play with various types of toys that stimulate intellectual and physical development. Among such toys, geometric blocks are widely used by children across broad age groups. These toys, unlike other toys or games, are well defined for observing manipulation patterns and developmental transformations during play. They are also well suited for enhancing and learning fundamental mathematics, physics, and general problem solving skills. For these reasons, geometric blocks are often employed in education and clinical practice as a play-based tool for assessing cognitive and learning capability [2]. In addition, experiments using simple geometric blocks demonstrated infants' consistent understanding of how to rotate objects to make them fit into an aperture beginning at the age of two [3]. Enabling up-to-date technology, Mitsubishi Electric Research Laboratories developed self-described building blocks (MERL's blocks), which detect how they are connected to their immediate neighbors to describe the assembled configuration [4]. AlgoBlock with a tangible programming language and Cognitive Cubes are also examples of technology-enhanced geometric blocks with computer-human interfaces [5, 6].

In this paper, we present a conceptual framework and a physical prototype of sensor-integrated geometric blocks (SIG-Blocks) that provide a novel procedural and methodological tool for automated play-based assessment of children's cognitive and intellectual skills. Furthermore, they are fully individual homogeneous modules without a specific master block, and each block communicates with a computer independently and wirelessly. This paper also presents an information-theoretic method to analyze the complexity associated with play, given a set of geometric blocks. This method is then applied to the design of a physical prototype.

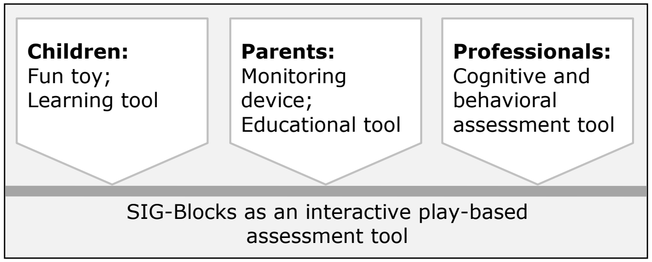


figure 2. Conceptual overview: SIG-Blocks target three groups of end-users, children, parents and professionals.

Conceptual and Design Framework

Despite the great potential for wide applications and a large number of existing end-users, commercially available geometric toys are not comprehensively designed for research purposes. Without any built-in feedback mechanism in these toys, an external device and/or a person is needed to monitor the child's behaviors during the entire play. SIG-Blocks provide real-time feedback and monitoring capabilities by integrating state-of-the-art technology, including sensors and wireless communication. This new generation of toys will be fun games for children, a self-assessment and educational tool for parents or teachers, and an advanced research or diagnostic device for related professionals (figure 2).

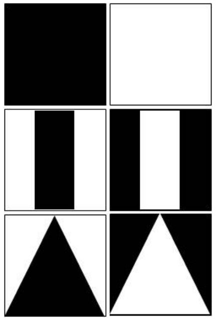


figure 3. Images of re-attachable cover cards with 4-, 2-, or 1-fold symmetry

In the assessment using SIG-Blocks, a child will be given a set of SIG-Blocks and a series of goal assembly configurations to accomplish by manipulating the blocks. Target information to be acquired during play include the following: ***a***. overall activities; ***b***. step-by-step completion times; ***c***. assembly or manipulation patterns; and ***d***. performance changes through repeated play and/or varying levels of support provided to a child. Hand manipulations required to play with geometric blocks are broadly categorized into insertion, reconfiguration, and assembly. The SIG-Blocks presented in this paper is designed for assembly tasks.

Play Complexity: In order for SIG-Blocks to be implemented as an assessment tool, they should be neither too difficult nor too easy to effectively capture individual differences. To provide additional computational data for analysis, we define *play complexity* associated with geometric blocks based on information-theoretic entropy. Entropy is a statistical tool for quantifying the amount of uncertainty or information associated with an event that involves a random variable(s). We first assume that each set of geometric blocks is intended for a specific type of play (e.g., insertion, reconfiguration or assembly) and the final objective is well defined. Then, the *play complexity* is defined based on the entropy changes in geometric blocks during play:

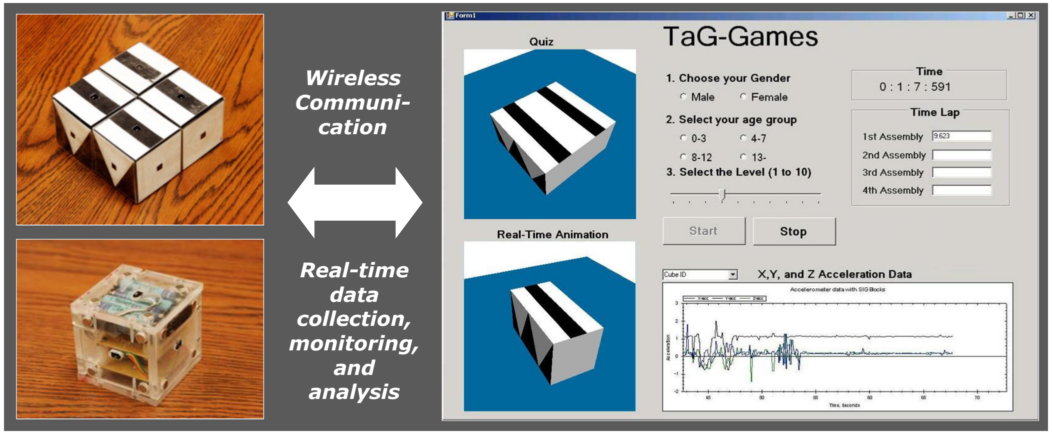
$$\mathbf{C}^{play} = \mathbf{H}^{initial} - \mathbf{H}^{final}$$

where $\mathbf{H}^{initial}$ is the entropy for a given set of geometric blocks before play and $\mathbf{H}^{final}$ is the entropy computed for the blocks after a child accomplishes the goal. In other words, $\mathbf{H}^{initial}$ implies the amount of uncertainty initially existing in the blocks and $\mathbf{H}^{final}$ is the amount of uncertainty remaining after play. Thus, the difference between the two indicates the amount of uncertainty reduced, or information handled, by a child manipulating the blocks to achieve the goal configuration. The play complexity can be used to design SIG-Blocks with varying levels of difficulty in terms of the amount of information required to complete the task. We note that a higher value of $\mathbf{C}^{play}$ implies a more difficult level of play.

Prototype

Hardware: SIG-Blocks consist of four homogeneous modules. Each block contains a microprocessor, a wireless communication module, and several sensors including a tri-axial accelerometer and six optical sensors. An accelerometer provides rotational information for each block, and six reflective optical sensors detect the assembly configuration of the blocks. Each SIG-Block has a unique ID that enables communication with the host computer independently. The blocks presented in this paper are identical to each other; however, replacing the outer covers with different shapes or figures can easily change the outer design of each block. Therefore, SIG-Blocks can be used for various types of experiments with varying play complexity while significantly reducing the manufacturing time and cost. Each block is self-powered with four 1.2 Volts rechargeable batteries where the running time is between 4 to 5 hours. The data collected by the host computer can be read in real time via wireless communication. 3D graphic models of SIG-Blocks are displayed and shown along with collected sensor data in a GUI designed using OpenGL and C#.

Re-attachable cover images used in the physical prototype are shown figure 3. These six images are placed in the surfaces of each block. Using the play



1. Choose your Gender
○ Male ○ Female
2. Select your age group
○ 0-3 ○ 4-7
○ 8-12 ○ 13-
3. Select the Level (1 to 10)

Time
0 : 1 : 7 : 591

Time Lap
1st Assembly 9.623
2nd Assembly
3rd Assembly
4th Assembly

figure 4. SIG-Blocks and the interactive GUI: The layout and display components of the GUI can be easily customized depending on each use.

complexity defined in this paper, $\mathbf{C}^{play}$ for our prototype can be calculated based on the number of possible orientations and assembly configurations, such that $\mathbf{H}=\log_2 W$, where W is the number of all distinctive configurations [7]. Depending on the goal assembly configuration (shown as "Quiz" in figure 4), $\mathbf{C}^{play}$ can vary from 10.34 to 22.92.

User Interface: The GUI provides a 3D animation of the blocks and sensor data (orientation and assembly detection) in real time. The collected data is stored in a host computer and can be easily retrieved at any time for further data analysis. Figure 4 shows our initial user interface displayed on a computer screen. The game interface animates the 3D models on the left side of the screen and shows the real-time rotational movements and assembly configurations of SIG-Blocks; time for each assembly is recorded on the right side. The graph at the bottom shows tri-axial acceleration data simultaneously. The game level can be selected by a player or an assessor.

Discussion and Future Work

We presented a conceptual framework and a physical prototype of SIG-Blocks as a means for a new automated and procedural method for play-based assessment. The developed system has been tested in a laboratory setting to verify technical feasibility. In order for the proposed technology to be used beyond the level of currently available assessment tools, extensive and large-scale experiments would be necessary.

References

[1] Center for Disease Control and Prevention, Child Development: http://www.cdc.gov/ncbddd/child/default.htm

[2] Begley, S. Your Child's Brain, Newsweek-American Edition, 1996, Online: http://www.dbpeds.org/media/childbrain.pdf

[3] Ornkloo, H. and Hofsten, C., Fitting Objects into Holes: On the Development of Spatial Cognitive Skills, *the 15th Biennial Intl. Conf. on Infant Studies,* 2006

[4] Anderson, D., Frankel, J. L., Marks, J., Leigh, D., Ryall, K., Sullivan, E. and Yedidia, J., Building Virtual Structures With Physical Blocks, UISI 1999

[5] Suzuki, H. and Kata, H., Interaction-Level Support for Collaborative Learning: AlgoBlock-An Open Programming Language, CSCL 1995

[6] Sharlin, E., Itoh, Y., Watson, B., Kitamura, Y., Sutphen, S. and Liu, L., Cognitive Cubes: A Tangible User Interface for Cognitive Assessment, CHI 2002

[7] Lee, K., Moses, M., and Chirikjian, G. S., Robotic Self-Replication in Partially Structured environments: Physical Demonstrations and Complexity Measures, International Journal of Robotics Research, 27(3-4): 387-401, 2008

Can Your Avatar Improve Your Health? The Impact of Avatar Customization

Youjeong Kim
Media Effects Research Laboratory
The Pennsylvania State University
115 Carnegie Building
University Park, PA 16802
yuk130@psu.edu

S. Shyam Sundar
Media Effects Research Laboratory
The Pennsylvania State University
212 Carnegie Building
University Park, PA 16802
sss12@psu.edu

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Abstract

As health communication campaigns enter the realm of games and virtual worlds, an important affordance is the ability to navigate a mediated environment through an avatar. Our investigation explores the psychological significance of avatar selection and customization on health outcomes. In particular, it examines how self-presentation through avatar creation influences avatar creators' self-concepts and, furthermore, their motivation to physically improve their bodies, by testing two competing propositions: the behavior confirmation theory and the agency model of customization. This study employs a between-subjects design involving 100 participants who will be randomly assigned to one of four conditions: a desired avatar condition in which users are directed to customize their avatars to be like their desired selves, an actual avatar condition in which users are directed to customize their avatars to be like their actual selves, assigned attractive avatar condition (wherein the user is assigned an attractive avatar by the system), and assigned unattractive avatar condition. Expected results and design implications will be discussed.

Keywords

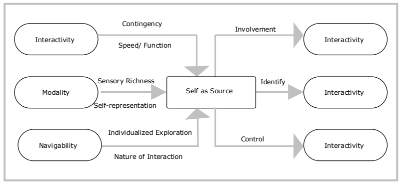
Avatar customization, self-presence, agency, self-preservation, second life, agency model of customization, behavior confirmation theory

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

Behavior confirmation theory [5] predicts that when a perceiver believes that the target that he/she is interacting with is attractive, the perceiver behaves in a friendly way. Furthermore, the expected behavior of a perceiver changes the target’s behavior. In other words, when we have an interaction with an attractive partner, we become very friendly. The attractive partner also expects our friendly behavior before the interaction and, in fact, behaves in confident and friendly way during the interaction. Therefore, regardless of a perceiver’s behavior, a physically attractive person behaves in confident and friendly ways, thus conforming to the perceiver’s expectations. Based on this framework, Yee and Bailenson [8] found empirical support for the “Proteus effect,” which can be summarized as follows: Just as people change their behavior by simply changing wardrobes in an offline context, the different looks of avatars will have a significant impact on avatar users’ behaviors online. In a series of experiments, they found that when users were assigned to attractive avatars, they showed higher confidence and higher self-disclosure. For example, when users see their really attractive, and then behave in the confident and friendly way that attractive people are expected to behave. In addition, when they see their avatars as being old, they show more positive attitudes and less negative biases toward the elderly [7]. Like in role playing, different faces on an avatar influences a user's self-perception and behavior. Cognitive dissonance theory [2] and self-perception theory [1] also support this idea by arguing that the public display of the self carries over to subsequent private self-appraisals and, in turn, influences one's public behavior.



Sundar’s Agency Model of Customization

The nature of the public display of self was determined by random assignment in the aforementioned Proteus Effect study. Some participants were assigned an attractive or tall avatar while others were assigned unattractive or short avatars. However, in reality, avatar assignment is not random and not objectively attractive all the time. As technologies advance, interfaces offer sophisticated interactive tools enabling users to construct richly detailed avatars to represent themselves. Users will represent themselves in ways that might reflect their self-schema, but may not be attractive by an objective measure. They could be subjectively attractive to the users because they created them. Therefore, an important conceptual consideration is the agency afforded to users when it comes to creating avatars to reflect their own selves. This would mean that users have a greater sense of ownership of their avatar. Regardless of how the created avatars look objectively, avatar users are more likely to be aware of their own "self" in virtual environments, which consequently could influence their private behaviors, particularly health behaviors to preserve the self.

The agency model of customization [6] emphasizes the role of the self as a “creator” and “source” for filtering individual needs and connecting the technological affordances (interactivity, modality, and navigability) underlying customization and the resulting psychological outcomes (i.e., cognitive, affective, and behavioral). Given that an avatar presents a user’s sense of self, it is probable that avatar customization highlights the sense of self more than any other type customization. More specifically, richer modalities, including the availability of facial expressions and movement, facilitate users’ self-representation. In addition, by providing idiosyncratic features of the virtual self that are different from others, the user’s feeling of ‘self as source’ is likely to be heightened. Furthermore, users have more control over their interaction with the system and with the avatars that they create. Identity, control, and involvement are theorized by the agency model to govern the sense of ‘self as source,’ with significant psychological benefits. Therefore, avatar creators are more likely to elicit a strong sense of self-presence, which consequently influence creators’ cognitive, affective, and behavioral outcomes. In particular, given that avatar customization highlights the sense of self, it is likely that avatar creators would develop a positive disposition toward self-created avatars, which would, in turn, motivate their own well-being. In a pilot study, we found that avatar users perceived higher risks to their physical bodies upon exposure to a public service advertisement about skin cancer [4].

Guided by these theories, we investigate whether assignment of avatars versus user customization of avatars makes a difference to attitudes toward the health issue being communicated. Furthermore, we enquire whether the attractiveness of the assigned avatar and the design of the customized avatar (actual vs. desired self) make a difference to users' sense of self-preservation.

Method

Stimulus

A health island was created for this experiment. Modeled after CDC (Centers for Disease Control and Prevention; http://www.cdc.gov/) in Second Life, the island disseminates health information.

Study design and procedures

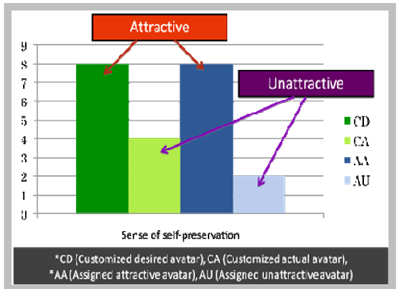
This study employs a between-subjects design involving 100 participants (25 in each condition) who will be randomly assigned to one of four conditions: a desired avatar condition in which users are directed to customize their avatars to be like their desired selves, an actual avatar condition in which users are directed to customize their avatars to be like their actual selves, assigned attractive avatar condition (wherein the user is assigned an attractive avatar by the system), and assigned unattractive avatar condition. The avatars in the last two conditions were pretested and found to be significantly different on perceived attractiveness.

As part of the experimental procedure, study participants explore Second Life, during which they are teleported to the CDC island, where their avatar is greeted by the experimenter's avatar for an interaction about a health topic, e.g., sleep disorders, with the CDC agent (experimenter's avatar) providing information about risk factors, symptoms, treatments and related topics. This is followed by an online questionnaire measuring their sense of self-presence, sense of agency, and sense of self-preservation. Once the participant is done with the questionnaire, the experimenter asks to take 2 pictures of him/her (one for whole body, and one for face). Then, the participant is asked to step out to the waiting room and asked to select 3 out of the 6 coupons for random drawings for discounted products (3 healthy ones, e.g., discounts for yoga class, and 3 unhealthy ones, e.g., discount for indoor tan service) to measure actual behaviors and write his/her name on each slip and put each one into the corresponding box. After the participant leaves the room, the experimenter debriefs him/her immediately.

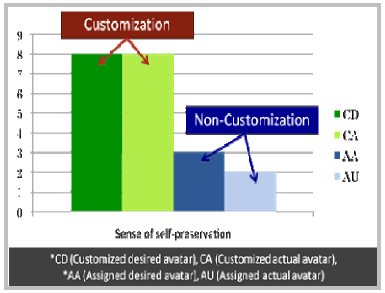
For dependent variables, sense of self-presence, sense of agency, visualization of ideal body, perceived risk to physical body, and sense of self-preservation will be measured. Furthermore, to create more valid measures for users' sense of self-preservation, this study attempts to measure users' behavioral intentions with self-reports as well as their actual behavior of picking up coupons related to health services and products (e.g., discounts for yoga class or fitness products). For control variables, identification with avatar, involvement, familiarity with second life, and body satisfaction using Body Esteem Scale (BES), Physical Attractiveness Questionnaire (PAQ), Body size drawings will be measured.

Expected Findings

This study attempts to test two competing theories: behaviour confirmation theory and agency model of customization. If customized desired avatar group and attractive avatar group show higher sense of self-preservation than customized actual avatar group and unattractive avatar group, the result shows that



Result supporting behavior confirmation theory



Result supporting the agency model of customization

physical attractiveness is key to predicting avatar users' sense of self-preservation, thereby supporting behaviour confirmation theory. On the contrary, if customization groups (customized desired group and customized actual group) show higher sense of self-preservation than non-customization groups (assigned attractive and assigned unattractive avatar conditions), it means agency is key to predicting avatar users' sense of self-preservation.

By the time of CHI 2010, we expect to have collected all our data and therefore share our findings with workshop participants, stimulating discussions relevant to WISH's theme.

Implications

The key contribution of this study is determining if (and how) self-presentation through avatars can translate into self-preservation, with implications for health interventions. Unlike previous studies focusing on the effects of self-presentation within the context of impression formation or impression management, this study investigates how the use of an avatar that reflects a user's specific aspect of self enhances his/her motivation to be involved in healthy behaviors. This has implications for design of interactive health systems, by suggesting the importance of affordances pertaining to avatar choice, customization, and creation, particularly as they pertain to appearance and ownership of one's avatar. More broadly, it proposes psychological mechanisms for developing interface features that not only engage users but also motivate them to adopt health-related actions.

Acknowledgement

This research was supported by the Korea Science and Engineering Foundation under the WCU (World Class University) program funded by the Ministry of Education, Science and Technology, S. Korea (Grant No. R31-2008-000-10062-0).

References

[1] Bern, D. J. Self-perception theory. In L. Berkowitz (Ed.), *Advances in experimental social psychology* (Vol. 6). New York: Academic Press, 1972.

[2] Festinger, L. *A theory of cognitive dissonance.* Evanston, JJ: Row, Peterso, 1957.

[3] Kalyanaraman, S., & Sundar, S. S. The psychological appeal of personalized content in web portals: Does customization affect attitudes and behavior? *Journal of Communication, 56* (2006), 110-132.

[4] Kim, Y., & Sundar. S. S. Me, myself, and my Avatar: The effects of avatars on users' attitudes toward website and its ad content. In N. T. Wood & M. R. Solomon (Eds.), *Virtual Social Identity and Consumer Behavior* (pp. 141-156). Armonk, NY: M. E. Sharpe, 2009.

[5] Snyder, M., & Swann, W. B. Behavioral confirmation in social interaction: From social perception to social reality. *Journal of Experimental Social Psychology, 14* (1978), 148-162.

[6] Sundar, S. S. Self as source: Agency and customization in interactive media. In S. U. E. Konijn, M. Tanis, & S. Barnes (Ed.), *Mediated interpersonal communication*. Mahwah, NJ: Lawrence Erlbaum, 2008.

[7] Yee, N., & Bailenson, J. *Walk A Mile in Digital Shoes: The Impact of Embodied Perspective-Taking on The Reduction of Negative Stereotyping in Immersive Virtual Environments.* Paper presented at the PRESENCE 2006: The 9th Annual International Workshop on Presence, 2006.

[8] Yee, N., & Bailenson, J. The proteus effect: The effect of transformed self-representation on behavior. *Human Communication Research, 33* (2007), 271-290

Post Traumatic Stress Disorder: Issues and Opportunities

Brian M. Landry
Information School & DUB
University of Washington
Seattle, WA 98195 USA
bmlandry@uw.edu

Julie A. Kientz
Information School, Human-Centered
Design and Engineering & DUB
University of Washington
Seattle, WA 98195 USA
jkientz@uw.edu

Eun Kyoung Choe
Information School & DUB
University of Washington
Seattle, WA 98195 USA
eunky@uw.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

Post-traumatic stress disorder (PTSD) affects 30% of United States war veterans. In this paper, we review some of the challenges therapists face when treating PTSD patients and discuss challenges and opportunities for technology to make an impact.

Keywords

Post-traumatic stress disorder, exposure therapy, narrative

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

Post-traumatic stress disorder (PTSD) describes a condition occurring as a result of exposure to a traumatic event (e.g. witnessing a fatal car accident). While anyone can develop PTSD, it is a condition typically associated with war veterans. In fact, 30% of war veterans develop PTSD [2]. Given this statistic, we have initiated a project to explore the impact technology can have in PTSD treatment. In this paper, we discuss our investigation of technologies used to support treatment of PTSD. Based on this investigation and conversations with domain experts, we suggest opportunities designing interactive systems, which can address challenges to treatment.

Background on PTSD

PTSD is diagnosed according to the DSM-IV-TR as a mental disorder occurring when:

- a person witnesses or experiences events that involve death or serious injury, and
- the person's response is one of intense fear, helplessness or horror.

Symptoms include intrusive recollection of the event (e.g., nightmares), avoiding activities, people and situations that recall memories of the event and hyper-arousal (e.g., insomnia).

A number of treatments have been developed to address PTSD. In our work we focus on cognitive behavior therapies. In particular we are interested in exposure therapy and cognitive restructuring. We chose these therapies because they are considered to be some of the most effective forms of treatment [1].

Exposure therapy involves exposing patients to the memories of the traumatic situation to help them overcome their responses to reliving the event. Cognitive restructuring or Cognitive Processing Therapy (CPT) focuses on challenging unreasonable beliefs patients develop about the world. For example, someone who experiences a life-threatening car accident may begin to believe anytime they leave the house they will experience a life-threatening car accident.

Both exposure therapy and CPT involve a writing component. In the former case, it is used to revisit the traumatic experience, whereas in the latter it is used to help the patient re-write his or her beliefs about the world.

PTSD Treatment Issues

While cognitive behavior therapies have been shown to be effective treatments, lack of patient compliance reduces the efficaciousness of the treatment [6]. Patients either choose not to seek treatment or do not consistently attend treatment sessions. Reasons for this include the difficulty of revisiting traumatic memories and the stigma associated with seeking treatment for a mental disorder (especially among war veterans).

In a discussion with a domain expert from the Seattle Veterans Affairs (VA) Hospital, we learned palatability and barriers to remembering are also issues that make administering treatment difficult. Despite the effectiveness of exposure therapy and CPT, they both rely on asking the patient to revisit the traumatic situation. The expert discussed a desire to make the therapy more palatable for the patient.

The expert also indicated that helping people make adjustments in the way they remember the event can be beneficial. In particular, he cited members of the United States Armed Forces tend to block out the negative memories associated with a traumatic event, which has the effect of blocking out positive memories as well. He expressed a desire for a means to support better remembering.

Researchers have developed technologies to address some of these issues, but we believe there is great potential for technology to have further impact in this space.

Technologies Supporting PTSD Treatment

While there have been some efforts to use technology as part of treatment delivery for PTSD, these efforts have been largely confined to Computer-Based Therapy and Virtual Reality.

Computer-Based Therapy

Computer-based therapies typically involve either a therapist delivering the treatment protocol remotely (e.g., using video conferencing) or converting the protocol into a digital form that can be accessed (without significant involvement of a therapist) through a CD-ROM on a local PC or over the Internet. For example, Lange et al. developed and studied a website in which patients received treatment (e.g., writing about the traumatic event) and interacted with the therapist [3]. Similarly, Litz et al. developed a website for self-managed PTSD treatment [4].

Virtual Reality

The second major type of technology developed for PTSD treatment has been in virtual reality. VR experiences resembling the environment in which the trauma occurred are created for patients to experience. The VR serves as a form of exposure through which the patient must endure. Rizzo et al. developed a VR simulation to support exposure therapy and initially showed improvement in the patients receiving treatment through the system.

Opportunities for Interaction Design

While computer- and VR-based therapies have made some initial strides toward improving PTSD treatment delivery, Tarrier et al. found these technologies were least preferred among patients [6]. We believe there are many other technologies that could be leveraged to address the issues of compliance, palatability, anonymity and remembering.

Mobile and Ubiquitous Computing

In the mobile and ubiquitous computing domain we posit the use of capture-and-access as well as context-aware devices can deliver treatment in novel ways. For example, the use of life-logging technologies like the SenseCam might capture aspects of the event, which could be used to evoke memories during therapy sessions.

In addition a just in time (JIT) type of therapy could be provided at the point when symptoms occur. For example, if a door slamming triggers recollection of the traumatic event, ubiquitous devices (e.g., a mobile phone) might be used to document the incident and deliver treatment. A more proactive approach might use devices with GPS capability to deliver treatment when the patient is in proximity to triggers of symptoms. In either case, the treatment could be delivered when symptoms are occurring rather than induce the symptoms in therapy sessions via recollection. This approach might address our expert's concern for palatability by providing treatment when symptoms naturally occur.

Storytelling Support

Both exposure therapy and CPT involve some level of narrative composition concerning the traumatic event.

Pennebaker found people who write about emotional trauma show signs of rehabilitation more quickly than those who do not [5]. We believe the use of storytelling technologies can provide yet another means of delivering treatment. Whether providing patients with a structured journaling experience or a social network of veterans to develop and share stories with, we believe exploring more explicit support for telling one's story can make a significant impact. The former could serve as a means to provide self-managed care that allows anonymity. The latter could address challenges with compliance and remembering by adding social support.

Conclusion

We have provided an overview of the challenges associated with treating PTSD and highlighted some opportunities for improving delivery of care using technology. In particular, we underscored the potential of mobile and ubiquitous computing researchers and storytelling and narrative technology researchers to bring their expertise to this problem. In the future we plan to continue conduct formative design work with domain experts, therapists, and patients at the Seattle VA to learn more about what technologies would be of benefit. Given the number of veterans alone this condition affects, we expect this work to not only yield innovative approaches to treatment, but also make a significant societal impact.

References

[1] Hamblen, J., Schnurr, P., Rosenberg, A., and Eftekhari, A. A Guide to the Literature on Pschotherapy for PTSD. *Psychiatric Annals* 39(6). 348-353

[2] National Center for PTSD. http://www.ptsd.va.gov/professional/pages/vietnam-vets-study.asp#major-findings. Accessed 1/2010

[3] Lange, A., Rietdijk, D., Hudcovicova M., van de Ven, J., Schrieken B. and Emmelkamp, P. Interapy: A Controlled Randomized Trial of the Standardized Treatment of Posttraumatic Stress Through the Internet. *Journal of Consulting and Clinical Psychology.* 71(5). 901-909

[4] Litz, B., Engel C., Bryant, R. and Anthony Papa. A Randomized, Controlled Proof-of-Concept Trial of an Internet-Based, Therapist Assisted Self Management Treatment for Posttraumatic Stress Disorder. *American Journal of Psychiatry.* 164(11). 1676-1683.

[5] Pennebaker, J. Telling Stories: The Health Benefits of Narrative. Literature and Medicine. *Literature and Medicin*e. 19(1). 3-18.

[6] Tarrier, N., Liversidge, T., and Gregg, L. The acceptability and preference for the psychological treatment of PTSD. 44(2006). 1643-1656.

Participatory Design in Health Informatics: The MECP2 Duplication Syndrome Portal Version 2.0

Roderick L. Lee
School of Business Administration
Pennsylvania State University at Harrisburg
Middletown, PA 17057 USA
rlee@psu.edu

Elliot J. McConnell
School of Business Administration
Pennsylvania State University at Harrisburg
Middletown, PA 17057 USA
musickid22@gmail.com

Pam Albert
Founder, mecp2duplication.com
Middletown, PA 17057 USA
(717)-944-4981

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

This research-in-progress reports on the initial experiences that we encountered during the development of a global online environment to provide computer-mediated social and informational support to families who have children affected by MECP2 Duplication Syndrome.

Keywords

Participatory Design, Online Communities, Social Support, MECP2 Duplication Syndrome

ACM Classification Keywords

H5.2. User Interfaces: H5.3. Group and Organization Interfaces: J.3. Life and Medical Sciences

General Terms

Participatory Design, Online Communities, Social Support, MECP2 Duplication Syndrome

Introduction

Prior research has demonstrated that people in general benefit from social and informational support when coping with stressful circumstances [12]. These stressful circumstances are more pronounced when parents receive news that their child has been diagnosed with a rare genetic disorder. Stress and uncertainly is compounded when there is a lack of publicly available information regarding the illness and when parents lack access to others in their local communities who face the same circumstance. As a result, more and more people are turning to the Internet in search of health information. Indeed, Fox and Jones [6] found that 61% of Americans have searched the Internet for health information; however, very few are generating new content.

An approach that is receiving considered attention is participatory design (PD). PD is a design methodology that is aimed at the development of socio-technical solutions to real-world problems that groups, organizations, and communities face. Recently PD has been successfully used to develop health information systems [4, 10]. In this research-in-progress, we used PD in a service-learning project in order to partner with a local family to develop a global online environment.

MECP2 Duplication Syndrome Community

MECP2 Duplication Syndrome is a rare genetic neurological disorder for which there is currently no known cure. Symptoms include severe physical and mental developmental problems along with a number of other complications, including daily seizures.

Pam Albert's son Braden was diagnosed with MECP2 Duplication Syndrome in 2007. When Pam was presented the diagnosis, she attempted to search the Internet for information on the disease. However, she became very frustrated by the lack of public knowledge that existed online.

Pam envisioned providing a way for parents with children who are affected by MECP2 Duplication Syndrome to communicate with each other, learn more about symptoms, and explore possible treatment options. To achieve this goal, Pam and a friend developed a website to support the exchange of information regarding MECP2.

The Methodology of Participatory Design

The methodology of participatory design (PD) originated in Scandinavia during the 1970s labor movement as a way to empower workers by involving them in the design of tools and artifacts [5]. During the same time, an action research inspired version of participatory design was developing in the UK [9]. The PD movement entered the North American discourse on human-computer interaction during the 1990s [2].

We prefer an approach that resembles its predecessor, participatory action research. According to the literature, PD shares five characteristics with participatory action research: (1) a problem focus; (2) collaboration between the researcher and user; (3) an action or change orientation; (4) empowerment; and (5) an "organic" process involving systematic and sometimes iterative stages [1, 11]. The most widely cited form of participatory action research [11] details a five-phase, cyclical process: *diagnosing, action planning, action taking, evaluation,* and *specifying learning.*

Applying PD to Develop the MECP2 Website

Diagnosis

We began the PD process through one-on-one discussions with the primary stakeholder, Pam Albert, in order to collaboratively define the problem. Through these initial discussions, we learned that Pam was dissatisfied with version 1.0 for three reasons. First, this initial version was not scalable due to the unforeseen increase in diagnoses worldwide. Second, the website was not very easy to update. Finally, a comments section was used to facilitate discussions. Therefore, the solution was a complete redesign of the site.

In order to develop a solution that was sustainable, we emphasized user participation throughout the design process. According to IS participation theory, participation in system development facilitates systems and implementation success [8].

Action Planning

The action planning process relied solely on low-fidelity prototyping. Students used index-card prototyping, which is often used during website development. Using 3 x 5 index cards, students constructed three very different interfaces. After receiving feedback, students refined the prototypes. Next, the students constructed three very different higher-fidelity prototypes using Adobe Photoshop. Based on continual feedback, the process continued in an iterative fashion until the Alberts agreed on a suitable prototype.

Action Taking

In order to facilitate control and ownership, Pam acquired web space from a hosting provider that would support Joomla. Next, rapid prototyping was used in order to develop the final application.

Outcome

The redesigned system was implemented successfully. The Albert family was positively impressed with the development process and the solution outcome [see, http://www.mecp2duplication.com].

Initial Experiences

The User's Initial Experiences

Pam and her husband, Scot, were involved in the process from beginning to end. The students asked their opinions and included the Alberts in all decision making aspects. In addition to the numerous e-mail exchanges between the Albert's and the students, they also met on two separate occasions and had a follow-up meeting. At the conclusion of the project, the Alberts were given a walk through of all proponents of the site and instructed on how to make updates and changes.

The Albert's are extremely grateful that they were able to partner with the University on this endeavor. They were impressed with the students' dedication and follow-through and are finding the website to be very user friendly. The Alberts learned a great deal by being directly involved in the process. The knowledge they acquired by working so closely with the students is now helping them maintain the site with little to no problems.

The Designers' Initial Experiences

The use of a service-learning group project was very rewarding. The opportunity to aid an actual community that faced a real-world challenge provided an excellent context to explore information systems development and design. Students were able to develop and implement a working application over the course of a semester. This is supported by research that suggests that students involved in structured service learning benefit from increased academic achievement, academic engagement, and civic responsibility [3, 7].

The iterative design process discussed in class was clearly mirrored in the development of the site. The cyclical process of gathering feedback and modifying designs affected every aspect of the site including custom graphics and navigation verbiage. This project has given the students a better feel for the role of a technical professional. Their involvement throughout the entire lifecycle of the project, from initial requirements gathering to stakeholder sign-off, provided them with an invaluable experience that will help prepare them for the IT workforce.

Discussion

PD is a viable alternative combining systems development and health informatics in a way that allows users to shape the development of the technology. We predict that participation in the MECP2 Duplication Syndrome online community will improve the social and information support among parents and caregivers. Therefore, an area of future research is to empirically explore these relationships.

Several implications can be derived from this research. First, it is important to include a medical professional when developing health information systems. Second, socially relevant projects can be used as service-learning projects in order to enhance IS education.

Acknowledgements

We would like to thank all students in IST 331 – Fall 2009 – for their hard work and dedication.

References

1. Baskerville, R.L. Investigating information systems with action research. *Communications of the AIS 2*(19). 1-31.
2. Bødker, S. *Through the interface: A human activity approach to user interface design* L. Erlbaum, Hillsdale, N.J, 1991.
3. Buckley, M., Kershner, H., Schindler, K., Alphonce, C. and Braswell, J., Benefits of using socially-relevant projects in computer science and engineering education. in *ACM Technical Symposium on Computer Science Education* (Norfolk, VA, 2004), 482-486.
4. Clemensen, J., Larsen, S.B., Kyng, M. and Kirkevold, M. Participatory design in health sciences: Using cooperative experimental methods in developing health services and computer technology *Qualitative Health Research*, *17* (1). 122-130.
5. Ehn, P. and Kyng, M. The collective resource approach to systems design. in G. Bjerknes, P. Ehn and Kyng, M. eds. *Computers and democracy: A Scandinavian challenge*, Avebury, Aldershot, UK, 1987, 17-57.
6. Fox, S. and Jones, S. The Social Life of Health Information Pew Internet & American Life Project, Washington, D.C., 2009.
7. Hoxmeier, J. and Lenk, M.L. Service-learning in information systems courses: Community projects that make a difference. *Journal of Information Systems Education*, *14* (1). 91-100.
8. Markus, M.L. and Mao, J.Y. Participation in development and implementation: Updating an old, tired concept for today's IS contexts *Journal of the Association for Information Systems*, *5* (11-12). 514-544.
9. Mumford, E. and Weir, M. *Computer systems in work design: The ETHICS method*. Wiley, New York 1979.
10. Pilemalm, S. and T., T. Third generation participatory design in health informatics: Making user participation applicable to large-scale information system projects. *Journal of Biomedical Informatics*, *41* (2). 327-339
11. Susman, G.I. and Evered, R.D. An assessment of the scientific merits of action research. *Administrative Science Quarterly*, *23* (4). 582-603.
12. Thoits, P.A. Social support as coping assistance. *Journal of Consulting and Clinical Psychology*, *54* (4). 416-423.

Strengthening HIS in Low-Resource Settings

Carl Leitner
IntraHealth International
6340 Quadrangle Dr., Suite 200
Chapel Hill, NC 27517 USA
cleitner@intrahealth.org

Carol Bales
IntraHealth International
6340 Quadrangle Dr., Suite 200
Chapel Hill, NC 27517 USA
cbales@intrahealth.org

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

This paper characterizes challenges of implementing health information systems (HIS) in low-resource settings and outlines successful implementation strategies.

Keywords

Low-resource, health information system, human resources information system

ACM Classification Keywords

H.1.2 User/machine systems—human factors, J.3 Life and Medical Sciences—medical information systems

General Terms

Low-resource, health information system, human resources information system

Background

Many low-resource countries suffer from a critical shortage of health workers. In order to best address this situation, health planners and leaders require accurate information about health worker cadres, qualifications, deployment, and unfilled vacancies. Ideally, this information will be captured and maintained in a human resources information system (HRIS) that links all human resources (HR) data from the time health professionals enter pre-service education until they leave the health workforce. Many countries use an HRIS but rely heavily on data that exist in paper form and are stored in different agencies, making data difficult to aggregate and analyze.

IntraHealth International, through the USAID-funded Capacity Project and the follow-on Capacity*Plus* project, supported HRIS strengthening in twelve countries: Botswana, Ghana, Kenya, India, Lesotho, Namibia, Pakistan, Rwanda, Southern Sudan, Swaziland, Tanzania, and Uganda. Based on in-country experience, IntraHealth created a participatory HRIS strengthening process to build stakeholder leadership; assess, integrate and improve existing systems; develop HRIS software solutions; effectively use and analyze data for policy and management; and ensure sustainability and continuous improvement. IntraHealth also developed free Open Source software products—the iHRIS Suite—for use in low-resource countries to supply health leaders with the information they need. Because the iHRIS products are Open Source, anyone can use, copy, share, or modify them without paying a licensing fee.

IntraHealth's experience strengthening HRIS is applicable to strengthening other health information systems (HIS). Below are challenges and strategies based on our findings to implementing and strengthening HIS in low-resource settings.

Low-Resource Setting Challenges

There are several factors that characterize a low-resource setting that need to be addressed when developing a successful and sustainable HIS. Some of the technological and infrastructure limitations are immediately obvious, such as inadequate mobile phone and Internet access and unreliable electricity supply. In addition, there are often extremely modest budgets dedicated to HIS strengthening, such as funding for equipment procurement, which may fluctuate rapidly based on donor interest.

Other challenges are based on limited computing skills, limited experience in data-driven decision-making, and few available and qualified local information technology (IT) administrators. These issues are further compounded by limited local HR management experience. Finally, there is a need to adapt an HIS to existing paper-based processes to avoid drastic changes in daily use.

It is an unfortunately common occurrence in low-resource settings that an IT solution is adopted and then dropped when donor funding ends. Therefore, IT solutions that only address the technological issues while ignoring the human side of things will likely fail.

Each of the recommendations below directly addresses at least one of these challenges with the end goal of creating a sustainable and useful HIS.

Strategies: Working with People

An essential component of a successful and sustainable HIS is establishing a stakeholder leadership group (SLG) to lead, coordinate, and provide oversight for all HIS-strengthening activities. The SLG should be moderate in size and composed of governmental and nongovernmental representatives who will be providing, using, and making decisions based on the data being collected in the HIS. A smoothly functioning and communicating SLG that takes ownership of the HIS ensures it is properly resourced and encourages further development and improvement. In April 2009, IntraHealth published the HRIS Strengthening Toolkit, which goes into detail about establishing an SLG. [1]

To enable the SLG, as well as its representative organizations, to use the HIS effectively, it is often beneficial to provide training in the understanding and effective use of data. With the wealth of new data that will come with the HIS, training in data-driven decision-making empowers local management and policy makers, increasing local ownership and value of the HIS. [2]

In order to have meaningful data, the stakeholders often have to go through the time-consuming process of standardizing data and models with existing processes in mind—for example, adopting the International Labour Organization’s International Standard Classification of Occupation (ISCO) job codes for HR job classification [3]. Adoption of standards such as ISCO codes aids in reporting and analysis. The involvement of the SLG helps to ensure adherence to standardized data sets among the various representative organizations.

In some instances, a *step-solution* is preferable to implementing a mature software system: first there is a transition from a paper-based system to electronic records, at which point data consolidation and cleansing can occur before moving to a standards-based HIS.

Often the existing technological capacity of in-country IT professionals will not meet the long-term requirements for maintaining an HIS. Thus, efforts should be made to develop the local technical capacity. This might involve working with a nearby university to provide local and remote training in the applicable technologies, which can have direct impact on HIS success and sustainability. Another possibility is to leverage skills already attained by improving the interoperability between the HIS with an existing, related information system.

On a broader level, low-resource countries are not working in isolation and are often addressing similar needs. Hence, it is important to foster regional and global communities between these countries. Developing and strengthening these communities provides opportunities for “South-South" collaboration in dealing with issues in both policy and technology. [4]

Finally, one should look at practicing *open-implementation.* Project management often becomes quickly complicated due to the diverse requirements of the SLG as well as the donors. Open discussions on a phased implementation to meet these requirements decrease misunderstandings and keep expectations realistic. Sharing of information about relevant and related projects increases opportunities for communication and collaboration. Making implementation documents and details publicly accessible also creates an opportunity for collaboration with other related information systems.

Strategies: Working with Technology

Many of the technological challenges can be addressed with a coherent, phased and scalable implementation strategy with appropriate software and hardware components. Simply transferring data models and IT solutions used in high-resource settings is often ineffective. In particular, commonly used data models often assume high connectivity, which is seldom the case.

Often, Open Source software will be an appropriate alternative solution as it avoids vendor lock-in and creates the opportunity for local development, and therefore increasing sustainability. In particular, modular Open Source IT solutions increase code reuse among similar HIS. For example, a training module developed in one country can be modified and used in another. Particularly with Open Source, stakeholders should be cautious not to introduce a plethora of different technologies which increases the learning curve and can reduce the ability for local developers and administrators to take ownership of their systems. One should also look for IT solutions whose implementation has a scalable complexity so that immediate benefits and customizations can be obtained with limited skill sets while at the same time providing a path to further development.

Finally, procuring a large central server is often assumed but may not be an appropriate solution for many countries as it could overburden an already taxed system with the additional need for IT support personnel as well as reliable power and climate control. Moreover, you would also need reliable Internet access in order for remote districts to connect to the central office. Rather, stakeholders should look to an *appliance* model which is an inexpensive, small computer that requires minimal maintenance.

Such appliances can be distributed throughout the region, thereby providing access to the HIS even in the case of limited connectivity to a central office.

figure 1. iHRIS appliance loaded with the iHRIS Suite

Where We Are Going

In addition to the continued development and implementation assistance, IntraHealth is currently undertaking two projects to provide a clear foundation for implementing an HIS in a low-resource environment. The first is to develop a costing model to determine the real cost of Open Source solutions to provide an honest assessment of needs for long-term sustainability. The second, under an initiative of the Health Metric Network at the World Health Organization, will provide a reference framework for HRIS.

Citations

[1] HRIS Strengthening Implementation Toolkit. www.capacityproject.org/hris/hris-toolkit/index.html.

[2] Adano, Ummuro. Building the Bridge from Human Resources Data to Effective Decisions: Ten Pillars of Successful Data-Driven Decision-Making. *Capacity Project* (2008).

[3] International Standard Classification of Occupations. www.ilo.org/public/english/bureau/stat/isco/index.htm.

[4] Special Unit for South-South Cooperation. http://tcdc.undp.org/.

Heuristic Evaluation of Personal Health Records Systems

Leslie S. Liu
Department of Informatics
University of California, Irvine
lsliu@ics.uci.edu

Gillian R. Hayes
Department of Informatics
University of California, Irvine
gillianrh@ics.uci.edu

Abstract

Evaluation of Health Information Technology can be expensive and complex. In this work, we explored the use of heuristic evaluation as a low-cost evaluation method for Personal Health Records (PHR). We evaluate three PHR using both a traditional and a modified heuristic evaluation. The results of these evaluations demonstrate that heuristic evaluation can be used successfully to find many of the challenges to use of particular healthcare technologies.

Keywords

Personal health records, usability, discount evaluation

WISH 2010, April 10–15, 2010, Atlanta, Georgia, USA.

ACM Classification Keywords

J.3 Computer Applications: Life and Medical Sciences; H.4 Information Systems Applications.

Introduction

Personal health records (PHR) maintained by patients and their families offer one solution for ensuring accurate and comprehensive health records even in health care systems that lack comprehensive interoperable standards for data storage and exchange. They can be desktop-based, Internet-based, or mobile (e.g., phone-based or located entirely on portable storage). They can be linked to Electronic Medical Record (EMR) systems, which are provider-owned and operated or stand-alone. These records are created and monitored by the patients themselves, typically without the substantial restrictions and limitations of paper-based, centrally located medical records. If properly maintained and up-to-date, these systems can help a patient communicate important health information with clinicians, saving both patient and clinician time.

In this work, we set out to understand the particular challenges limiting the adoption and use of PHR through a systematic evaluation of three Internet-based PHR systems. Recognizing, however, that many hospitals and clinics lack the resources to conduct substantial usability evaluations in practice, we explored the use of heuristic evaluation (HE) [2] for

PHR through the use of two separate heuristic evaluations, one using Nielsen's original ten heuristics and one with a modified set created by us for HIT specifically. We compare the results using our modified heuristics with the traditional set.

Related Work

Usability testing of information systems has been a known benefit for decades. The cost of conducting extensive usability tests depends on the number of end-users, the site, and the process of the evaluation. This cost can grow quite large when considering complex medical systems. Thus, it is important to consider methods that are lower-cost, such as "discount" usability methods. Discount methods, as originally articulated by Nielsen and others, include scenarios, the think-aloud method, and heuristic evaluations. In this work, we were particularly interested in the potential applicability of heuristic evaluation (HE) to HIT. HE is a "discount" method for low-cost evaluation of an interface. The standard method involves a small set of evaluators (typically 3 to 5) who "inspect" the interface for issues of non-compliance (bugs) with a set of standard known usability principles (heuristics) [6]. A benefit of performing heuristic evaluations rather than other discount usability techniques is that these evaluations do not require end-user participation. Interfacing with potential end users—including both patients and clinicians—can be a substantial burden for HIT, thereby making HE an appealing choice.

Although heuristic evaluation has been shown repeatedly to be useful for uncovering usability problems for many types of applications with only a minimal number of evaluators, the original ten recommended heuristics may not always be adequately applied to particular systems. Such is the case for both Baker et al. and Mankoff et al., who not only applied heuristic evaluations to computer supported cooperative work (CSCW) and ambient displays, respectively, but also modified and used a different set of heuristics than Nielsen's original ten to fit the evaluated system [1, 4].

Methods

We evaluated three specific PHR systems: Microsoft HealthVault[1], Google Health[2], and WorldMedCard, now known as WorldHealthRecord[3]. These were chosen from a field of dozens based on the following criteria:

- Available to the public, not just patients of a particular healthcare system (e.g, Blue Cross or Veterans Affairs)
- Internet-based
- Mix of familiar and less known corporations

Following the work of Baker *et al.* who applied heuristic evaluation to CSCW [1] and Mankoff *et al.* who applied the technique to ambient displays [4], we were interested in whether and how heuristic evaluation might be used for HIT, in particular for PHR.

While heuristic evaluations are a useful means for obtaining feedback about interfaces, the general heuristics originally provided by Nielsen[4] do not necessarily apply in the HIT realm when considering

---

[1] http://www.healthvault.com
[2] http://google.com/health
[3] http://www.worldhealthrecord.com
[4] http://www.useit.com/papers/heuristic/heuristic_list.html

PHR. For example, there are multiple simultaneous functions and users of a PHR system. Furthermore, multiple individuals—parents of a sick child for example—may modify records for a single patient at once. Ensuring that all information is synchronized across users and views, however, is imperative to the usability and usefulness of these systems as well as to the health outcomes of individual patients. As another example, Nielsen's original heuristics emphasize the interface notifying users of any errors generated through the system. This heuristic, when applied to PHR, tended to uncover only technological errors.

In medical systems, however, many errors are technologically acceptable but medically problematic. For example, Koppel *et al.* found that in computerized physician order entry (CPOE) systems, systems in which physicians can enter medication orders into a computer, medical personnel regularly depended on CPOE displays to indicate what the effective minimum dosage of medication should be for the patient. However, CPOE displays would show dosages that were not based on clinical guidelines, but rather pharmacy warehouse purchasing decisions, leading to errors [3]. To address the need for medically relevant usability evaluation, we developed a set of modified heuristics to be used in our evaluation of PHR. We first modified Nielsen's canonical heuristics and then added two more to fit the needs of health technologies.

We conducted two distinct heuristic evaluations. Five HCI experts evaluated the PHR systems based solely on Nielsen's set of heuristics. Five other HCI experts evaluated the PHR systems based on the modified set of heuristics. In both cases, each HCI expert also had the end-user task list for reference. The expert logged into each of the PHR systems to evaluate the specific system based on their assigned heuristics—either a modified or the original set of heuristics. For each heuristic, experts documented how they believed the heuristic and the actual system matched up. The evaluations lasted approximately 90 minutes. At the end of each evaluation session, the HCI experts were encouraged to give general feedback regarding their perceptions of PHR systems. After scoring the results for each heuristic evaluation, we further assessed the differences between those bugs and usability problems uncovered with each set of heuristics.

Results

Our Heuristic Evaluation comparison results indicate that although HE with Nielsen's ten recommended heuristics does in fact uncover many usability bugs, slight modifications to these heuristics perform better with the same number of evaluators.

To assess the ability of our heuristics to uncover usability bugs in PHR, we calculated the number of unique bugs found with the addition of each evaluator. For each case, beginning with the first evaluator until all evaluators were summed together, we calculated the number of distinct usability bugs—that is, only bugs that had not already been accounted for by a previous evaluator were added to the total. Five expert evaluators using the modified set of heuristics were able to identify more unique usability bugs (45) than eighteen end-users in lab testing (44). Although the modified set of heuristics were built upon the original Nielsen ten and explicitly only modified slightly, there were still usability problems found by the modified HE that were not found with the original set (see Figure 1).

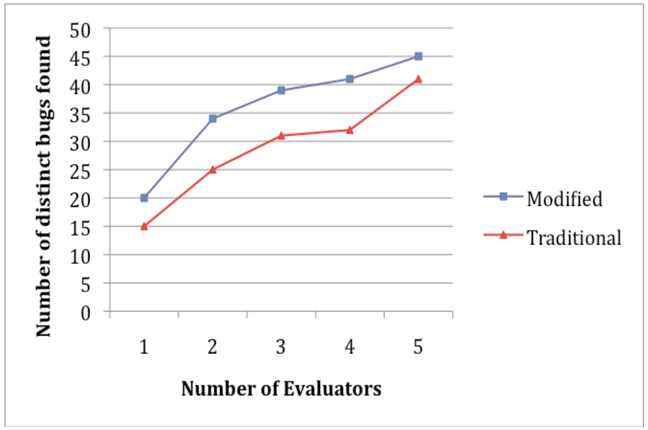


Figure 1. Comparison of unique bugs found across all systems per quantity of evaluators for each set of heuristics.

Conclusions and Future Work

PHR have enormous potential for empowering patients, increasing patient-provider communication, and tracking and monitoring health and wellness over time. Tracking these data over extended periods of time have the potential to provide baseline data, making detection of decline more efficient [5]. Furthermore, regular use of PHR can be beneficial in critical care situations, such as a trip to Emergency care, providing up-to-date information for a patient who may not normally be seen at the hospital that is currently providing treatment. Like any novel interactive system, before successful adoption can occur, however, the substantially challenges to usability and usefulness present in these systems must be addressed. Our results reinforce the need for integrating traditional and more recently developed methods from the HCI literature into the field of medical informatics, in particular in light of designing online systems for the general user population, such as PHR.

Our use of multiple heuristic evaluation techniques, using both traditional and modified heuristics, provide an example of how HIT may be effectively evaluated bearing in mind both standard usability and usefulness criteria as well as medically-relevant concerns. Furthermore, this approach of using modified heuristics can aid in evaluation of other HIT systems, an area for future work.

Acknowledgements

We thank all evaluators who participated in this study.

References

[1] Baker, K., Greenberg, S., Gutwin, C. Heuristic Evaluation of Groupware Based on the Mechanics of Collaboration, *Springer 2006.*

[2] Friedman, C., Wyatt, J., Ash, J. Evaluation Methods in Biomedical Informatics. *Springer, 2006.*

[3] Koppel, R., Metlay, J., Cohen, A., Abaluck, B., Localio, R., Kimmel, S., Strom, B., Role of Computerized Physician Order Entry Systems in Facilitating Medical Errors. *JAMA,* 1677-1682. 2005.

[4] Mankoff, J., Dey, A., Hsieh, G., Kientz, J., Lederer, S., Ames, M. Heuristic Evaluation of Ambient Displays. In *Proc. CHI'03*, 69-176.

[5] Morris, M., Intille, S., Beaudin, J. Embedded Assessment: Overcoming Barriers to Early Detection with Pervasive Computing. In *Proc. Pervasive'05*, 333-346.

[6] Nielsen, J., Mack, R. Usability Inspection Methods. *John Wiley & Sons, 1994.*

[7] Tang, P., Ash, J., Bates, D., Overhage, M., Sands D. Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption. *JAMIA*, 121-127. 2005

Learning User Models to Improve Wayfinding Assistance for Individuals with Cognitive Impairment

Alan L. Liu
Dept. of Comp. Sci. & Eng.
University of Washington
Seattle, WA 98195 USA
aliu@cs.washington.edu

Gaetano Borriello
Dept. of Comp. Sci & Eng.
University of Washington
Seattle, WA 98195 USA
gaetano@cs.washington.edu

Henry Kautz
Dept. of Computer Science
University of Rochester
Rochester, NY 14627 USA
kautz@cs.rochester.edu

Pat A. Brown
Dept. of Rehabilitation Medicine
University of Washington
Seattle, WA 98195 USA
pabrown@u.washington.edu

Mark Harniss
Dept. of Rehabilitation Medicine
University of Washington
Seattle, WA 98195 USA
mharniss@u.washington.edu

Kurt Johnson
Dept. of Rehabilitation Medicine
University of Washington
Seattle, WA 98195 USA
kjohnson@u.washington.edu

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Abstract

In this paper we discuss the benefits and challenges of designing customizable and adaptable applications for individuals to help improve their quality of life. As a supporting example, we describe our work learning user models to produce tailored pedestrian wayfinding directions for individuals with cognitive impairments.

Keywords

User modeling, cognitive impairments, wayfinding

ACM Classification Keywords

H.5.2 [User Interfaces]: User-centered design, K.4.2 [Computers and Society]: Social Issues – Assistive technologies for persons with disabilities

Introduction

There is growing recognition that applications should be designed to better match the needs and activities of individual users, rather than provide a “one-size-fits-all” usage model. It is especially important to consider user variation when designing applications in the healthcare domain, because an individual’s health condition can make it significantly more difficult to use certain designs. In contrast, a design tailored to an individual can provide significant improvements in usability [2].

Follow the path straight ahead

Follow the path straight ahead, then take the next left

Take the path slightly to your right

Turn around

Follow the path straight ahead, then take the second right you come to

Follow the path straight ahead toward the fountain

Go toward this building, then turn right

Follow the sidewalk toward the lawn, then take the next left and cross the crosswalk

Figure 1. Examples of direction types that differ by description of locations and message complexity

Researchers, including ourselves, have observed the need for customizable and adaptable design to support individuals with cognitive impairments in wayfinding, the process of traveling from one location to another [1,4]. Each individual's unique combination of abilities and disabilities creates a "universe-of-one" situation [3] where certain types of guidance may be understood and helpful while others may be confusing and even detrimental in wayfinding. A good design must therefore take into account such wide variation in potential users' ability to follow different types of wayfinding directions (see Figure 1 for examples) in different contexts, as well as their preferences over the presentation of directions.

The Importance of Customization

Current wayfinding supports assume a simplistic, default user model that takes little to no account of individual user preference. Written directions are worded without regard for how a user prefers to identify locations, so a person who prefers navigating by landmarks may find directions that refer solely on street names to be unhelpful. Maps can include labels for both streets and landmarks, but since space is limited, users are left with only the labels the map makers chose. Both are often difficult to follow by individuals with cognitive impairment because associating the physical environment with the symbolic labels is cognitively challenging.

Current navigation devices that use the Global Positioning System (GPS) also have poor support for user preference. Though they dynamically route a user based on current location, routing choices are limited to a few static options such as "fastest" or "avoid toll roads," under the assumption that all users respond to given directions the same way. Missing is the notion that some directions may be more difficult to follow for an individual, and subsequently that some routes consisting of such directions may be as well.

To overcome these limitations, we chose a framework by which we can incorporate individual user preference into wayfinding decisions as costs in a Markov Decision Process (MDP) [6]. This allows us to not only model preference for one type of direction over another at the same location, but to also compute lowest-cost routes from starting location to destination [5]. In related work, researchers have studied route preferences by observing expert drivers under the assumption that certain routes used by experts may be superior [7].

Adaptation to Complement Customization

We believe supporting customization can produce a better user experience for individuals in wayfinding, however it is not without challenges of its own. One such challenge is in eliciting those preferences. Self-report may be sufficient for some, but there are many individuals with cognitive impairments who may not have formed opinions about the different choices available, or who have difficulty communicating them. We could give the latter type of individual examples to rate, ideally in situ with a trial route. The problem is that due to the physical nature of wayfinding plus the time and effort involved in performing a trial route, the number of data points / preferences we can gather will be relatively small. Thus, there is a risk that a trial route is insufficient for gathering data representative of an individual's actual preferences.

A reasonable approach is to use trial data to seed a user model and incorporate subsequent observations of

Figure 2. N95 8GB phone used in our study. The keypad was divided into four input areas to request help (alternate direction), repeat directions, and switch between a photo-based direction involving a turn and a view from the turn facing the correct orientation (to disambiguate turn location).

wayfinding success and failure. We can then adapt models with additional data, and also learn participant tendencies or capabilities rather than simply preference. From the modeling perspective, we want to develop a model that can compute *direction difficulty*, the likelihood of a successful outcome when a user is presented with a certain direction, based on observations of a user in wayfinding.

Learning a Model of Difficulty

To test the feasibility of learning a difficulty model, we collected observations via a user study with 10 individuals (7 male) with cognitive impairment who were tasked with following a sequence of directions given by a prototype wayfinding application. The prototype ran on a Nokia N95 phone and supported audio, text, and image display (see Figure 2). Each direction was given as a participant approached an intersection of the predetermined route. We noted whether the participant followed each direction correctly, expressed confusion, or requested help.

For the analysis, we labeled each direction given to each participant as being difficult if the participant incorrectly followed it, showed signs of confusion, or used the Help button to request an alternate direction. We created a set of features, informed by this and previous studies, to describe each direction and then used linear regression to calculate several individual difficulty models. We used different training sets to train the models because we expected that a model trained on observations from only a single individual would overfit the relatively small number of data points, much like a single trial run might not yield a representative model of individual preference. The different models were:

- *Only p:* Each individual's observations were split into training and test sets, and linear regression was performed on the training set
- *Train:* Each individual's model was trained on all other participants' observations
- *Train + 1x p:* Each individual's model was trained on the union of the *Only p* and *Train* training sets
- *Train + 2x/4x/8x/10x/20x p:* Similar to *Train + 1x p*, but the individual's observations (their *Only* p training set) were weighed more heavily by being included 2/4/8/10/20 times, respectively

Results

Here we describe our initial approach to analyzing the collected data. We define a measure to quantify the models' performance, the *remainder incident rate*, as the percentage of observations among the directions in the participants' test sets ≥ a given predicted difficulty value. Intuitively, a good model produces remainder incident rate values that increase as the predicted difficulty rate increases. Then the correlation coefficient of predicted difficulty to remainder incident rate serves as an estimate of how well a model performs. Figure 3 shows the aggregate correlation coefficient values for all models across all participants, suggesting that the variation in performance decreases when we mix participants' observations but value an individual's data slightly more (4x and 8x in our data set). This occurs because using that individual's relatively small amount of training data causes overfitting, while not weighing it enough causes underfitting. Direct analysis of the incident remainder values for each model supports this, and we are collecting more data to make stronger claims of statistical significance.

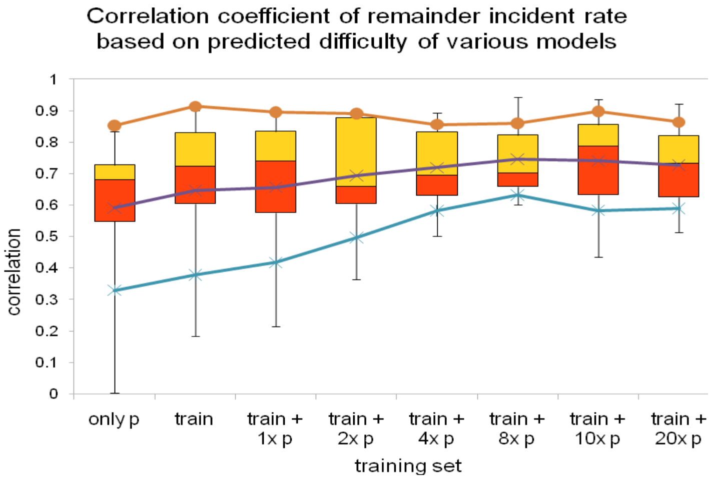


Figure 3. The correlation coefficient of remainder incident rate to predicted difficulty of our various models, shown for all 10 participants with median, 1st and 3rd quartile values represented by the boxes, minimum and maximum values as the whiskers, and the mean and one standard deviation above and below plotted as points.

Conclusion

Research has shown that user modeling can improve the usability of applications for individuals with unique requirements, positively impacting the quality of life for previously underserved users. Individuals with cognitive impairments would benefit from more customizable and adaptable wayfinding methods. As the time and effort involved in trial wayfinding runs limits the amount of training data that can be gathered for training an individual user's model, we investigated the performance of models trained on a combination of observations from both an individual and other users. Our initial results suggest that such a combination, with the individual's observations weighed somewhat more heavily, can predict wayfinding difficulty better than models trained only on other users or on just the individual. We are currently incorporating these findings into the design of an automated wayfinding system that will provide customized and adaptable directions and routes for individuals with cognitive impairments.

References

[1] Carmien, S., Dawe, M., Fischer, G., Gorman, A., Kintsch, A., and Sullivan, J.F. Socio-technical environments supporting people with cognitive disabilities using public transportation. *ACM Transactions on Computer-Human Interaction 12*, 2 (2005), 233-262.

[2] Gajos, K.Z., Wobbrock, J.O., and Weld, D.S. Improving the performance of motor-impaired users with automatically-generated, ability-based interfaces. *Proc. CHI '08*. ACM Press (2008), 257-1266.

[3] Kintsch, A. and dePaula, R. A framework for the adoption of assistive technology. *SWAAAC 2002*, Assistive Technology Partners (2002).

[4] Liu, A.L., Hile, H., Kautz, H., Borriello, G., Brown, P.A., Harniss, M., and Johnson, K. Informing the design of an automated wayfinding system for individuals with cognitive impairments. *Proc. Pervasive Health 2009*. IEEE 2009.

[5] Liu, A.L., Hile, H., Borriello., G., Brown, P.A., Harniss, M., Kautz, H., and Johnson, K. Customizing directions in an automated wayfinding system for individuals with cognitivie impairment. *Proc. ASSETS 2009*, ACM Press (2009), 27-34.

[6] Sutton, R.S. and Barto, A.G. *Reinforcement Learning: An Introduction*. MIT Press (1998).

[7] Ziebart, B.D., Maas, A.L., Dey, A.K., and Bagnell, J.A. Navigate like a cabbie: probabilistic reasoning from observed context-aware behavior. *Proc. UbiComp '08*, ACM Press (2008), 322-331.

Uncertainty in Chronic Illness and Patients' Online Experiences

Jennifer Mankoff and Sara Kiesler
HCI Institute,
Carnegie Mellon University
Pittsburgh, PA 15213
author1@anotherco.com

Kateryna Kuksenok
Oberlin College
Oberlin, OH 44074
Katie.kuksenok@gmail.com

Kelly Waldman
Duke University
Durham, NC 27708
Kelly.waldman@duke.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

Many people go online for information and support in response to life experiences such as parenting or investigating an illness. Online resources may be particularly important to those with a chronic illness whose diagnosis and treatment is uncertain. This paper focuses on people with Lyme disease, the most common vector-borne illness in the U.S. today. The patient experience of Lyme disease is fraught with variability in symptoms and uncertainty surrounding treatment and the progress of the disease. This uncertainty is reflected in an active, vocal, and contradictory presence on the web. We interviewed 21 patients about their real world and online health-related experiences. Here we discuss the strategies that support effective online resource use. An unexpectedly prevalent form of online activity was patient activism.

Keywords

Health, Ethnography, Search, Social Forums

ACM Classification Keywords

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

Introduction

Although many people depend on their doctors to diagnose and treat acute conditions such as a broken ankle, patients tend to take a more active role in managing chronic conditions [5]. Almost everyone eventually encounters chronic illness directly or indirectly. People with chronic illness face ongoing, often debilitating symptoms and uncertainty about the future. Importantly, “it is neither clinicians nor health systems that manage chronic disease, but rather patients themselves” ([5], p. 290).

Seeking health information online happens frequently, and online information can influence how people manage and treat their chronic condition [8]. The web can provide support, information, a place to research treatment options, and a mechanism for sharing information with others [6].

Online health information can be inaccurate, incomplete, controversial, and otherwise problematic for individuals with health questions [7]. Perhaps because of this, people who use health resources online may experience increased depressive symptoms [2]. Misleading information may lead them to take harmful actions or become alarmed about symptoms that are in fact not serious. Reading about disease might increase people’s health anxiety, reinforce hypochondria or cause them unnecessary concern about their health status [10].

Other studies suggest more positive outcomes for some patients (*e.g.,* [2]). For those seeking new information about a problem, unconnected networks can link people to knowledge that is unavailable in their existing networks such as family, friends, and doctors (*e.g.,* [11]). Accessing new social environments can have value for people who are isolated or have ill-functioning existing social ties [12].

Our work focuses on an increasingly common and highly controversial illness, Lyme disease. Lyme’s varied and changeable symptoms include, *e.g.,* fatigue, joint or muscle pain, headaches, rashes, and neurological symptoms [4]. There are no conclusive studies showing how to cure chronic Lyme disease, and there is disagreement in the medical community about its diagnosis, progression and treatment (*e.g.*, [9], and the commentary on [4]). As a result, people with Lyme disease may face difficulties obtaining a timely diagnosis [13]. Once diagnosed, patients may have difficulty finding a doctor or getting insurance companies to pay for treatment [13]. This controversy significantly affects online resources and people’s experience with online health resources.

Study

Four of the authors have personal or professional experience with chronic illness, including chronic Lyme disease. We expanded our horizon by talking informally with people we had met with Lyme disease, searching the literature on Lyme disease, and documenting online resources for Lyme disease and health sites that contain information or communications relevant to Lyme disease. Based on this we conducted in-depth interviews with 21 people with Lyme Disease to gain more insight into patients’ experiences.

We conducted interviews by phone (in one case, Instant Messenger), in one to three sessions of forty-five minutes to ninety minutes. We advertised for participants online and placed ads in the office of a Lyme specialist. Participants completed a pre-interview questionnaire listing the online and offline resources they use. In the interview, they were asked about their experience with their disease, health practitioners, treatment, and particularly helpful or unhelpful online resources. Much of the interview was open ended. Payment was $10/hour.

We used a bottom-up coding method drawn from grounded theory. One author conducted open coding of the interview transcripts for concepts that were significant in the data such as abstract representations of usage of health information, experience of disease, relationships with people and online interactions. The resulting list of 35 codes was then grouped into themes ("axial coding"). The themes were integrated into findings by contextualizing them within our problem space of chronic disease and online information and communication.

Interview Results

All of the participants we spoke with were diagnosed, and either in treatment, unable to afford treatment, or in remission. Five participants were male, most were single. The mean age was 41-50. Over 80% were unemployed, about 60% of these due to disability. Over 80% characterized their diagnosis as complex, and the mean time from symptom onset to diagnosis was two years.

The resources our participants used included interpersonal email, community resources (support groups, live group chat, and mailing lists), content (research articles, organizational websites, medical portals, Wikipedia, *etc.*), blogs (read and/or written by participants), symptom tracking applications, and medical record sites. Information seeking was described as a social, often iterative process. Forums helped eleven participants to find information. The presence of conflict online impacted this process. For example, Susan avoided certain resources because **"you know, we're going to disagree and I'm not going to change their minds by reading … and they're not going to change my mind."** Lisa visited many resources because: **"It's kind of hard to wade through all of the information and find out what is an appropriate choice for my own treatment, when there's so much controversy."**

Participants developed a strikingly sophisticated understanding of how to vet online resources. As Jen says, **"You just can't start reading any old thing and think that this is what it's all about…. You've got to read any-thing and everything and in doing that … you know which one is telling you the truth…"** Sixteen participants described a research process that included selecting among different types of information and/or triangulating sources. Participants described how forums helped them to vet the trustworthiness of information they found, and avoid scams. Scam awareness and discerning information consumption were actively taught and monitored in support group settings.

Participants used online resources at specific times for specific reasons including ongoing disease management, support, and tracking new research results: **"…when I really feel desperate for something, you know, support, information, whatever it may be. At those times, all your life is websites. (Gail)"** At the same time, participants actively managed the negative side of going online by reducing some online activities.

Although not predicted by past work, the pull toward activism was strong among participants (12 of 21).

"I would risk my life to get the truth out, and to get people who are suffering from this disease … the right kind of treatment, just information…. I feel really strongly about that. (Erica)" Participants described numerous acts that protected or advanced the interests of the Lyme community. Each person brought his or her own skills to the table. For example, Sarah moderated a mailing list. Jackie described a sub group of people that "**do research … I call them `braniacs,' … they are scientists, they're PhD's…. And I know if I have a question … I'm gonna get a lot of scientific information, and get it answered."** Kate kept an online diary detailing symptoms and treatments to **"see if I can get any attention to it… and pull their attention into everything I had to go through to get any treatment at all."** Rachel answered questions **"If I have information I reach out…. it's very comforting… and empowering to have real people out there that are trying to help that have been there."** Jackie provided support **"…in LymeChat if someone's suicidal, we'll stay up all night with them."**

Conclusions

Participants used online resources in different ways at all phases of their illness. Because of the uncertainty surrounding Lyme disease, they did not find answers on a single site. Despite chronic pain and, in some cases, cognitive difficulties, many approached online information with sophistication. Participants actively managed the negative impacts of going online mentioned in the literature. Overall, despite the presence of contradictory and uncertain online information about Lyme disease, participants said that their access to this information helped them to find a diagnosis, manage their disease, and ultimately contribute back to the community.

Acknowledgements

Thanks to our participants, Google and NSF (NSF IIS-091459).

Bibliography

[1] Baker, L., Wagner, T. H., Singer, S. & Bundorf, M. K. (2003). Use of the Internet and e-mail for health care information: Results from a national survey. *J. of the AMA,* **298**(18):2400-2406.

[2] Bessiere, K., Pressman, S., Kiesler, S. & Kraut, R. (2009). The impact of using the Internet for health purposes: A longitudinal study. *Paper under review.*

[3] Broom, A. (2005). Virtually he@lthy: The impact of Internet use on disease experience and the doctor-patient relationship. *Qual. Health Res.*, **15**(3):325-345.

[4] Cairns, V. & Godwin, J. (2005). Post-Lyme borreliosis syndrome: A meta-analysis of reported symptoms. *Int. J. of Epid.,* **34**(6):1340-1345.

[5] Clark, N. M. (2003). Management of chronic disease by patients. *Ann. Rev. of Pub. Health*, **24**:289-313.

[6] Eysenbach, G. (2003): The impact of the Internet on cancer outcomes. *CA: A Cancer J. for Clin.,* **54**:356-371.

[7] Eysenbach, G., Powell, J., Kuss, O. & Sa, E. R. (2002). Empirical studies assessing the quality of health information for consumers on the World Wide Web: A systematic review. *J. of the AMA* **287**(20):2691-2700.

[8] Fox, S. (2007). *E-patients with a disability or chronic disease*. Pew Internet and the American Life Project.

[9] France, D. (1999). Scientist at work: Allen C. Steere; Lyme expert developed big picture of tiny tick. www.NYTimes.com. Archived at http://www.webcitation.org/5jqHhP0DM.

[10] Hardy, M. S. & Calhoun, L. G. (1997). Psychological distress and the "medical student syndrome" in abnormal psychology students. *Teach. of Psych.,* **24**(3):192-193.

[11] Lin, N. Ensel, W. M. & Vaughn, J. C. (1981). Social resources and strength of ties: Structural factors in occupational status attainment. *Am. Soc. Rev.* **46**:393-405.

[12] McKenna, K. & Bargh, J. (1998). Coming out in the age of the Internet: "Demarginalization" through virtual group participation. *J. of Pers. and Soc. Psych.,* **75**(3):681-694.

[13] Weintraub, P. (2008). *Cure unknown: Inside the Lyme epidemic.* New York, NY: St. Martin's Press.

Use of a Wearable Recording Device in Therapeutic Interventions for Children with Autism

Gabriela Marcu
HCI Institute
Carnegie Mellon University
5000 Forbes Avenue
Pittsburgh, PA 15213
gmarcu@cs.cmu.edu

Gillian R. Hayes
Department of Informatics
University of California, Irvine
Irvine, CA 92697
gillianrh@ics.uci.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

Caring for a child with autism and limited speech involves overcoming communication challenges and understanding how best to provide care. In this research, we used Microsoft SenseCam as a platform for exploring the potential for automatically generated, situated and contextualized picture-based communication and therapy. We present the results of an exploratory qualitative study examining the day-to-day use of SenseCam by children with autism and their caregivers. Our findings indicate that SenseCam has a variety of potential for improving both communication and care for children with autism and their caregivers.

Keywords

Capture and access, autism, SenseCam, augmentative communication, assistive technology

ACM Classification Keywords

K.4.2 Computers and Society: Social Issues, Assistive technologies.

Introduction

Interventions to support individuals with autism often include the use of images—both those captured automatically and those manually recorded. Use of these visual artifacts has been shown to reduce the symptoms associated with many disabilities, in particular for individuals with autism [2], and can be used to encourage communication and learning in children. Non-verbal children with autism often communicate via pictures [1]. Specifically, visual supports are "those things we see that enhance the communication process" [3] and can support children learning about the world. Visual supports can include things like body language or natural cues within the environment [3], but of interest here are those tools explicitly created to support individuals who may have trouble interpreting naturally occurring visual cues. These constructed artifacts use images to represent simple everyday needs and elements of basic communication [2]. In these cases, visual supports are used to augment communication, in much the same way that sign language can be a visual representation of language for someone with a hearing impairment. Visual supports have been shown to reduce the symptoms associated with autism [3].

In designing an intervention involving visual supports, to meet the challenges of communication and documentation in everyday life, we used SenseCam, a novel recording technology developed by Microsoft Research [4]. SenseCam is a wearable digital camera designed to take photographs of everyday life without user intervention, while it is being worn. Our use of SenseCam enabled us to explore the potential for automatically generated, contextualized picture-based communication and therapy. SenseCam does not have a viewfinder or a display. Therefore, to ensure that relevant images are captured, it is fitted with a wide-angle (fish-eye) lens that maximizes its field-of-view. It has multiple electronic sensors, including a light sensor, temperature sensor, and accelerometer, which enable SenseCam to capture images automatically when changes are detected in the sensors' readings. SenseCam images are transferred to a computer and reviewed at various speeds using SenseCam's accompanying viewing interface.

In our work, we aimed to gain a nuanced understanding of the challenges that can emerge for caregivers of children with autism with their everyday facilitation and support of SenseCam use.

Method

We present the experiences of three families with the SenseCam intervention over three to five weeks each. Each participating family consisted of one child with autism, a parent who was the primary participant of the study and the primary facilitator of SenseCam's use, and sometimes other family members and caregivers who acted as secondary users or stakeholders. All of the children were either 14 or 15 years old. Two were non-verbal and used augmentative communication devices, which turned text to speech, allowing them to speak to others. All of the primary users were the children's mothers.

During an initial meeting, each mother received a SenseCam demonstration and overview. The study was explained as largely user-driven, and they were encouraged to be creative with their use of SenseCam. After a short training session, the mothers were instructed to use SenseCam with their child each day for at least an hour when, how, and where they found most useful. Each week, each mother participated in an interview that lasted approximately one hour. During these weekly interviews, the mothers were asked to describe their experiences in using SenseCam. They also reviewed the images with the interviewer, noting any images of interest and often describing their own, their children's, and others' reactions to the images. To capture both the creativity and challenges that emerged in our study, interview and observational data from the participants' homes were collected and analyzed by the research team using a grounded theory approach.

Results

The three families participating in this study appropriated SenseCam and our associated intervention into their lives in vastly different ways, making for compelling case studies across the varied potential uses of this novel ubicomp technology.

Our results suggest that use of SenseCam can encourage more communication from a child with autism, a significant goal of many educational and therapeutic interventions and the explicit purpose of augmentative communication technologies. For example, Christine, one of the mothers, perceived that SenseCam images increased her daughter's communication through her text-to-speech device:

"Sometimes… she's really resistant to using [her current augmentative technology device that does text-to-speech]. She'll just use it like – I'll give her a choice. 'What do you want to do' or 'what do you want to eat right now'. Things like that. But she's a little bit more talkative when she has the visual [images from SenseCam] there too."

Shared access of this media also introduced opportunities for a child to communicate about events, concerns, and even moments of joy that would have otherwise been missed:

"With the [text-to-speech device] it's so… she doesn't always feel like using it. And it's not so accessible. So like if we're in the middle of SeaWorld that wouldn't be a time to go 'how do you feel right now?' But later, [we can] talk about that [through the review of the SenseCam images]. … My [neurotypical] son, he processes and talks about things all the time. But she doesn't really get that opportunity to do that."

Our results also indicate that SenseCam has the ability to give a non-verbal child a "voice." SenseCam empowers a caregiver to view the child's world from his or her own perspective, and the resulting images say what the child may not be able to. For example, by reviewing images and asking her daughter about what she noticed in them, Christine made a surprising discovery:

"I noticed [in the images] that she's sitting there reading music. So I was asking her about that. And she's telling me that she could read music and that she taught herself. I never knew that. So I asked her 'do you want me to get you other music to read, like if I bought you sheet music' and she said 'yeah'. So that was something we just discovered."

Caregivers also tended to examine the images very purposefully to find out about their children's experiences. For example, Elaine considered how she might better interpret her child's behavior on an upcoming family trip:

"It'll be interesting for me to see… like what direction does she look at? Does she actually look at the animals [in the zoo]? Is she not interested in the animals at all? … If the animal moves, is she actually looking or is she just looking at the people's backs? Because I don't know if she enjoys this or not. I mean if I see that all she does is look at people's back, like why am I gonna take her to the zoo? [If] I don't think she's capturing the essence of going to the zoo. So she can't talk and I don't know where her mind is at. It would be kind of interesting to see, what is she looking at? What is she interested in?"

In a later interview, after the visit to the zoo she was anticipating had taken place, Elaine reviewed the images with the interviewer, noting that she was able to recognize that her daughter was in fact attending to the animals:

"There she's definitely looking at the elephants. That's kind of cute. Because she's leaning I think on the rail."

SenseCam also has storytelling abilities that have the potential to bring families together through a shared experience:

"Even if she's not typing back about it, she's responding. She's lighting up and excited that she can share through her pictures what she did."

Conclusions

The three case studies presented in this work demonstrate that novel capture and access technologies—such as SenseCam—can be used successfully as augmentative communication tools for children with special needs. These technologies can provide a "voice" for a child who cannot speak, as well as additional information to support communication among caregivers and their children. The case studies also demonstrate how caregivers can creatively make use of flexible capture and access technologies for a variety of purposes. The results of this work indicate promise for the use of capture and access technologies for augmentative communication and other related uses. Their applicability and potential for adoption over long-term use, however, should be investigated further.

Acknowledgements

We thank our participants, and Microsoft Research.

References

[1] Cohen, M.J. and Sloan, D.L. *Visual Supports for People with Autism: A Guide for Parents and Professionals.* Woodbine House, USA, 2007.

[2] Charlop-Christy, M.H., Carpenter, M., Le, L., LeBlanc, L.A., and Kellet, K. Using the picture exchange communication system (PECS) with children with autism: assessment of PECS acquisition, speech, social-communicative behavior, and problem behavior. *Journal of Applied Behavior Analysis*. 35(3), 213-231, 2002.

[3] Hodgdon, L.A. *Visual strategies for improving visual communication: Volume I: Practical support for school and home.* Quirk Roberts Publishing, 1999.

[4] Hodges, S., Williams, L., Berry, E., Izadi, S., Srinivasan, J., Butler, A., Smyth, G., Kapur, N. and Wood, K. SenseCam: A Retrospective Memory Aid. In *Proc. UbiComp 2006*, Springer, 177-193, 2006.

Complimenting Informatization: Engaging Socio-affective Practices in Healthcare Information Technology

Helena M. Mentis
Mobile Life Centre/ Swedish Institute of Computer Science
Kista, Sweden
mentis@acm.org

Abstract

In this paper, I present a preliminary argument for the consideration of socio-affective practices in the design of healthcare technologies. I present a summary of my findings on the purpose of emotion expressions in an emergency room and the various rules that modify those expressions. Current formal documentation does not provide the necessary medium for fostering socio-affective practices and thus, different technologies are needed.

Keywords

Socio-affective, emotions, informatization, medical informatics, cooperation

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Introduction

The notion that information technology will have a positive transformative effect on the management and effectiveness of healthcare has conflated the practice of medicine with information. As Mort and Smith [4] recently argued, the 'informatization' of medicine has eclipsed the importance of other contextual factors that are not 'informatized'. "While seeing images or clinical data or hearing vital signs signals offers the practitioner insight, we argue that it is in allowing for randomness and disorder that clinical practice is strengthened and patient safety underpinned" ([4], p.226). They argue that the design of medical information technologies may be enhanced by taking the "often messy knowledge generated in the clinic back into the domains of evidence and design" ([4], p.227). In this workshop paper, I briefly argue for the consideration of the 'messy knowledge' constructed through socio-affective practices in the design of new technologies for the medical domain. One such socio-affective practice is the expression and negotiation of feelings and attitudes between medical collaborators.

Socio-affective Practices in Action

There exists a growing canon of research that touches upon the role of the expression of feelings and attitudes between workers in a medical domain. These have focused primarily on communication between nurses and verbal handoffs between healthcare workers.

For example, during handoffs, nurses wrap objective medical data within personal or subjective comments, stories, and experiences with patients [2, 6]. These stories provide a basis for reflection on these experiences and a co-development of norms and values towards patient care. In addition, nurses use generalized statements to describe patients (e.g. 'he is fussy' or 'she is very demanding') that encapsulate subjective feelings about a patient and are used to give implicit guidance to the on-coming nurse about how to handle the patient [1]. Thus, they showed their feelings towards the patients and directed their colleague as to how to approach and consider the patient without explicit directions.

Physicians also use socio-affective information during verbal handoffs such as what the outgoing physician *felt* about the patient – what was his or her *intuition* about how the patient was fairing and what does he or she feel may happen in the next few hours [5]. This is a direct request for the personal, non-factual assessment of the patient based on a *gut-feeling*. Even though these summary statements include ambiguous terms and phrases, the physicians indicate that offering them is an important aspect of information transfer that helps them to be effective at their job.

The important thing to note here is that little of this information is transferred via formal documentation (paper or otherwise) and, thus, this is exactly the type of data that is ultimately left out of the representation of medical work through information technology.

For instance, in one study, temporary written documents that contained socio-affective information were replaced along with other formal written documentation by a new digital medical record [7]. However, after a new permanent digital record replaced all paper documents, socio-affective information virtually disappeared from written records, due to concern regarding the permanence and far-reaching distribution of the electronic documentation. The researchers observed a corrective trend to include more socio-affective information in the verbal information sharing activities, even though this removed one of the benefits of a persistent record from shift to shift. Of particular interest is that the nurses themselves did not perceive the loss of this information as detrimental to their work. They "cheered the termination" of the temporary documents once they realized all of the objective information could be easily found in the new information system (p.2067). They did not perceive the loss of the written socio-affective information as important as the objective information. However, this raises the question of the changes to the verbal handoffs: if the socio-affective information was not important, then why did the nurses generate longer verbal reports so as to provide the socio-affective information?

Expressing Emotions as Part of the Work

Recently, I studied the expression of emotion in the collaborative work of an information-intensive, tightly coordinated emergency room (ER) of a large urban academic hospital. I employed an ethnographic approach involving observations, interviews, artifact analysis, and a reflective diary over the course of six months. As detailed in [3], I learned that the expression of one's emotions is integrated within the work of the ER. For instance, expressing one's emotion helped to form shared mental models that enabled collaborators to agree on the direction of care and work independently towards these shared goals. Likewise, expressing one's feelings can be used as a call to action (e.g. treat a patient with more care since she has recently gone through a traumatic event).

Although emotions were an important part of the work and were often shared in a face-to-face setting, there was minimal indication of emotion in formal documentation media such as the paper patient records. Most emotion words found in these formal records were those of patients. As for any assessment of the patient's condition by the medical practitioner, only objective, data-driven notes were formally written down.

The reason for this disconnect is that formally written emotional content was explicitly viewed as unprofessional and inappropriate to the standard of care. This had been codified in official ER documents. One administrative document specifies that the medical record is to be "objective" and "factual" and to "refrain from including your emotions and frustrations" since this is unprofessional. Yet at the same time, this document expresses that the medical documentation's purpose is for "interdisciplinary planning and facilitate communication" and to create a "vivid picture" of the patient. There is clearly a disconnect between what is acceptable and what is required.

The primary reason for constraining emotion expressions in the formal documentation is the organizational role of these information media. Formal documentation is created for traceability of treatment decisions and justification of diagnosis. The patient's formal record is designed to communicate the course of care and medical diagnosis to external agents, including (1) insurance companies, (2) lawyers, and (3) admitting physician in other units or hospitals. Note that this record is *not* designed to be the primary medium for the communication of care to other ER personnel, nor is it a medium for jotting down 'possibilities' or 'concerns'. Thus, it is not the appropriate medium to debate or discuss the patient's diagnosis and care, nor is it the proper venue to share one's feelings about the patient.

An attending physician explained it thusly: *"You chart down information in order to make a case for admission, for medical insurance, etc. You need objective data."* This means that unless there is data-driven evidence for a diagnosis or course of care it is not recorded in the official ED Record.

These studies indicate that there are many instances of a nurse or doctor expressing their feelings to their coworkers as an important aspect of the work. In addition, this information is sensitive enough to not be included in formal and persistent sharing media such as the digitized patient record. However, this information provides context for the objective data and can provide guidance in how to proceed in a patient's course of care. Removing diagnoses and course of care from the socio-affective context provides dangerously incomplete information to future healthcare providers who are not privy to this equally important information.

A Socio-Affective 'Place'

In my observations, within the formal documentation there was no place for recording that which did not have evidence to back it up including feelings, data interpolation, or intuition.

As described by the physicians and nurses in this study, formal documentation is for recording data (i.e. hard evidence) as well as the "final story" (i.e. the diagnosis and evidence that supports that diagnosis). There is no room for superfluous information that veers the story off course from leading to a conclusive diagnosis and course of treatment. Unfortunately, not all cases are always clear in the beginning. Medical personnel need more time to work out the answer and new residents could benefit from seeing as well as hearing the decision-making process. Medical mystery solving is also the time when emotions that are felt towards the patient, one's coworkers, as well as the work itself affect the diagnosis. Thus, the emotions that arise and are expressed as a part of the work should be felt, examined, and discussed by those feeling them and possibly everyone who is working on the case.

Because of this structure and intent of the formal documentation, there were a number of attending physicians who mentioned the need for a medium to ruminate on decisions and share their feelings. A medium used to mull over care trajectories would support collaborative decision exploration. Such a medium would also be a safe place to share or consider one's feelings about the patient and the current course of care, and thus might be experienced as a safe place to discuss the patient's feelings and state of mind. The entire patient care team can track and reflect on what they are doing, why they are doing it, and how they expect it to progress. The lack of formality gives rise to more ambiguous expressions, which in turn encourage a more constructive interpretive process between collaborators.

Conclusion

The current direction for healthcare information systems is focused on one aspect of the information used in cooperative medical decision-making and treatment. But cooperative work, in any domain, is much more than pieces of information being passed between independent workers. It is a system that is both social and affective. In this paper I present an initial viewpoint to begin this discussion.

References

[1] Evans, A. M., Pereira, D. A., & Parker, J. M. (2008). Discourses of anxiety in nursing practice: a psychoanalytic case study of the change-of-shift handover ritual. *Nursing Inquiry, 15*(1), 40-48.

[2] Kerr, M. P. (2002). A qualitative study of shift handover practice and function from a socio-technical perspective. *Nursing and Health Care Management Issues, 37*(2), 125-134.

[3] Mentis, H.M., Reddy, M., Rosson, M. (2010). Invisible Emotion: Information and Interaction in an Emergency Room. *Proceedings of CSCW.*

[4] Mort, M. & Smith, A. (2009). Beyond information: Intimate relations in sociotechnical practice. *Sociology, 43*(2), 215-231.

[5] Mueller, F., Kethers, K., Alem, L., & Wilkinson, R. (2006). *From information transfer to ambiguity in hospital handovers.* Paper presented at OzCHI, Sydney, Australia.

[6] Philpin, S. (2006). 'Handing Over': transmission of information between nurses in an intensive therapy unit. *Nursing in Critical Care, 11*(2), 86-93.

[7] Zhou, X., Ackerman, M. S., & Zheng, K. (2009). I just don't know why it's gone: Maintaining informal information use in inpatient care. *CHI*, Boston, MA.

Trust and interactive health technology

Enid Montague, PhD
University of Wisconsin-Madison
Industrial and Systems Engineering Department
University of Wisconsin-Madison
3270 Mechanical Engineering
Madison, WI 53706
emontague@wisc.edu

Abstract

Trust is an integral component of all relationships and successful organizations. Trust in health systems takes on many forms. This paper will identify the important trust relationships in health systems and propose an integrative framework for the evaluation of trust in health related technologies.

Keywords

Trust, Health Care, Human Computer Interaction, Technology, Patients

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous. See [3] for help using the ACM Classification system.

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

General Terms

Human-Computer Interaction, Human Factors, Trust

Introduction

G Eysenbach (2001) defines ehealth as “an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology” (p. 20) [1]. The term ehealth has come to encompass a variety of types interactions in health care systems including business to consumer, where consumers interact with their health system via the Internet; business to business, where organizations interact with one another; and consumer to consumer where consumers interact with each other through technology [1]. eHealth includes a variety of technologies such as electronic medical records, telemedicine, consumer health informatics, and virtual healthcare teams. Human computer interaction researchers have explored the use of technology in terms of communication mediated by technology, consumer to consumer communication information technology and consumers interaction with businesses through technology.

Researchers have also explored the concept of developing and maintaining trust when information technology is introduced into relationships. However, studies have shown that users may have different ways of developing trust in health systems than they do in other technological systems [2].

As ehealth technologies become more widespread attention is turning to the factors that determine successful adoption and appropriate use. Currently trust is gaining the attention of those who develop and design websites that contain medical information [3, 4]. Trust is also a topic of interest to health care administrators and educators in terms of understanding interpersonal relationships between patients and care providers who believe that the presence of trust is a key factor in a successful health care relationship [5-7]. In this paper we explore the definition of trust in health technologies by gathering findings from trust in technology literature from a variety of domains. Trust in medical technology is the focus of this paper; the efforts expressed in this paper focus on trust related to medical technologies that are used in health care environments or to manage health information. The outcome of this paper is a trust in ehealth technology model that adopts our definition and can serve as a framework for experimental research.

Patient-provider trust

Understanding patient-physician relationships is an important precursor to understanding patient and physician relationships with health information technology. Much information is still needed in understanding patient physicians relationships, specifically in terms of the major research questions what is patient trust in physician, what factors are related to patients trust in physician, what are the outcomes of patient trust or distrust in physician.

Studies have found that patient trust in provider is correlated with satisfaction [6], perception of provider skill [8, 9], perception of interpersonal treatment [10], communication [8-10], the length of relationship with physician [6, 10], patient health status [6], certain patient demographics [6], how patient pays [6], and patient choice in physician. However differences in these findings have been identified across studies; for example some studies find no difference in a person's inclination to be trusting towards their physician based on ethnicity or socioeconomic status, while other studies have found trust in physician ratings to be significantly correlated with being White and health status [6]. Other studies have satisfaction to be a correlate of trust while others argues that there is little data to support a correlation between patients' assessments of satisfaction and trust in provider [5].

Understanding trust in ehealth has the potential to add to existing trust in physician literature; it is clear that ehealth initiatives have the potential to effect how patients and providers interact with one another about technology, with technology and in the presence of technology.

Human-technology trust

There is an abundance of research on trust in technology, though most of it may not be useful in the context of trust between users and health related technologies [2, 11]. In one set of research, researchers have explored user trust in automation technology by looking at how the design of automatic equipment in manufacturing or production processes systems influences users to trust or distrust the resultant technologies. This scholarship does not successfully represent the processes that patients as users and consumers undergo when forming trusting relationships with ehealth technologies [12]. In another group of trust in technology scholarship, researchers look at users trust in web based technologies, with a large portion of scholarship focusing on e-commerce. Researchers have looked at the relationship between the design of websites and user behaviors of trusting the websites with personal information. The scholarship involving trust between people and websites may serve as a useful model for patient and physician users of ehealth technology, but it fails to account for the effects of technologies on the interpersonal patient-provider relationship.

Patient Trust in eHealth

Health related technology has become an important aspect of health consumerism. Health information and services in an electronic format were primarily "informational" in the past; now patients can engage in many health-related activities electronically [13]. For example patients can: View their health records online, view health information for family, interact with others with similar health concerns, communicate with care providers online, communicate with other non-providers about their health electronically, search for information about their health symptoms and diagnoses online (see Figure 1).

The added complexity of technology in health care adds new dimensions of risk, communication and privacy. At the root of these constructs trust must be considered. In one way, we must examine how using technology changes the provider patient relationship for better or worse. In another aspect we must examine how patients use health technology while keeping their own information safe and find useful and reliable information for their care. In an ehealth model the patient holds a great deal of power in their health care, which also gives them more entities to trust or distrust. Future research must address how patients negotiate information from different sources, how their decisions effect the patient-provider relationship and important outcome variables such as patients adhering to advice, completing treatment plans, and seeking care when they need it rather than self diagnosis.

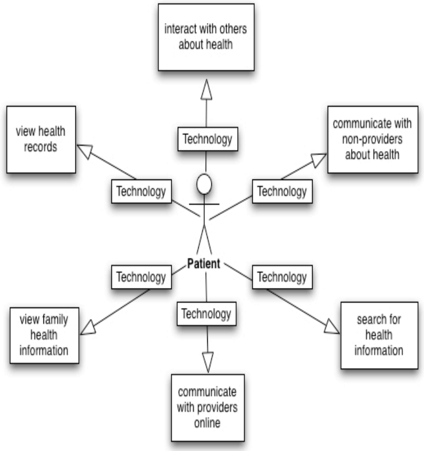


Figure 1 Patient ehealth relationships

Integrative model of trust and ehealth

In this paper we argue that medical technology cannot be removed from the relationships that are present in the existing health system. Specifically provider patient relationships are fundamental to patient technology relationships, as provider technology relationships have the ability to affect the patient provider relationship. The conceptual model for trust in medical technology builds upon socio-technical systems theory [14]. In this model interpersonal trust has the ability to effect trust between users and technologies. In order to engage in collaborative disease tracking with personal health records, the relationship between the patient and the technology depends on both the providers' relationship with the patient and the providers' relationship with the technology. The patient and the provider must both believe that using the technology will benefit the care providing process.

Acknowledgements

Supported by grant 1UL1RR025011 from the Clinical and Translational Science Award (CTSA) program of the National Center for Research Resources (NCRR), National Institutes of Health (NIH)

Citations

[1] Eysenbach, G. What is e-health? J Med Internet Res, 3, 2 (2001), e20-e20.
[2] Montague, E., Kleiner, B.M., & Winchester, W.W. Empirical evaluation of the construct trust in medical technology. International Journal of Industrial Ergonomics, 39, 4 (2009), 628-634.
[3] Eysenbach, G., Powell, J., Kuss, O. and Sa, E. R. Empirical studies assessing the quality of health information for consumers on the World Wide Web - A systematic review. Jama-Journal of the American Medical Association, 287, 20 (May 2002), 2691-2700.
[4] Eysenbach, G. and Köhler, C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews BMJ, 34 (2002).
[5] Pearson, S. D. and Raeke, L. H. Patients' trust in physicians: Many theories, few measure, and little data. Journal of General Internal Medicine, 15 (2000), 509-513.
[6] Kao, A. C., Green, D. C., Davis, N. A., Koplan, J. P. and Cleary, P. D. Patients' trust in their physician: Effects of choice, continuity, and payment method. Journal of General Internal Medicine, 13, 10 (1998), 681-686.
[7] Thom, D. H. and Campbell, B. B. Patient-physician trust: an exploratory study. J. Fam. Pract., 44, 2 (1997).
[8] Thom, D. H., Kravitz, R. L., Bell, R. A., Krupat, E. and Azari, R. Patient trust in physician: Relationship to patient requests. Family Practice, 19, 5 (2002).
[9] Thom, D. H., Ribisl, K. M., Stewart, A. L. and Luke, D. A. Further validation and reliability testing of the Trust in Physician Scale. Med Care, 37, 5 (May 1999), 510-517.
[10] Safran, D. G., Kosinski, M. and Tarlov, A. R. The Primary Care Assessment Survey: Tests of data quality and measurement performance. Medical Care, 36 (1998), 728-739.
[11] Timmons, S., Harrison-Paul, R. and Crosbie, B. How do lay people come to trust the Automatic External Defibrillator? Health Risk Soc., 10, 3 (2008), 207-220.
[12] Montague, E., Winchester, W.W. Kleiner, B.M. Trust in medical technology by patients and health care providers in obstetric work systems. Behaviour & Information Technology (in press).
[13] Wilson, E. V., Dobrzykowski, D. D. and Cazier, J. A. The Influence of Media Trust and Internet Trust on Privacy-Risking Uses of E-Health. International Journal of Information Security and Privacy, 2, 3 (2008), 8-7.
[14] Trist, E. The evolution of socio-technical systems: A conceptual framework and an action research program. Wiley Interscience, City, (1981).

Experiencing without interacting: Patient user experiences with medical technologies

Enid Montague, PhD
Department of Industrial and Systems Engineering
University of Wisconsin-Madison
Madison WI 53706 USA
emontague@wisc.edu

Abstract

Patient user experiences with medical technology may be important predictors of patient ratings of satisfaction with health care systems and of acceptance of technologies used in their care. The purpose of this study was to understand how patients experience medical technology during medical events as passive users. 25 women were interviewed about the technologies that were used to provide them care during the birth of their child. Interviews were transcribed verbatim and reduced to codes in the qualitative data analysis tradition. Results show that patients have user experiences with technologies as passive users.

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Keywords
User Experience, Theory, Health, Experience Design

ACM Classification Keywords
H.1.2 User/Machine Systems, J.3 Medical information systems, H5.m. Information interfaces and presentation

Introduction

Human computer interaction theorists have begun to explore new definitions of user experience that include concepts such as trust, engagement, fun and fidelity [1, 2]. This study used qualitative research methods to develop a typology of obstetric patients' user experiences with medical technology and proposes a socio-technical systems framework for measuring and understanding patients' total user experience with medical technology. We examined patients' user experiences with medical technologies during the birth of their child using open-ended interviews with 25 mothers after they had given birth. The decision to explore patients' experiences with the technologies used in their care, was based on our hypothesis that patients have experiences with technologies and the technologies affect patients' experiences, even when patients are not active users of the technologies, in the same sense that their care providers might be.

Researchers have argued for the importance of Users bring an array of individual characteristics such as emotions, values, experiences, and mental models for interpreting sounds, sight, and touch; each of these characteristics effects new and current experiences [3]. To design a user experience the designer must understand the user holistically, which is particularly important when designing technologies for a health care experience. The experience of being a patient is one of inherent vulnerability and consternation; which may be created at the moment of the medical event or over time as one prepares for the event with smaller medical events. An experience contains countless discrete experiences that are associated with various environments, individuals and objects [3]. The experience of having a baby is made of many small experiences such as the physical experience of being pregnant, having an ultrasound, visiting a hospital, interacting with a doctor and attending a childbirth class. A woman may have many key stakeholders in her experience, such as her friends and family who have had babies before her, her doctor, and her partner. The context of her interactions with her health care providers has the potential to create a type of experience for her; a warm homely doctors office creates a different experience from a sterile, clinic office.

This study examined the user experiences of patients in an obstetric work system to build upon theoretical perspectives of user experience that move user experience with technology beyond usability. We were interested in how patients developed and expressed user experiences with technologies they might not use. We also wanted to understand the emotional aspect of user experience in health care, emphasizing how aspects of interactions with technologies and systems might lead to positive or negative user experiences. Lastly, we wanted to define user experience in the context of humans as both patients in a health care environment and as passive users of a technology.

Methods

Participants. Twenty-five new mothers represented the patient group. All mothers had given birth in a hospital and were between the ages of 19 and 35. To explore patients' experiences with the technology they were interviewed about the kinds of technologies that were used in their childbirth experience, what they noticed about the technology and how the technology made them feel. Interviews were transcribed verbatim and data were analyzed using grounded theory methods, processes, actions and interactions involving many individuals were studied [4].

Results

Patients reported the technologies that were used during the births of their children; which were coded individually and then grouped into singular codes to describe technologies that were essentially the same. Participants' responses to what they noticed about the technology were divided into what they could see, hear and feel. Thirty-three codes were derived from sight, 14 codes were derived from feelings and 13 codes from hearing. Example codes for seeing included being able to see the monitor, alarms, pulse rate, and graphical readouts. The group feeling contained codes such as feeling the internal fetal monitor, the monitor during contractions, the oxygen mask, and straps of the monitor around the stomach area and blood pressure cuffs. Hearing included codes such as hearing heart beats, unidentified beeps, unidentified noises, the baby's heart beat, and monitor print outs. After open coding, patients' experiences with the technologies were categorized into ten positive experiences and twelve negative experiences.

Discussion

The results show that patients have user experiences with technologies that are used in their care and translate the feedback they receive into positive and negative feelings. Examples of negative experience included:

1) Generally feeling that technology was uncomfortable because it restricted their movement and movement affected monitors functioning. Nicole expressed negative feelings about immobility and depending on others when she said "I didn't like having to wear the monitors. I mean they put them around and she… kind of… you're kind of on a leash, so if you are trying to turn around to get comfortable, you can't."

2) Participants described frustration about having to use intervention that they perceived to be unnecessary. These interventions included intravenous therapy, automated blood pressure cuffs, and points where doctors suggested they interventions that had not planned for such as induction and epidurals.

3) Unreliability was a salient theme in negative experiences as indicated by the number codes between and within interviews. Participants expressed negative feelings when they could not depend on the technology to accurately reflect the health and well being of their baby. Jennifer discussed how unreliability contributed to a negative experience when she said:

> *"It's a little nerve wracking when they are like okay you know uh you know we are suppose[d] to be able to monitor the baby's heart rate and we can't find it. Even the attitude of the nurses in the room, they were agitated when they couldn't find the heart rate so you know and then, you know, you hear the beeeeeep, the loud beeps of straight lines and things like that. So it is, you know"*

4) A final major theme in negative experiences included participants' feelings that the technology was unnatural in their experience. The unwanted presence of technology was expressed by codes that described the presence of the machines and their outputs as distracting, the technology as unnatural and feeling like they were "in a hospital" as an unwelcomed experience.

Conclusion

One of our objectives was to define user experience in context for patients in a health care environment. Our results provide evidence to support the notion that patients have experiences with technologies used in their care. We also hoped to understand the relationship between characteristics of the technologies and positive or negative user experiences. When technology worked well, it had the potential to create positive experiences and enhance the patients' connection with their babies. Examples of designs that enhanced the emotional experience were the audible simulated heartbeat; when patients could hear the heartbeat they felt reassured that their baby was ok. Negative experiences occurred when technology did not work well or when care providers could not get technologies to work properly. We hypothesized that patients would expect their interactions with the technology to reflect their expected emotional experiences. Patients identified mismatches between the experience the technology afforded them and their desired experience. These experiential mismatches were reflected in patients' desire not to feel like they were in a hospital or feeling the technology was an unnatural artifact in their experience. Patients also identified experiences where technologies met their expected needs, such as a need for more information or assurance that they were receiving high quality care. Patients' experiences with technologies contributed to positive and negative experiences as individuals and the resultant co-experiences patients experienced with their birth partners and care providers [3].

This study was limited by its small sample size, study population. The qualitative methodology used, was not intended to build causal relationships but to generate hypotheses about patient user experiences. Future studies should explore patient user experiences in other health care contexts and the effects of patients' positive or negative user experiences on the health care work system. Understanding how to design technologies that create positive experiences for both patients and workers will lead to more effective health care systems.

Acknowledgements

Supported by grant 1UL1RR025011 from the Clinical and Translational Science Award (CTSA) program of the National Center for Research Resources (NCRR), National Institutes of Health (NIH).

Citations

[1] Blythe, M. W., P. From usability to enjoyment. Introduction in Funology: From usability to Enjoyment. Kluwer Academic Publishers.

[2] Davis, M. Theoretical foundations for experiential systems design. In Proceedings of the Proceedings of the 2003 ACM SIGMM workshop on Experiential telepresence (Berkeley, California, 2003). ACM Press.

[3] Forlizzi, J. and Battarbee, K. Understanding Experience in Interactive Systems. In Proceedings of the DIS2004 (Cambridge, Massachusetts, USA, 2004).

[4] Creswell, J. W. Qualitative inquiry and research design. SAGE, Thousand Oaks, Calif, 2007.

Designing Interactive Systems for College Students' Health

F. Daniel Nicolalde
Department of Industrial and
Systems Engineering
University of Wisconsin
Madison, WI 53706 USA
fdnicolalde@wisc.edu

Elizabeth Konkol
Department of Industrial and
Systems Engineering
University of Wisconsin
Madison, WI 53706 USA
ekonkol@wisc.edu

John Capista
Department of Industrial and
Systems Engineering
University of Wisconsin
Madison, WI 53706 USA
jacapista@wisc.edu

Mitchelle B. Lyle
Department of Industrial and
Systems Engineering
University of Wisconsin
Madison, WI 53706 USA
lyle@wisc.edu

Enid Montague
Department of Industrial and
Systems Engineering
University of Wisconsin
Madison, WI 53706 USA
emontague@wisc.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

Weight gain is a common challenge for college students, and designing interactive systems that provide health information can help students make better lifestyle choices. Busy schedules and long homework assignments leave little time to exercise and eat healthily. The goal of this study was to determine if online and mobile interactive health applications can help students to manage their schedules by capturing workout data and providing diet information. This project developed and evaluated a health management application for students to manage diet and exercise plans. The study found that information and communication technologies (ICT) integrated with university resources can help students set health goals and provide an easy tracking system to help students stay healthy during the college adaptation process.

Keywords

Students, Interface Design, Wellness, Health, Mobile Application.

ACM Classification Keywords

H.5.2 User Interfaces, H.5.m. Miscellaneous.

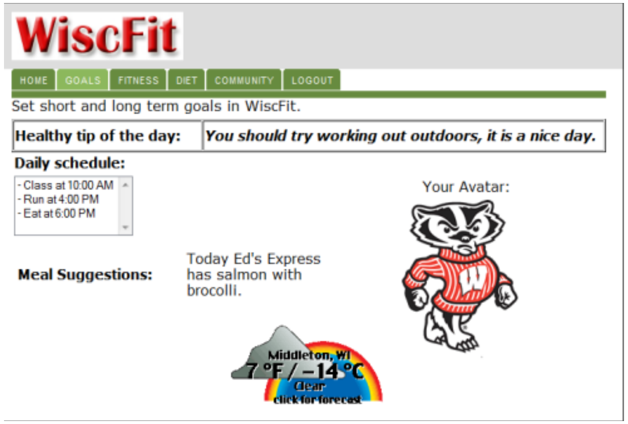
General Terms

Health management, Adolescent, College

Introduction

The “freshman 15” is a reality among the majority of college students in the U.S. Approximately 70 percent of students gain weight between the start of college and the end of sophomore year [5]. Overall, students are not meeting their dietary and exercise needs [1]. The design of interactive systems for health management has the potential to help maintain healthy lifestyles by providing meaningful information. These systems should be human-centered and focused on individual health to meet user needs. Some of the barriers documented for college students include poor time management and lack of accessible healthy foods [5]. Ubiquitous technology can assist in minimizing or eliminating some of these barriers by managing and tracking diet and exercise. College students are ideal candidates for using interactive health applications to make better choices regarding their diet and exercise, and findings in this population can be used to develop interactive systems for other age groups. ICTs for health management should be designed following user-centered design principles and through constant feedback from end-users to match user mental models. Health informatics tools should target problem areas and help users adapt to new environments by evolving with user needs, thus preventing adverse health outcomes (e.g. weight gain, alcoholism)[1][5].

This study developed and evaluated an interactive health system called WiscFit, for a class project. This system advises students about their diet and exercise schedules. WiscFit can help users find workout partners, set wellness goals, reach goals, and monitor progress. The system was evaluated based on the following questions: Would users find the system helpful to manage their health goals? Does the system match user mental models for interactive health tools? Are users willing to upload workout information on a regular basis?



Set short and long term goals in WiscFit.

Healthy tip of the day: ***You should try working out outdoors, it is a nice day.***

Daily schedule:

- Class at 10:00 AM
- Run at 4:00 PM
- Eat at 6:00 PM

Meal Suggestions: Today Ed's Express has salmon with brocolli.

Figure 1. Homepage of the WiscFit online application homepage

Design Process

The design team used a contextual inquiry process to develop a health management product concept. The target population was observed in their everyday environment and their interactions with ICT were examined to identify how ICTs could be used for health management. Available products for maintaining healthy lifestyles such as caloriecount.about.com, realage.com, UbiFit Garden [2], and healthvault.com were also evaluated. The design process included the creation of storyboards, paper prototypes, a video prototype, and an interactive prototype. All prototypes were evaluated and tested by college students. The paper prototype featured tasks that were important for the goals of the project, which included registering, completing a fitness test, creating a workout schedule,

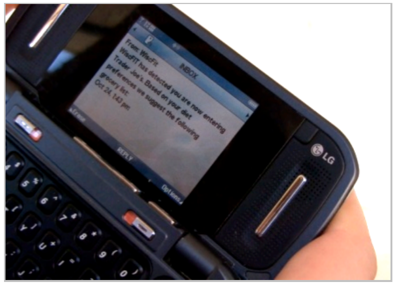


Figure 2. Integration of WiscFit with the SMS system of a cell phone, used during the video prototype.

and setting goals. The paper prototype was tested using the verbal protocol think-aloud method during observations. After completing the tasks, follow up questions were asked. The video prototype (Figure 2) was evaluated with three students, the class professor, and classmates. Their feedback was used to develop the interactive prototype. This prototype had two access interfaces to WiscFit: a mobile application and an online health management website (Figure 1). The mobile application was used to test the input of workout information from smart phones, and the health management website was used to test user interaction with the system and usability of the site design.

User Testing

Two groups of five students tested the system; each individual evaluated one interface. For the mobile interface, users recorded workout times via the mobile application for five consecutive days. The online health management site was evaluated by asking users to complete tasks which included: registering for WiscFit, scheduling time to work out, completing a fitness test, and posting a message on the wellness community board. The overall measures of the effectiveness and success of WiscFit included the completion of tasks and daily use of the mobile application.

Results

Mobile WiscFit Application Results

Students produced health data to help reach fitness goals by uploading workout times on smart phones. Four of the five participants used the WiscFit mobile application daily. Of the users who answered a post-survey, all answered "yes" to the application being easy to access. Two users stated that the application was easily integrated into their daily lives.

Online WiscFit Application Results

Users were able to provide and obtain health information through the online application. During the registration, some users were confused with interface labels and wanted to know their registration progress. Integration with other calendar systems was identified as a helpful feature. The instructions for the fitness test were not clear for some users. In addition, some users had difficulties accessing the online community page.

Discussion

Interactive systems for health management, such as WiscFit, should be designed for access in user homes and "on the go." Integrating health management systems with available resources, such as those provided by universities to students, is necessary to promote regular use. These systems can help students maintain healthy lifestyles and prevent weight gain or other adverse health outcomes. University students are avid users of internet tools [3], thus, online health management applications that can be accessed through computers or smart phones are suitable for this population. Moreover, students have access to sport facilities and food plans that can be used to meet their health goals.

The team built a proof of concept health management application, tested its key features and designed mock-up mobile and online applications with the purpose of tracking user workouts and providing data input into a health management system. Overall, the team learned several important design improvements for the development of health management applications. For the mobile application, the results were ecologically valid as users input data "on the go" during their daily routines. The application should focus on individual health by allowing user customization depending on user goals. The following are some trends seen throughout the project:

- Users found the fitness schedule useful
- Registration and fitness test were unclear
- Fitness test took longest to complete
- Forgot to enter times in the mobile application
- Interface clarity and simplicity is crucial

In the future, ubiquitous computing would allow the system to automatically detect when a user enters a sports facility or begins exercising. The interface of online applications must be simple, secure and straightforward when users are inputting health data. The user testing was beneficial in this regard, and the team was able to note changes to be made in a future version of the application such as tab order, unify login, and progress status. Adding clear labels and help options are also useful features. Mobile applications must not be cumbersome for the users and should also work without internet access.

Some of the unanswered questions that the team has include: Would users continue to use WiscFit after they have identified a routine in college? Would users tolerate uploading their exercise and diet to an online application? If users do not carry their phone to the gym, how will the system keep track of their exercise?

Health management systems should adapt to user needs as they progress toward their goals. Uploading and storing personal health information on online services is a concern among users [4]. Finding alternative methods for entering data can allow more students to use the system. These research topics and questions can only be answered by testing with a fully functional application for an extended period of time.

Acknowledgements

The team thanks Dr. Ricardo Prada for feedback during the design process and to Brennan's Health Systems Lab. The project was supported by grant 1UL1RR025011 from the National Institutes of Health (NIH).

References

[1] Cluskey, M. and Grobe, D. College weight gain and behavior transitions: male and female differences. *Journal of the American Dietetic Association 109*, 2 (2009), 325-329.

[2] Consolvo, S., McDonald, D.W., Toscos, T., et al. Activity sensing in the wild: a field trial of ubifit garden. *Proceeding of the twenty-sixth annual SIGCHI conference on Human factors in computing systems*, ACM (2008), 1797-1806.

[3] DeBar, L.L., Dickerson, J., Clarke, G., Stevens, V.J., Ritenbaugh, C., and Aickin, M. Using a website to build community and enhance outcomes in a group, multi-component intervention promoting healthy diet and exercise in adolescents. *Journal of Pediatric Psychology 34*, 5 (2009), 539-550.

[4] Lobach, D.F., Willis, J.M., Macri, J.M., Simo, J., and Anstrom, K.J. Perceptions of Medicaid beneficiaries regarding the usefulness of accessing personal health information and services through a patient Internet portal. *Annual Symposium Proceedings. AMIA Symposium*, (2006), 509-513.

[5] Racette, S.B., Deusinger, S.S., Strube, M.J., Highstein, G.R., and Deusinger, R.H. Weight changes, exercise, and dietary patterns during freshman and sophomore years of college. *Journal of American College Health: J of ACH 53*, 6 (2005), 245-251.

Exploring Persuasive Techniques for Medication Compliance

Rodrigo de Oliveira
Telefonica Research
Via Augusta 177
Barcelona, 08021 Spain
oliveira@tid.es

Mauro Cherubini
Telefonica Research
Via Augusta 177
Barcelona, 08021 Spain
mauro@tid.es

Nuria Oliver
Telefonica Research
Via Augusta 177
Barcelona, 08021 Spain
nuriao@tid.es

WISH 2010 April 11, 2010, Atlanta, Georgia, USA

Abstract

Mobile applications that incorporate persuasive techniques have recently been shown to have a positive impact in helping their users achieve pre-defined wellness goals (*e.g.*, keeping active, eating healthier, *etc.*). In this paper, we present MoviPill, a mobile phone based application that combines a set of persuasive techniques (*i.e.*, social competition through a game, social support, virtual rewards and entertaining self-monitoring) to help patients improve their levels of medication compliance. In a 6-week field study, 18 elders used a simplified version of MoviPill that included only the game component. Still, both their compliance levels and the precision of the drug intake time improved by 60% and 43% respectively, when compared to the baseline (*i.e.* their usual medication reminding tools). We plan on evaluating the additional persuasive techniques with further studies.

Keywords

Mobile interface, elderly, medication compliance, healthcare, game, user study

ACM Classification Keywords

H5.2. Information interfaces and presentation (e.g., HCI): User-centered design.

Introduction

Medication adherence is an essential component of a successful health outcome. However, a recent review of 139 studies reporting compliance data showed that only 63% of patients continue with their medication after a year and patients take their medication only 72% of the time [1]. The World Health Organization envisions a

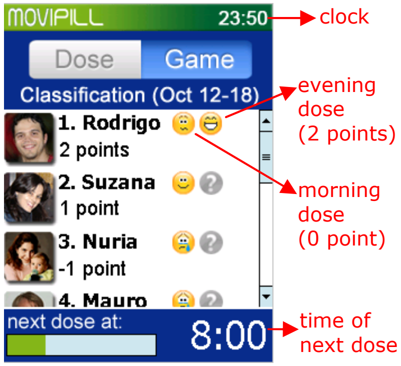


figure 1 MoviPill game screen with the ranking of players. Emoticons represent how compliant they were with that dose (*i.e.*, a laughing face is 2 points, smiling is 1 point, worried is 0 point, and crying is -1 point).

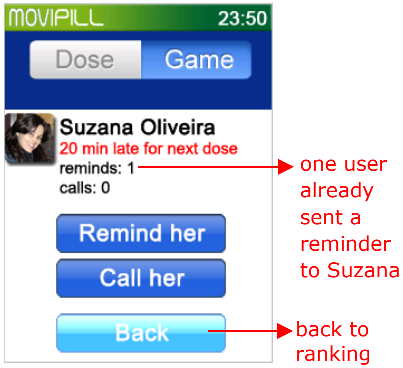


figure 2. Mockup of the social support persuasive technique applied as part of the MoviPill game. In the example, information on how late the user “Suzana” is to take her medication (screen visualized after choosing this user from the ranking list in figure 1).

more pessimistic scenario estimating that only 50% of patients follow their doctors’ prescriptions. In order to tackle this challenge, medical experts have tried a variety of approaches, such as creating special calendars, “smart containers”[1] , mobile phone-based reminders, systems for pharmacist telephone follow-up intervention [3], among others (Kripalani et al. [5] compiled a review with several of these approaches). Still, previous work reports cases in which medication compliance was not improved by reminders *alone* [4], or even where automated reminders were perceived negatively by the users [6]. The problem lies on the fact that passive reminders do not typically engage users in doing the tasks by themselves. Hence, the main hypothesis that motivates the work presented here is that *patients can become more compliant in taking their medications when the task is not seen as an obligation*, *but rather as an engaging experience.* We propose a mobile phone-based system called MoviPill that combines four different persuasive strategies in order to address engagement: social competition, social support, virtual reward and entertaining self-monitoring. Next, we present the MoviPill system and outline major findings derived from the field study.

MoviPill system

Our approach towards increasing levels of compliance (remembering to take a dose) and adherence to medication regimens (taking doses at the prescribed time) aims to change how the drug intake task is perceived. In order to provide an engaging experience, our solution is based on a mobile phone application that applies four different principles of persuasion [2]:

- Social competition: Users of the MoviPill system are connected through a social network that relates their illness with the reality of other people. Implemented as a game, this technique persuades patients to be more compliant to their medication by trying to win their peers in weekly competitions. The game dynamics are simple: more points are given to players that take their medication very close to or at the prescribed time, and fewer points otherwise (see figure 1). Most compliant patients are highlighted in a virtual “hall of fame” and a record of their drug intake routine is stored as an additional resource for their caregivers;
- Social support: Game players can also get more points by reminding peers to take their medication on time (see figure 2). We expect patients to be more engaged in the drug intake task by receiving *social reminders* instead of system reminders.
- Virtual rewards: Whenever MoviPill users take their medication on time throughout the day, they are offered a virtual reward, such as a family photo, a favorite song, or a joke (see figure 3).
- Entertaining self-monitoring: MoviPill minimizes the boredom and complexity of tracking medication compliance by combining appropriate statistics with an engaging virtual character that is shown on the idle screen of the mobile phone (*e.g.*, if the character is a dog, it looks and acts happy when the patient is being compliant and sick otherwise – see figure 4);

The current version of the MoviPill prototype implements the social competition principle. We describe next the methodology of the user study to evaluate the impact of this persuasive technique on medication compliance.

Field Study

Participants

Eighteen participants (male: 9; mean age: 68 years, *S*=4.19) were recruited by phone for a 6-week user study. A randomized sampling methodology was used and participants were assessed by FASS[2], a social service foundation in the autonomous community of Andalusia (Spain). All subjects were retired, did not know each other, received 40 euro (about 59 USD) as a gift for participating in the experiment, and they *did not* receive any monetary incentive for winning the weekly

---

[1] MEMS (aardexgroup.com), Glowcaps (rxvitality.com)

[2] www.juntadeandalucia.es/fundaciondeserviciossociales

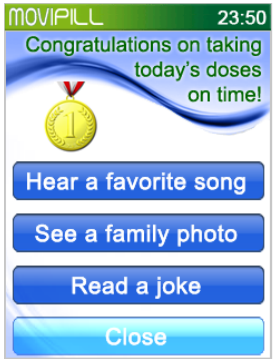
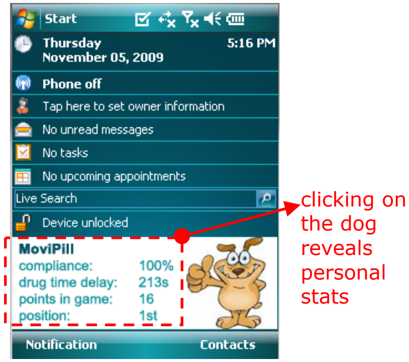


figure 3. Mockup of the virtual reward reward persuasive technique. In the example, the user took his/her daily medications on time and can opt for hearing a favorite song, seeing a family photo or reading a joke.



MoviPill
compliance: 100%
drug time delay: 213s
points in game: 16
position: 1st

figure 4. Mockup of the self-monitoring persuasive technique. In the example, the startup screen on the user's mobile phone with a happy dog on the bottom indicating that, so far, the patient has been compliant to his/her medication prescription.

competitions of the MoviPill game. Thirty-nine percent lived with a husband or spouse, while the rest lived alone. Ten (55%) did not have any experience with computers, while 4 (22%) had an intermediary knowledge, and the remaining 4 (22%) were advanced users. In terms of medication compliance, the majority of the participants (12 or 67%) reported that they did not typically forget to take their medications; four participants (22%) forgot rarely, and 2 (11%) forgot sometimes. As for the strategy that participants used to remember to take their medications, 3 participants (17%) reported using some form of spatial arrangements of the pillboxes, while the majority (14 or 78%) remembered to take their medications because of their daily routines. Only one participant (5%) declared taking advantage of family members that reminded her to take her medications.

Apparatus

Each participant was assigned a HTC smartphone (model P3300, with its charger) with the MoviPill application and a pillbox equipped with a sensor (maker AARDEX model MEMS 6 – see figure 5). The pillbox was used to collect ground truth on the users' medication intake in order to compare with data manually entered by them via the Dose interface in the MoviPill application (see figure 6). Drug intake information entered via the Dose interface was transmitted in real time to the remote server and MoviPill refreshed the game status after every 5 minutes to ensure the data presented in the game was always updated.

Procedure

During the first meeting with each participant, we explained the mechanics of the game, supervised the initial interactions with the application, and helped them to transfer their medication into the MEMS pillbox. For this study, we focused on one –not life threatening, *e.g.*, prescribed for pain, attention, *etc.*– medication that needed to be taken twice per day so that each participant had the same chances of winning points. Participants were asked to continue taking their other medications using their usual routines.

Two intervention methods were evaluated in the study: *Button* and *Game*. On the *Button* treatment, subjects used the smartphone to register each drug intake by pressing a single button on the screen (equivalent to the button shown in figure 6, but on a blank screen). In this treatment, participants had to trust their own methods to remember when to take their medication. In the *Game* treatment, subjects also used the smartphone to register each drug intake (see figure 6), but they also had a "Game" button on the screen to view the weekly ranking –by compliance– of all the participants in the game and their daily drug intake status (see figure 1). The *Button* treatment was used instead of a standard control group (*i.e.*, electronic pillbox *without* the phone) because in the case of proving that subjects were more compliant in the Game treatment, we wanted to guarantee that the reason was the game, and not simply because of introducing new technology to the participants' day-to-day life.

Given the size and nature of our sample, we decided to conduct a crossover experimental design to eliminate individual differences from the overall treatment effect. Therefore, our sample was randomly divided in two groups of nine subjects, and each group was submitted to one of the treatments in the first three weeks (*i.e.*, users 1-9: *Game*; users 10-18: *Button*) and to the other treatment in the remaining three weeks (*i.e.*, users 1-9: *Button*; users 10-18: *Game*).

Results and Discussion

From a total of 1512 doses over the 6-week period, only 15 doses were not taken in the Button treatment (1%). However, when participants were playing the game, this small level of noncompliance was reduced by 60% (six missing doses). Moreover, only one out of 18 subjects was more compliant when submitted to the Button treatment than to the Game treatment, which is a good indicator of why a significant difference could be found between the medians of prescription adherence in both treatments ($N = 18, Z = -2.263, p = .024$). These results reveal that even with a very compliant sample, a significant improvement could be observed, thus

figure 5. MEMS electronic pillbox used by the participants of the study.

figure 6. MoviPill dose screen where patients inform medication intake. Drug intake data gathered by the phone was matched with ground truth data gathered by the MEMS pillbox to check if elders were pressing the button at the right time but taking the dose later on (game cheating).

confirming that *a mobile social persuasive game can help elders adhere to their medication prescription.*

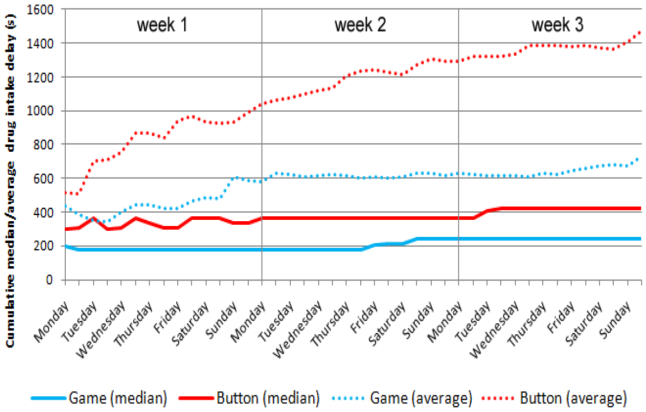


figure 7. Comparison of median and average drug intake delays over time in the Game and Button treatments

With respect to adherence to medication regimen, participants took their medication with a shift of ±25 minutes on average of the prescribed drug intake time ($\overline{x} = 1471s$ in Button; $\overline{x} = 731s$ in Game). Due to the presence of outliers, the median drug intake delay better characterizes the data, revealing a 43% improvement when participants played the game ($\tilde{x} = 240s$ vs. $\tilde{x} = 420s$; $N = 720$, $Z = -8.944$, $p < .001$). Another way to analyze this data is to consider each participant's median drug intake time as a single output and compare the median of the medians between treatments. Again, a significant difference could be found between regimen adherence in the Game and Button treatments ($N = 18$, $Z = -2.250$, $p = .024$). Therefore, we corroborate that *a mobile social persuasive game can help elders adhere to their medication regimen (i.e., take doses at the prescribed time)*. Figure 7 compares median and average drug intake delays over time for each treatment.

These results led us to reflect on the impact of social competition for the elderly. Note that none of the users knew each other and no incentives were offered to those winning the weekly competitions. It is very interesting to see that such a simple persuasive technique is able to motivate compliant patients to be even more compliant. We expect the impact of the MoviPill prototype to be even more significant on samples of non-compliant subjects.

Conclusions and future work

We have explored the use of social competition as an effective persuasive technique to improve adherence to both medication prescription and medication regimen. In ongoing work, we plan to validate the impact of the other persuasive techniques that are part of the MoviPill system: virtual rewards, entertaining self-monitoring and social support during the game.

Acknowledgement. We would like to thank the FASS staff and the e-Health Telefonica I+D Granada. R. de Oliveira is partially funded by the Torres Quevedo program (Spanish Ministery of Science and Innovation, co-financed by the European Social Fund).

References

[1] Cramer, J. A., Benedict, A., Muszbek, N., Keskinaslan, A., Khan, Z. M. The significance of compliance and persistence in the treatment of diabetes, hypertension and dyslipidaemia: a review. *Int. Journal of Clinical Practice* 62,1 (2008), 76–87.

[2] Fogg, B. J. *Persuasive technology: using computers to change what we think and do.* Morgan Kaufmann, 2003.

[3] Garnett, W. R., Davis, L. J., McKenney, J. M., Steiner, K. C. Effect of telephone follow-up on medication compliance. *American Journal of Hospital Pharmacy* 38, 5 (1981), 676–679.

[4] Hayes, T. L., Larimer, N., Adami, A., Kaye, J. A. Medication adherence in healthy elders: Small cognitive changes make a big difference. *Int. Journal of Aging Health* 21, 4 (2009), 567–580.

[5] Kripalani, S., Yao, X., Haynes, R. B. Interventions to enhance medication adherence in chronic medical conditions: a systematic review. *Archives of Internal Medicine* 167, 6 (2007), 540–550.

[6] Toscos, T., Faber, A., Connelly, K., Upoma, A. M. Encouraging physical activity in teens: Can technology help reduce barriers to physical activity in adolescent girls? *In Proc. PervasiveHealth* (Tampere, Finland, 2008), pp. 218–221.

Using ICT in the Design of Health Preventions in Developing Countries: Lessons from Angola

Daniel J. Ortiz
Charles Drew University of Medicine and Science
Department of Psychiatry and Human Behavior
1731 East 120th Street, Building N
Los Angeles, CA 90059 USA
danortiz@cdrewu.edu

Karen G. Cheng
Charles Drew University of Medicine and Science
Department of Psychiatry and Human Behavior
1731 East 120th Street, Building N
Los Angeles, CA 90059 USA
karencheng@cdrewu.edu

Ricardo Ovalle-Bahamón
Charles Drew University of Medicine and Science
Drew Center for AIDS Research, Education, and Services
Luanda, Angola
ovalleri@gmail.com

Eric G. Bing
Charles Drew University of Medicine and Science
Department of Psychiatry and Human Behavior
1731 East 120th Street, Building N
Los Angeles, CA 90059 USA
Eric.g.bing@gmail.com

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

This paper compares the degree of engagement and sustainability across several modalities of presentation by examining multiple HIV prevention interventions for the Angolan military.

Keywords

User study, HIV/AIDS, ICT, health education, motivation, developing country.

ACM Classification Keywords

H5.2 [**User Interfaces**] User-centered design; K.4.2 [**Computers and Society**]: Social Issues.

Introduction

Many of the diseases affecting the world's population are preventable. Effective prevention behaviors for diseases like malaria and HIV can change the course of these pandemics. This is especially true in developing countries where effective treatment may be scarce or unaffordable.

Many of the strategies used for disease prevention focus on providing prevention information lectures, informational brochures and condoms. However well intentioned, these strategies may never capture the attention of the intended audience and the repetition of activities such as lectures or reading brochures can become dull, quickly reducing the likelihood of behavior change.

To create interest and motivate people to change their behavior, engaging prevention methods are necessary. In other words, people need to be engaged by the disease prevention strategies so they will learn and apply the information. However, given the resource limitations within many developing countries, it is often critical that the prevention strategies are cost-effective, efficient and sustainable within the local context.

In Angola, we were challenged to address the HIV prevention needs of the Angolan armed forces within an environment where the risk of HIV infection is high and access to technology is low. Sub-Saharan Africa remains the worst affected area of the pandemic with an estimated 22.4 million adults and children living with HIV/AIDS [1]. In Angola, like many developing countries, people have limited access to modern computer technology. For example, the number of internet users in North America, 253 million (74% of the population), is dramatically higher than internet users in Africa, 67.3 million (7% of the population) [2]. Limited access to technology makes it difficult to use of a number of ICT methods to disseminate information and motivate HIV risk behavior change.

The experience of developing of multiple HIV prevention interventions for the Angolan military provided the opportunity to compare degree of engagement and sustainability across several modalities of presentation.

Interventions

For over eight years members of this research team have worked on a number of HIV/AIDS related projects with the Angolan Armed Forces which have shaped our thinking. Through focus groups, behavioral surveillance, implementing and evaluating a 5-day intensive HIV prevention intervention, and creating a HIV prevention card game and HIV prevention radio drama, we have increased our knowledge and understanding of Angolan military life and how to engage soldier around HIV prevention behaviors.

In 8 focus groups, we found that although a number of soldiers were familiar with HIV/AIDS, the level of knowledge was very limited, and misperceptions regarding signs, symptoms, and transmission were pervasive [3]. One major concern was a lack of perceived vulnerability because soldiers did not personally know anyone who had died of AIDS. As one focus group member shared, "we never saw a person that said he had AIDS." This statement is not surprising given the high level of stigma associated with being HIV positive in Angola.

Results from a behavioral surveillance survey (n = 1977) we conducted with Angolan servicemen and police reveal a portrait of a high risk lifestyle and limited information about HIV prevention [4].

Paper-Based Intervention

During the piloting of a 5-day HIV intervention, we found that participants particularly enjoyed a HIV prevention comic book that had been created specifically for the intervention [5]. Participants were told the story of a soldiers who became infected with HIV. During the intervention the participants carefully wrapped the comic book in plastic to protect it from the inclement weather, and called each other by the main character’s name (Lunguka). This proved to be a fruitful vehicle for teaching the HIV prevention material, as well as a way of having participants describe the story of Lunguka to others to disseminate the prevention messages on the base. However, this method may be limited in that it is very repetitive for those teaching the information and didactic rather than interactive. Over time, these activities can lose their appeal for the teacher and the participant.

Game-based Intervention

In response to the interest in the Lunguka comic book and the desire for more engaging activities, our team developed a card game that complemented our program of prevention as well as provided an opportunity to test a new technologically appropriate method for HIV prevention. The goal of the game is to have the fewest number of "HIV risk" points at the end of the game. The card game, which incorporates rules similar to a number of popular card games such as "UNO" and a popular Angolan card game known as "Vassoura," was developed with a prevention focus. Cards have particular HIV risk behaviors (e.g., sex with a prostitute, being infected with an STD) that require players to pick up cards, while other cards will reduce points (e.g., practicing abstinence, condoms) to an individual's score. The game ends when one player gets rid of all of the cards in his or her hand.

ICT-Based Intervention

Given the technology used by the majority of the soldiers within Angola, we were limited to the ICT we could use. Therefore, to expand the reach of the HIV prevention messages and still maintain engagement with soldiers, we developed a HIV prevention radio drama. Building upon what learned in the previous interventions, we developed a program that incorporated narratives from real soldiers in an on-going radio program to address many of the challenges faced by soldiers in preventing infection with HIV. This program proved to engage military members to listen regularly, increase the legitimacy of HIV prevention programs, and increase involvement in HIV prevention by military members of all ranks.

These studies have revealed the importance of HIV prevention interventions in the Angolan military and the value of engaging activities to increase the motivation of participants to remember and teach others the HIV prevention messages.

Discussion

Through the process of developing multiple HIV prevention interventions for the Angolan military we learned important lessons about engagement and project sustainability. First, we realized that what is engaging in one format is not necessarily engaging in another. Using different formats required that we adjust the prevention messages according to the way people prefer to read, play games or listen to the radio.

Second, it is necessary to match the type of intervention with the level of HIV prevention awareness within the audience. For audiences with low levels of knowledge and experience with material, it was necessary to provide more opportunities for didactic training as interventions that present general messages without didactics may confuse the audience and lead to the creation of myths. For audiences with high levels of knowledge, providing an opportunity to engage in the material in new way and maintain salience of relevant information was more important as a repetition of information they already know can lead to boredom and low engagement.

Third, the issue of local costs and human resources proved to be critical for sustainability. It would be impossible to continue the programs without ensuring the interventions were low cost and locals were able to continue the work. While the initial costs of creating and implementing an intervention may be low, planning for long term costs and human resources is crucial. This was particularly true with the card game, as the cost to create the card game and produce the cards in the US was relatively low, but the cost to produce more card games in-country was prohibitively expensive and teaching locals how to create prevention card games was very challenging. In contrast, having locals in charge of developing and running the HIV prevention radio drama increases the likelihood that the program will continue.

In conclusion, successful implementation of ICT interventions in developing countries includes understanding the ways people in the country prefer to use the medium you are using to deliver your intervention (e.g., mobile phone, radio, etc), your intended audience's level of material mastery (low knowledge vs. high), and ensuring there are locally available resources to continue the intervention.

References

[1] U NAIDS, 2008. *Report on the Global AIDS Epidemic.* Geneva: Joint United Nations Program on HIV/AIDS.
[2] Internet World Stats, September 30 2009. Retrieved from http://www.internetworldstats.com
[3] Ortiz, D. J., Bing, E. G., Boyer, C. B., Russak, S. M., De Deus, F. J., & Ernesto, F. (2005). Evidence-based recommendations for prevention of HIV and STIs in the Angolan Armed Forces: Challenges and opportunities at the end of 30 years of war. *Military Medicine*, 170, 327-332.
[4] Bing, E. G., Ortiz, D. J., Ovalle-Bahamon, R. E., Cheng, K. G., Huang, F. H., Ernesto, F., & Duan, N. (2008). HIV/AIDS Behavioral Surveillance among Angolan Military Men. *AIDS and Behavior*, 12, 578-584.
[5] Bing, E. G., Cheng, K. G., Ortiz, D. J., Ovalle-Bahamon, R. E., Ernesto, F., & Weiss R. E. (2008). Evaluation of a Prevention Intervention to Reduce HIV Risk among Angolan Soldiers. *AIDS and Behavior*, 12, 384-95.

New hardware platforms for healthcare consultations

Rebecca Randell
Leeds Institute of Molecular
Medicine
University of Leeds
St. James's University Hospital
Leeds, LS9 7TF UK
r.randell@leeds.ac.uk

Stephanie Wilson
Centre for HCI Design
City University
London, EC1V 0HB UK
steph@soi.city.ac.uk

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Abstract

Innovative hardware platforms such as Mobile Clinical Assistants and tabletop computers are emerging that have the potential to significantly impact the interaction between clinician and patient. This position paper describes the results of interviews undertaken with General Practitioners as part of an experimental study to explore how innovative hardware platforms impact patient-clinician communication. We reflect on the lessons learnt from the study, both in terms of the implications for the design of such studies and possible directions for the introduction of new hardware technologies into healthcare consultations.

Keywords

Healthcare, evaluation

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

Innovative hardware platforms such as Mobile Clinical Assistants (MCAs) and tabletop computers are emerging that have the potential to significantly impact the interaction between clinician and patient. Previous studies of the impact of IT on patient-clinician communication have focused on interaction around a fixed position desktop computer. What has not been studied is how this coordination and communication is impacted by different hardware platforms. This position paper describes the results of interviews undertaken with General Practitioners (GPs) as part of a pilot experimental study to explore how innovative hardware platforms impact patient-clinician communication.

We begin by presenting the methods of our study. We then describe findings from the interviews, and then reflect on the lessons learnt from the study, both in terms of the implications for the design of such studies and possible directions for the introduction of new hardware technologies into healthcare consultations.

Methods

Experimental task: GPs participated in simulated consultations with actors as patients presenting with symptoms based on dummy scenarios. The scenarios were developed with the help of a practicing GP. The scenarios were selected to be straightforward, familiar to any GP. All three scenarios were designed to involve a combination of information gathering by the GP and sharing information with the patient. Dummy patient records were developed to support the scenarios. Rather than use an electronic patient record (EPR) system, we created the dummy patient records as spreadsheets in Google docs. We felt that this simple solution would allow us to focus on the impact of the hardware platforms, rather than have the GPs distracted by features of a particular EPR system.

Hardware solutions: We had three hardware solutions, a desktop computer, a Panasonic Toughbook CF-H1 MCA tablet PC with touch screen and stylus input device, and a tabletop computer.

Sample: Our intention was to recruit 9 participants. However, we stopped the pilot study after 3 participants, for reasons discussed below.

Procedure: A within-participant design was used, with each participant using each of the three hardware solutions by participating in three consultations.

Data: The simulated consultations were video-recorded. Once all three consultations were completed, a semi-structured interview was conducted, exploring the GPs' perceptions of the different hardware solutions.

Analysis: The video data was analysed using Transana (www.transana.org). The interviews were transcribed and the transcripts indexed in order to identify key themes.

Findings

Our intention in this position paper is to focus on describing what emerged in the interviews, not to describe what happened within the simulated consultations (this will be reported elsewhere). However, a key feature of all consultations was that none of the GPs recorded patient notes within the consultation, instead choosing to do this afterwards. Our assumption had been that the GPs would make notes within the consultation and we were interested to see how the impact of this on communication between the GP and patient varied according to the hardware used. The GPs also varied significantly in the extent to which they looked up information to share with the patient. This meant that our scenarios provided limited opportunity for us to understand the impact on communication. It was for this reason that we chose to stop the experiment after three participants, in order to review our scenarios.

The choice to record notes following the consultation was described by one GP in the following way:

'There's no point in writing and intruding into the flow of what's going on. [...] what you want to do is get the business of the consultation without interruption.' (GP1)

In discussing the use of the computer to look up information to share with the patient, this GP pointed to the fact that 'most consultations are only ten minutes' so that, although he 'might look something up very quickly', opportunities for looking up information within the consultation were limited.

Despite stopping the experiment after three participants, the interviews following the simulated consultations raised interesting issues that have implications for the choice of hardware in healthcare consultations. A key theme, expressed strongly by all three GPs, was a concern over patient confidentiality:

'If you have family members in the room and a screen of any sort, they can read what's on the screen, sexual history that they're not aware of and all these things they've got up to.' (GP2)

While all three GPs liked the larger screen provided by the tabletop computer because of the potential for easily sharing information with the patient, the consequence for patient confidentiality was raised as an issue:

'Patients often bring in other people with them so if she brought her mum, her boyfriend, and the last consultation that we'd had was about her contraception or her termination or you know the affair she was having [...] if you're using something that's very display centric then it's going to be much more obvious if you're scrabbling to [...] put the screen saver on.' (GP3)

While the MCA was generally unpopular with the GPs, due to difficulties using the stylus and onscreen keyboard/handwriting recognition, the concern for patient confidentiality led one GP to highlight the following advantage of the MCA:

'It does allow you to [...] position it in a way that you can do it privately, so I quite like that.' (GP1)

Another key theme in the interviews was the increased use of IT within GP consultations, something which our scenarios failed to adequately reflect:

'We print out labels for bottles, we print out request forms for tests [...], we do things like spirometry linked in with the computer, [...] Quality and Outcome Framework checks so that we're constantly referring to things that the computer's reminding us that we have to do, like take the blood pressure or weigh the patient.' (GP1)

Such increased use of IT within the consultation led one GP to anticipate a move to multiple screens. Again, the larger screen of the tabletop computer was seen as beneficial for this reason, while the smaller screen of the MCA was seen as impractical.

Increased use of IT also meant that speed of data entry was a key concern, hence the dissatisfaction with the stylus input provided by the MCA:

'For most GPs [...] a lot of it's about data entry [...] and so it's the input method is probably as important as anything else.' (GP3)

Discussion

The value of simulated consultations for research is accepted, with simulated consultations having been successfully used in previous research exploring the impact of IT on health care professional/patient interaction [1,2]. What is difficult is designing appropriate scenarios. Our scenarios, although developed with a practicing GP, were based on false assumptions about the nature of GP consultations. IT use within GP consultations has increased significantly over recent years. Conducting observations of current practice prior to designing the scenarios may have enabled us to design scenarios that better capture the challenges that GPs experience in fitting IT within the consultation. It is likely that such scenarios would require much more sophisticated patient records, significantly increasing the effort to set up the experimental study.

Our experience also raises questions about the validity of experimental studies. One of the GPs used the internet within each consultation to look up information to share with patients, but the limited time duration of standard consultations means that this may not be normal practice. Again, observations of current practice prior to conducting such studies would enable researchers to assess the extent to which behaviour observed within the experimental setting reflects current normal practice.

In terms of directions for the introduction of new hardware technologies into healthcare consultations, the concerns expressed by the GPs we interviewed suggest that maybe a combination of hardware platforms is required. For example, a larger screen may be beneficial for sharing information with the patient but a smaller screen that the GP can orient as they wish may be beneficial in terms of protecting patient confidentiality.

Acknowledgements

We would like to thank the GPs who participated in the study and Dr Peter Davis who assisted us in the development of the scenarios. This research was funded by a pump priming grant from City University London.

References

[1] Gibson M, Jenkings KN, Wilson R, Purves I. Multi-tasking in practice: Coordinated activities in the computer supported doctor-patient consultation. International Journal of Medical Informatics. 2005;74: 425-436.

[2] McGrath JM, Arar NH, Pugh JA. The influence of electronic medical record usage on nonverbal communication in the medical interview. Health Informatics Journal. 2007;13: 105-118.

Medical Intelligence Informatics

Susan Harkness Regli
Lockheed Martin ATL
3 Executive Campus, 6th Floor
Cherry Hill, NJ 08002 USA
sregli@atl.lmco.com

Polly Tremoulet
Lockheed Martin ATL
3 Executive Campus, 6th Floor
Cherry Hill, NJ 08002 USA
ptremoul@atl.lmco.com

Alexei Samoylov
Lockheed Martin ATL
3 Executive Campus, 6th Floor
Cherry Hill, NJ 08002 USA
asamoylo@atl.lmco.com

Kenny Sharma
Lockheed Martin ATL
3 Executive Campus, 6th Floor
Cherry Hill, NJ 08002 USA
ksharma@atl.lmco.com

Kathleen Stibler
Lockheed Martin ATL
3 Executive Campus, 6th Floor
Cherry Hill, NJ 08002 USA
kstibler@atl.lmco.com

Lisa Anthony
Lockheed Martin ATL
3 Executive Campus, 6th Floor
Cherry Hill, NJ 08002 USA
lanthony@atl.lmco.com

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Abstract

In this paper we discuss research efforts to apply technology designed for military intelligence operations to medical and health informatics applications.

Keywords

healthcare information, electronic health records, spoken language understanding, associate technology, user-centered design

ACM Classification Keywords

H.1.2 User/Machine Systems: Human information processing; H.5.2 User Interfaces: Natural language; H.3.3 Information Search and Retrieval: Query formulation; J.3 LIFE AND MEDICAL SCIENCES: Medical information systems.

General Terms

Human Factors, Design

Introduction

This paper addresses shortfalls in how healthcare information is collected, stored, distributed, and analyzed that thwart basic understanding about patient conditions, as well as efforts to understand patterns of health incidents in individuals and groups. The state of affairs for medical “intelligence” is similar to that of military intelligence. At the small unit level out on patrol, details are not often reported in a way that can be shared or analyzed across geography and time (different medical information systems and procedures), reported data is described differently by different people (different terminology and record fields), data is not easy to share among units (offices, hospitals, states), and the people who actually need information may not know what to ask for or how to create a valid query for it (patients and families rooting for information in medical records). The patient is often the only central repository for his own and his family's health history and the doctor or a distributed set of doctors is often the only window into the actual medical records that are behind that health history.

We discuss several user-centered technology efforts that have been designed to assist in the collection, analysis, and usage of military intelligence that needs to be collected on-the-fly, as it happens, and without interrupting the flow of normal events. We believe these efforts have the potential to be applied to the collection and usage of medical data to address similar constraints. Doctors, patients, and other medical professionals must be able to collect and store information more easily, ask the right questions to ensure comprehensiveness of data, and maintain context and history as events unfold in a way that captures both what happened and why it happened.

Collecting Health Information

The first step is improving mechanisms for basic reporting of information in formats that can be stored, shared, understood by multiple audiences, and ideally digitized in formats that can be analyzed by multiple systems for modeling and prediction. One way to improve the ease of reporting as well as the standardization of reporting formats is through the use of a spoken language understanding system that takes in audio data from a speaker, extracts critical information, and provides a consistent representation of the resulting data.

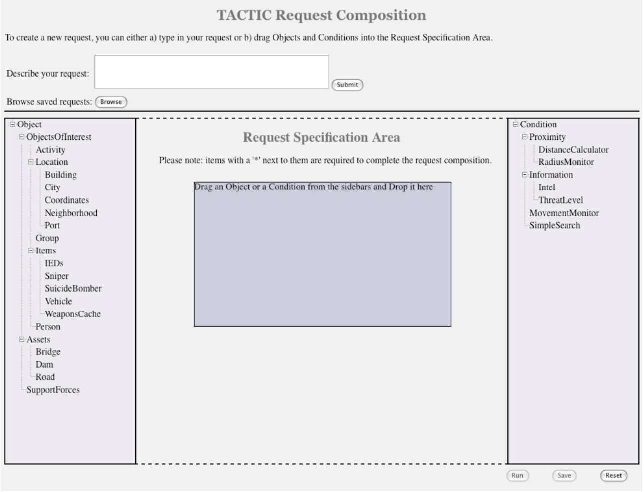
We have worked on Spoken Language Interaction for Computer Environments (SLICE) for multiple military contexts and are extending the domain to allow medical information to be reported in domain-appropriate language, parsed into machine readable formats, organized in more standardized ontologies without completely restricting individual preferences in reporting style, and requested as needed. SLICE goes beyond speech recognition by understanding the context in which utterances are spoken and determining the intent, and then communicating with both the user and networked information resources to compute user-centered solutions. To date, those solutions have included filling out reports, sending requests, database access, issuing alerts/notifications, and performing a variety of system commands. When there is insufficient information for the task at hand, the system prompts the user for that information.

We are working to improve the flexibility of describing medical situations using SLICE. With end-users, in this case medical experts, we define a vocabulary list and utterance grammar that is modeled on a standard medical ontology but remains flexible to allow for user preferences. The transcribed text is reduced to a subset of critical information. The grammar provides a set of rules and definitions that can efficiently categorize treatments, symptoms, and mechanisms of injuries into standardized report formats, consistently representing the data while providing the caregiver with flexibility to describe situations in a natural and appropriate style.

Doctors would use such a system in place of or as an enhancement to spoken dictation, thereby creating more usable data. The interactive and minimally intrusive nature of the technology could assist other medical personnel who are less used to relying on dictation (e.g., nurses, medical technicians, or first responders) in creating and updating medical information while on rounds or in transit. And ideally, patients themselves could learn to use such a system to continually monitor and document their changing conditions, symptoms, or applications of treatments such as medication or daily tests.

Asking the Right Questions

The second step for improved data and history collection is the ability to ask the right questions based on history and current status. Tactical Access to Complex Technology through Interactive Communication (TACTIC) technology is designed improve query construction to provide a bridge from human to information in any situation for which a) there is a complex information environment in which information requests are typically composed and executed by an expert (someone extremely familiar with the data sources, required values, parameters, and expected results that relate to an information query) and b) there is a need to enable relative novices to be able to use this complex information environment to acquire operationally relevant information in near real-time with minimal assistance.


TACTIC Request Composition

To create a new request, you can either a) type in your request or b) drag Objects and Conditions into the Request Specification Area.

Describe your request:

Browse saved requests:

Request Specification Area

Please note: items with a '*' next to them are required to complete the request composition.

Drag an Object or a Condition from the sidebars and Drop it here

figure 1: Example TACTIC interface.

In this research area, we consider the patient and his or her medical history to be the complex information source and the individuals rooting through medical records to be the information seekers. The TACTIC interface assists users in formulating requests for information by producing a set of templates that can easily be configured based on current information needs. As the queries are constructed, known information is used to help the user understand what other questions should be asked, what parameters should or can be specified, and what types of relationships between information can be explored. The system uses the rich store of data, such as patient and healthcare information that has been built up in electronic health records (EHRs), to ensure thorough interrogation of current information.

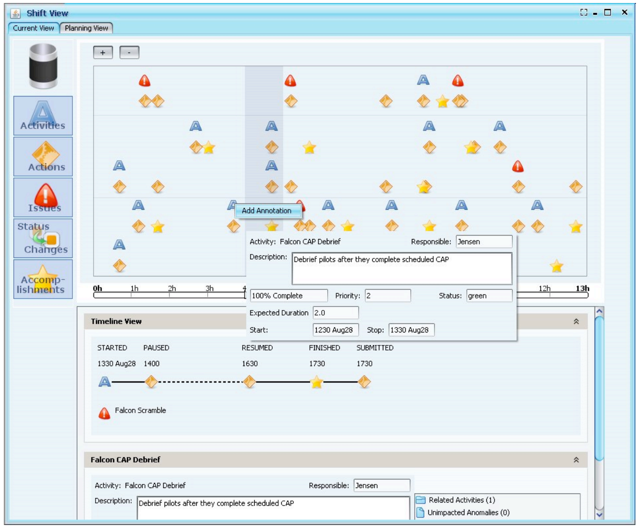
In one prototype of this technology (figure 1), the working area of the screen comprises three panes that contain the Objects and Conditions as well as the Request Specification Area (RSA), which is the primary workspace of the user. The user drags objects and conditions into the RSA which then uses an accordion-style interface element to expose required and optional characteristics to create a valid query. Object choices refine the list of possible conditions and vice versa.

Data in the underlying information source could be also used to suggest or prompt for questions to be asked. For example, a system for a first responder system like an EMT would be able to wirelessly access the data on an individual's EHR and suggest questions to ask based on chronic conditions or current medications of the injured person.

Maintaining Rationale over Time

Finally, there is the challenge of tracking linked data, or more simply, the progression of events over time. Technology developed to support operators in maintaining situation awareness across disruptive events (e.g. shift changes) illustrates techniques for lightweight capture of ongoing dynamic event data. The Situational Awareness Continuity Across Disruptive Events (SACADE) disruption assistant (figure 2) was designed to help people bridge gaps in situational awareness and prepare briefings to communicate information about event progress and dynamic situations to others. In the healthcare information collection domain, it could be an ongoing tool that individuals use to help log events and enter explanatory information about those events. It could also be used in hospitals to get information about patient status off the "whiteboard" and into a format that can be stored and used as part of a dynamically updated EHR.

The SACADE data model represents key activities, events, and decisions that occur during shift. It serves as the foundation for pre-positioning critical information required for a shift change briefing and is generic and extensible across multiple domains. Future research plans include integration with plan monitoring software so that the system could prompt users to add annotations when unexpected events happen. This would be particularly useful in a home healthcare monitoring application which would enable an individual to track progress of symptoms, vital signs, or medication administration and prompt for annotation when unexpected events (missed medication, anomalous levels, troubling trends over time) occur.



Activity: Falcon CAP Debrief
Responsible: Jensen
Description: Debrief pilots after they complete scheduled CAP
100% Complete
Priority: 2
Status: green
Expected Duration 2.0
Start: 1230 Aug28
Stop: 1330 Aug28

STARTED	PAUSED	RESUMED	FINISHED	SUBMITTED
1330 Aug28	1400	1630	1730	1730

Activity: Falcon CAP Debrief
Responsible: Jensen
Description: Debrief pilots after they complete scheduled CAP

figure 2. SACADE interface with annotation capability.

Summary

The technology assistance described in this paper combines to create a suite of information management assistance in the healthcare domain to support the dynamic maintenance of EHRs containing accurate, complete, and rich data about the health of individuals.

VisuExplore: Gaining New Medical Insights from Visual Exploration

Alexander Rind
Silvia Miksch
Wolfgang Aigner
Thomas Turic

Dept. of Information and Knowledge Engineering (ike),
Danube University Krems
Dr.-Karl-Dorrek-Strasse 30
3500 Krems, Austria
{alexander.rind, wolfgang.aigner, silvia.miksch,
thomas.turic}@donau-uni.ac.at

Margit Pohl

Institute of Design and Assessment of Technology,
Research Group Human Computer Interaction,
Vienna University of Technology
Favoritenstraße 9-11
1040 Wien, Austria
margit@igw.tuwien.ac.at

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Abstract

Overcoming information overload is a major challenge in current healthcare practice. Interactive Information Visualization methods are promising tools for physicians to ease this situation. We present our VisuExplore prototype, an interactive Information Visualization application for exploring patient data. Its user-centered design and development process involves physicians to match their requirements and needs. The VisuExplore prototype visualizes a flexible selection of medical parameters over time. It provides a range of interaction techniques, and is designed to be easy to use as well as unambiguous to interpret.

Keywords

Information Visualization, Medical Information Systems, Interaction Techniques, Time-Oriented Data

ACM Classification Keywords

H.5.m [Information Systems]: Information Interfaces And Presentation (e.g., HCI)—Miscellaneous; J.3 [Computer Applications]: Life and Medical Sciences; I.3.6 [Computing Methodologies]: Computer Graphics—Methodology and Techniques.

Introduction

The application of modern technology in clinical practice leads to a massive increase in quantity and complexity of electronically available medical data. Thus, medical records have become a write once read never medium [5] and users of current commercial hospital information systems ask for alternative, more intuitive solutions. Interactive *Information Visualization* (InfoVis) is an instrument to overcome information overload and to make information from multiple heterogeneous data sources comprehensible. Particularly in healthcare, *time-oriented data* plays a central role, but time has a complex structure and time models of parameters relevant to patient care diverge [1]. Thus, physicians can use InfoVis methods to analyze changes of patients' conditions, evaluate therapeutic interventions, and recognize trends, patterns, and relationships between parameters over time [6]. For handling such diverse and complex sets of medical parameters, physicians need advanced interaction mechanisms for their InfoVis systems. Obviously, these *interaction techniques* need to be easy to use, so that, above all, they do not hinder patient care, but improve it.

This paper presents our VisuExplore prototype, which allows physicians to visualize medical data available in the hospital information system and, thus, helps them do their daily tasks. Physicians can choose multiple medical parameters of varied time and data models and analyze these in a simple and unambiguous fashion. The prototype is based on LifeLines [4], but uses additional visualization and interaction techniques. Further, we present our working methods as a case study for interdisciplinary collaboration and we summarize the requirements emerging from our introductory user study.

User-Centered Design Process

Intensive study of *tasks and data of target users* is key to any successful InfoVis project [3]. For the VisuExplore project an interdisciplinary project team collaborates, which involves not only InfoVis researchers and physicians of a local hospital, but also human-computer interaction (HCI) researchers and experts in hospital informatics systems. We apply methods of user-centered design [7] as outlined below (Figure 1):

- For introductory input to the project, *interviews* with five physicians resulted in general requirements and an overview of medical tasks and parameters.
- A *contextual observation* with one more physician and a registered nurse yielded deeper insights into the users' needs.

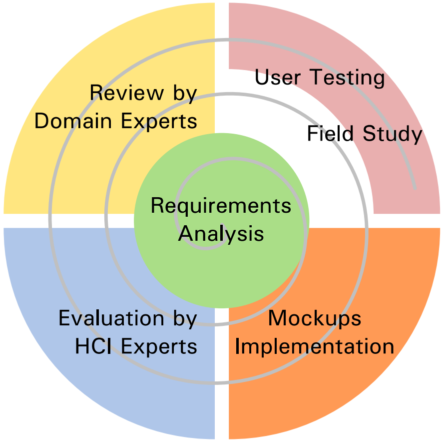


Figure 1: User-centered design process in the VisuExplore project

- Then, we started an iterative process of the InfoVis experts designing visualization and interaction techniques and physicians and HCI experts giving feedback. Earlier iterations involved *paper mockups*, and then we worked with *software prototypes*.
- For the final iterations, *usability experiments* are planned and a *field study* will conclude the project.

Requirements

Based on the introductory interviews with five physicians and contextual observation the following key requirements emerged:

- Simple user interface: The interfaces should be particularly clear, simple to use, and make it possible to gain unambiguous insights.
- Flexible for various medical parameters: Different patients or different medical disciplines require the analysis of different sets of parameters.
- Time-oriented data: Various measurements of a parameter over time need to be followed.
- Multiple patients: Data of multiple patients needs to be compared to find out whether some therapies are more effective than others.
- Interactivity: A variety of interaction techniques such as (semantic) zooming, filtering, grouping, opening medical documents from the visualization, and writing annotations should be included.

Interactive Prototype

Based on the requirements listed above, we designed a prototype for interactive visual exploration of medical data. The diabetes outpatient clinic was selected as prototypical medical scenario. Figure 2 presents a typical screenshot with four visualizations that are in alignment with a common horizontal time axis. The visualizations shown are well-known representation techniques for categorical and numerical data: Event chart, line plot, bar chart, and timeline chart. They form the basic package of the prototype because they are easy to use and interpret for physicians without extra training.

The prototype's interactive features allow physicians to get an overview of multiple medical parameters and focus on parts of the data. Physicians can add visualizations with one or more additional parameters. They may resize and rearrange visualizations. Further, it is possible to navigate and zoom across the time dimension by dragging the mouse, by using dedicated buttons, or by selecting predefined views (e.g., last

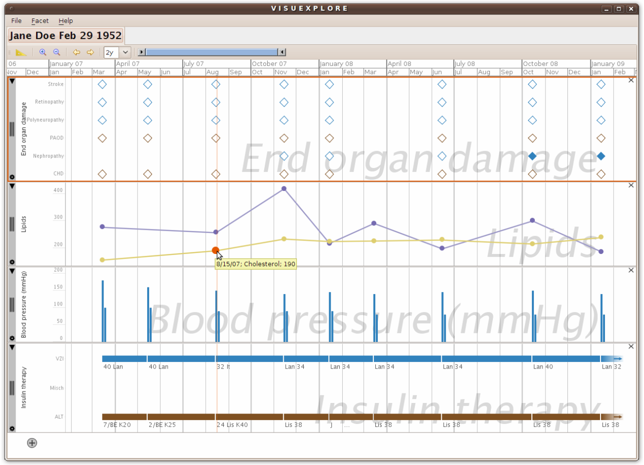


Figure 2: VisuExplore prototype showing categorical and numerical data for a diabetes patient (anonymized medical data)

year). Moreover, the prototype allows selecting and highlighting data elements.

Other time-based visualization and interaction techniques can extend the prototype to support special purposes. For example, the document visualization technique shows medical documents (e.g., discharge letters) as document icons (e.g., PDF, Word) that physicians can click on, if they want to open the document. The prototype integrates with the hospital information systems and accesses the medical data stored there. It uses the Java libraries prefuse [2] for visualization.

Future Work

As the prototype described above is still under refinement, more visualization and interaction techniques are being added. One particular direction for future work is the integration of data from patient cohorts. For example, physicians might want to compare medical values of a patient with their cohort over time. Further, we aim to provide annotation facilities, so that physicians can write down their medical insights directly within the visualization.

Finally, a key question is how InfoVis applications will be used in clinical practice: How much interactivity can physicians fit into their busy schedules? We need to examine this in user studies. Especially, field studies will be invaluable sources of information.

Conclusion

InfoVis provides powerful tools for patient care to ease the information overload of the medical staff. We presented our VisuExplore prototype, an interactive InfoVis application for exploring healthcare data. Its user-centered design and development process involves physicians to match their requirements and needs. Our VisuExplore prototype visualizes a flexible selection of medical parameters over time. It provides a range of interaction techniques, and is designed to be easy to use as well as unambiguous to interpret.

Acknowledgements

VisuExplore is supported by the Bridge program of the Austrian Research Promotion Agency (No. 814316). We thank our project partners: NÖGUS, NÖ Landeskliniken-Holding, Landesklinikum Krems, Systema.

References

[1] Aigner, W., Bertone, A., Miksch, S., Tominski, C., and Schumann, H. Towards a Conceptual Framework for Visual Analytics of Time and Time-oriented Data. In Proc. *Winter Simulation Conf.*, IEEE (2007), 721-729.

[2] Heer, J., Card, S.K., and Landay, J.A. prefuse: A Toolkit for Interactive Information Visualization. In *Proc. CHI 2005*, ACM (2005), 421-430.

[3] Munzner, T. A Nested Process Model for Visualization Design and Validation. *Visualization and Computer Graphics 15*, 6 (2009), 921-928.

[4] Plaisant, C., Mushlin, R., Snyder, A., Li, J., Heller, D., and Shneiderman, B. LifeLines: Using Visualization to Enhance Navigation and Analysis of Patient Records. In *Proc. AMIA Annual Fall Symp.*, AMIA (1998), 76-80.

[5] Powsner, S.M. and Tufte, E.R. Graphical Summary of Patient Status. *The Lancet 344* (1994) 386-389.

[6] Rind, A. *Interactive Information Visualization in Patient Care and Clinical Research: State of the Art*. Technical Report IKE-TR-2009-01, Danube University Krems, 2009.

[7] Sharp, H., Rogers, Y., and Preece, J. *Interaction Design: Beyond Human-Computer Interaction*. Second edition. Wiley & Sons, Chichester, 2007.

Clinical Information Flow and Variability in Practice in Healthcare

Cara Stitzlein
The University of Queensland
St. Lucia, QLD 4072 Australia
Cara.Stitzlein@uqconnect.edu.au

Penelope Sanderson
National ICT Australia and
The University of Queensland
St. Lucia, QLD 4072 Australia
psanderson@nicta.com.au

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

We summarise ongoing research directed to the problem of prospectively evaluating the impact of eHealth technologies on work in the critical care context. We outline our approach and present a simplified model of clinical information pathways in a large Australian intensive care unit some months after the implementation of an Electronic Health Record (EHR). Observations and discussion with stakeholders make it clear that there is considerable variability across patients and caregivers in how the EHR is configured and used by caregivers, and therefore what the information pathways might be. Such "variability in practice" creates a challenge for prospectively evaluating the impact of further technical changes.

Keywords

eHealth, evaluation, information pathways, critical care

ACM Classification Keywords

H.5.1. Information interfaces and presentation: Multimedia Information Systems---Evaluation/Methodology.

Introduction

Now that many health delivery organisations are starting to use eHealth systems, researchers have uncovered unintended negative consequences of such systems for work practice [1]. Stakeholders could benefit from methods to predict at least some of the consequences of implementing a new eHealth system. Changes needed in system design, work practices, or implementation plans could then be identified and negotiated well in advance of implementation.

Most evaluations of eHealth applications are *retrospective*, focusing on existing implementations that have been partially successful or unsuccessful [2]. As part of a broad program of research, we are developing methods and tools that support *prospective* evaluations of information and communication technology (ICT). One part of our research focuses on the introduction of electronic health records (EHR) to the intensive care unit (ICU). Much prior research in this area has taken work practices as a primary focus and information and communication technology (ICT) as a secondary consideration. In contrast, we take information flow as a primary focus, while noting that it reflects the work practices of users.

In this paper we present a simplified model of clinical information pathways in an ICU some months after the implementation of an EHR. We show information flow as a patient moves from the cardiac operating theatre (OT) to the ICU. Such modeling provides a basis for determining some of the changes in information flow that will occur with new ICT. However such modelling also reveals factors that challenge attempts to prospectively evaluate the impact of new information systems such as EHRs.

Methodology

Setting

The setting was the cardiac post-operative recovery area of a large Australian ICU.

Data collection

Traditionally, data flow diagrams depict information movement and state changes in an existing system [3]. Recent field studies of healthcare environments model system-wide workflow [4] and emphasize the fundamental interrelation between the technical and social features of a system [5]. We combined both approaches and collected data on information flow via occupational shadowing of ICU nurses, document analysis and semi-structured interviews with key ICT and nursing staff. We inventoried the contents of information artifacts, electronic and otherwise, and analysed how their contents were generated, preserved, and transmitted during a normal work shift.

Model preparation

Figure 1 shows a highly simplified version of some of our modelling. It shows the information sources, forms of transmission, and destinations in three areas of patient stay: a pre-operative area, the OT itself, and the cardiac post-operative part of the ICU. Computer screen icons represent various information systems that are working independently, in conjunction with biomedical devices, or with other information systems. Arrows with labels are information pathways indicating how and where information is passed between locations and/or devices, and what information becomes part of the paper-based record. Note that some objects persist across the three areas of Figure 1.

The model has three types of pathways, each associated with a work process. (1) A → D refers to analogue to digital conversion of physiological signals, (2) **(e)** refers to the exchange or transmission of electronic information, and (3) printout refers to printed artifacts such as lab results and progress notes.

Findings

The model plus fieldwork reveal a complex picture. First, separate pathways support the flow of medical, physiological, and administrative information, yet there are points at which they converge. Second, communication and coordination is required between physicians, nurses and staff to successfully execute patient care. Third, all the ICT requires some human interaction. Fourth, a large paper-based patient chart persists, despite the ICT present. Fifth, there is *variability in practice* across nurses and patients in how the EHR is used: work gets done in different ways, reflecting adaptive behavior in the face of change, uncertainty, or different knowledge levels.

Variability in practice also affects the flow of information. For example, the integration of bedside technologies with the EHR varied with operator knowledge and with the availability of basic resources such as adaptors and cables. Moreover, printouts were sometimes filed in the patient chart but sometimes just discarded. Finally, constraints imposed by the EHR on

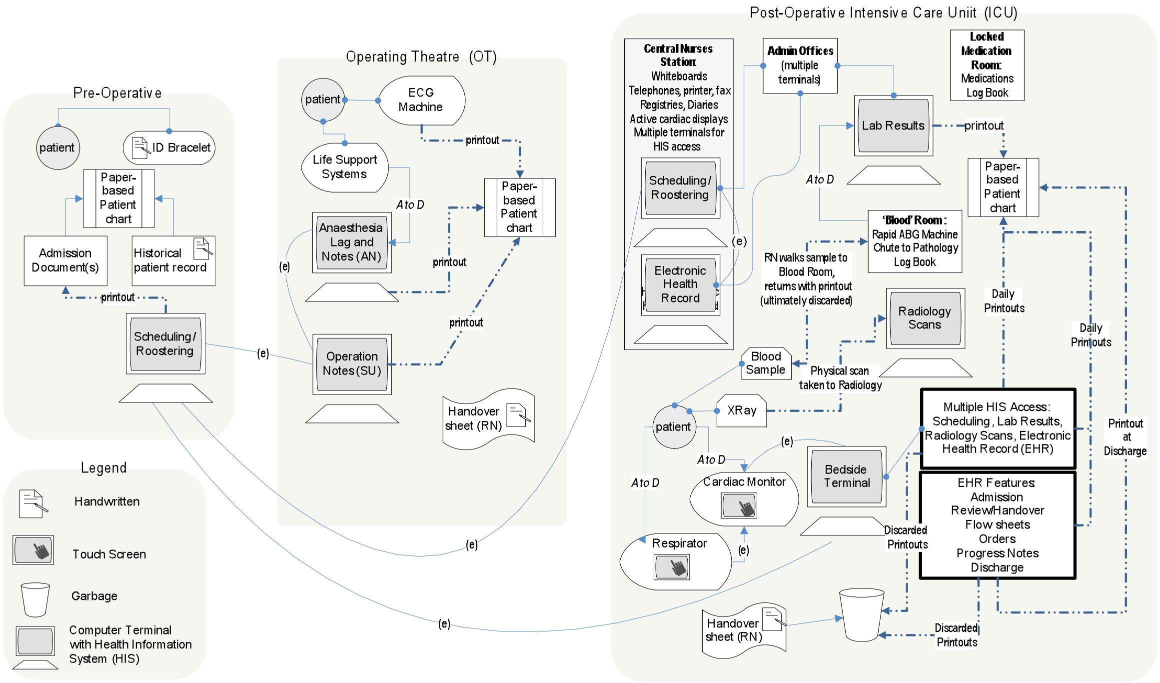


Figure 1. Highly simplified and partial model of ICU information pathways, showing various existing health and clinical information systems alongside the paper-based patient chart (square with vertical lines) and an EHR (lower right). Note persistence of some physical objects such as patient chart and patient (circle) which move across units.

work practices led to a variety of workarounds that became the means of keeping the record accurate (e.g. back-dating orders, writing in progress notes, and relying upon verbal handover).

Variability in practice presents a modelling challenge to prospective evaluation. Because different practitioners in different situations arrange their information environment in different ways, new technologies may enhance such arrangements, disrupt them, or leave them unaffected. Therefore, analysts attempting to evaluate ICT prospectively must infer forms of change from several versions of current practice. They must also determine if new technology will pose challenges that motivate new forms of variability in practice.

Implications and Future Work

Our approach of focusing primarily on information flow and secondarily on work practices gives us a solid basis for determining the impact of new ICT. Models such as Figure 1 let us view the exact technical changes that will occur, and also to see where further opportunities for interoperability may lie. An understanding of work practices and how they vary then lets us analyze the different ways that the impact of a technical change may be realised.

Our approach is useful for health informaticians, students of workplace practices, and healthcare professionals, all of whom in our experience appear to recognise its usefulness. Feedback about the model and process from stakeholders in the ICU has been very positive. In addition, information specialists managing ICT procurement within our healthcare system recognise that the model and process will add value to forthcoming eHealth initiatives, and they have expressed strong interest in using the approach.

In future work we will extend and formalise the prospective evaluation process, supplementing other work in progress with the highly specific visual tools that the present approach provides. We will then apply our approach to several local eHealth initiatives.

Acknowledgements

The authors acknowledge ARC DP0880920 and National ICT Australia. NICTA is funded through the Australian Government's Backing Australia's Ability initiative in part through the Australian Research Council. The authors also thank staff at Princess Alexandra Hospital (Brisbane, Queensland) for participation and feedback.

Citations

[1] Ash, J.S, Berg, M., and Coiera, E. Some unintended consequences of information technology in health care. *J Amer Med Inform Ass 11,* 2 (2004), 104-112.

[2] Niazkhani, Z., Pirnejad, H., and Berg, M. The impact of computerised provider order entry systems on inpatient clinical workflow: A literature review. *J Amer Med Inform Ass 16* (2009), 539-549.

[3] Barker, R.M., Dos Santos, B.L., Holsapple, C.W., et al. Tools for building information systems. In Salvendy, G. (Ed.) *Handbook of Industrial Engineering* (3rd Ed.) John Wiley & Sons, New York, NY, 2001. (pp. 65-109)

[4] Malhotra, S., Jordan, D., Shortliffe, E., and Patel, V.L. Workflow modeling in critical care: Piecing together your own puzzle. *J Biomed Inform 40* (2007), 81-92.

[5] Reddy, M.C., Shabot, M.M., and Bradner, E. Evaluating collaborative features of critical care systems: A methodological study of information technology in surgical intensive care units. *J Biomed Inform 41* (2008), 479-487.

Agency-Enhancing Technologies for Motivating Preventive Health Actions

S. Shyam Sundar, PhD
Media Effects Research Laboratory
The Pennsylvania State University
University Park, PA 16802 USA
sss12@psu.edu

Sampada Marathe
Media Effects Research Laboratory
The Pennsylvania State University
University Park, PA 16802 USA
sampada@psu.edu

Hyunjin Kang
Media Effects Research Laboratory
The Pennsylvania State University
University Park, PA 16802 USA
huk142@psu.edu

Saraswathi Bellur
Media Effects Research Laboratory
The Pennsylvania State University
University Park, PA 16802 USA
saras@psu.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

Health communicators have tended to deploy interactive systems for the purpose of message tailoring rather than seeking active user input through customization in message design. Based on studies conducted in our lab, we show that health websites seldom deploy customization tools, and when they do, only about half the users bother to customize, driven by considerations of efficiency, identity, and socialization, with the other half being generally oblivious to customization opportunities in the interface. An experimental intervention using customization tools that promote preventive health regimen reveals that user involvement is a critical factor, thus underscoring the need for designing scaffolds and other creative tools to motivate users to customize more actively and widely.

Keywords

Tailoring, Customization, Agency, Preventive Health

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI), J.4 Social and behavioral sciences.

Introduction

Message tailoring, achieved by constructing relevant health messages and targeting a specific group of individuals to influence health related behaviors and outcomes, has been a popular health intervention strategy for decades. Over the years, health communicators have successfully used computer technologies for tailoring and targeting [6]. However, such strategies tend to place individuals at the receiving end of messages, without much control over message content and message delivery, thus treating users as passive receivers of content, rather than active information consumers.

With the changing media landscape, however, that is exactly what many of us are becoming. We see more and more individuals going online to look for health and wellness related information [2], often using that information to seek better care from their providers [5]. Health care workers have responded by jumping on the ‘e-health’ bandwagon and using social media (web blogs, instant messaging platforms, video chat and social networks) to deliver health care information [3].

While these efforts have served to increase the amount of health information and the ease of accessing it, they do not adequately leverage the interactivity of new media technologies to motivate health-related behaviors. Studies have shown that the already efficacious individuals are the ones who go online for health information-seeking and act upon it [4]. Therefore, a strong motivational component underlies the success of interactive health systems. In order to maximize message impact, communication technologies should not simply deliver information but motivate users to interact with that information and act upon it. In order to realize this, health interfaces ought to be user-driven rather than sender-driven.

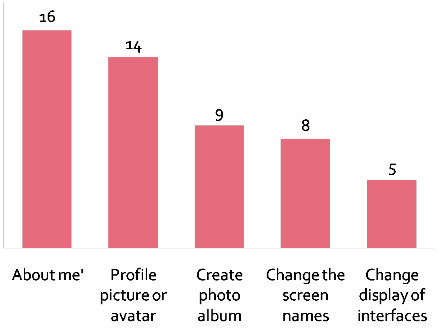
Customization

User-initiated customization is one of the most noteworthy features of interactive media interfaces. We define customization as a user-initiated and largely user-driven process [8] where information technology users are able to make changes to the functionality, interface, information content or distinctiveness of a system [1]. By situating the locus of control within the user and by enabling the user to actively solicit and manage information [9], customizable interfaces stimulate a sense of personal agency (a feeling of being in control and influential within the environment) thereby increasing their sense of empowerment. Nascent research using the agency model of customization [7] has shown many positive psychological consequences of customization (such as increased sense of self-efficacy, control, agency and message involvement) over simple message tailoring [9].

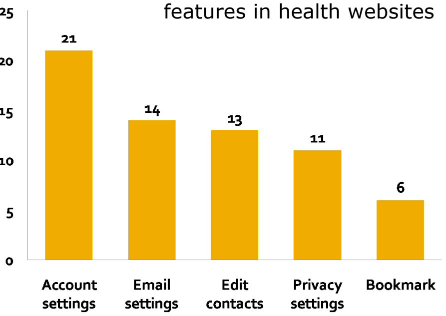
However, there is not enough published research on how the new media tools and interactive features are being used by health care professionals as well as laypersons. We conducted a quantitative content analysis of major health websites/ web portals in order to review the most popular health portals and produce a baseline estimate of deployment of interactive customization features.

Content Analysis

Based on rankings obtained from ebizmba.com (which takes into account a combination of indicators such as inbound links, Google page rank, Alexa rank and traffic data on number of visitors/ month), we sampled 20 most popular health websites, along with 25 other websites that belonged to the following 5 health



Top 5 cosmetic customization features in health websites



Top 5 functional customization features in health websites

categories: Child health, Nutrition, Fitness, Weight loss, and Mental health. We found that a total of 22 out of 45 health websites/ web portals had customization options, majority of them being .com websites. Medhelp.org had the highest number of customizable features (18 total: 5 cosmetic & 13 functional), followed by Everydayhealth.com (17 total: 5 cosmetic & 12 functional) and Realage.com (16 total: 3 cosmetic & 13 functional).

This content analysis shows that despite enormous potential of web portals to allow active customization, they still typically follow a traditional transmission model of health information delivery. We also found that there was no statistically significant relationship between the number (and type of) customization options and the number of visitors to the websites, implying that customization options are not yet a draw with users.

Survey

A follow up survey of health communication portal users was then conducted to investigate user motivations surrounding the use of existing customizable features on these portals. An online sample of Prevention.com users (n=318, 97.5% female) revealed three main customization gratifications sought by users: conveying personality, bringing efficiency to the task at hand and engaging in customization to enhance social life. Each gratification factor significantly predicted the number of customization features used.

We also found that the amount of online health information seeking was significantly correlated with each gratification factor. Interestingly, we also found that preventive, rather than therapeutic, information seeking was significantly correlated with each gratification factor.

Moreover, we also found that more than 40 percent (44.4%) of respondents who reported never customizing any features on Prevention.com were not aware that Prevention.com provided such features. Having no time to customize (30.0%) and not using prevention.com very often to spend effort in customizing (24.1%) were other major reasons why respondents reported not engaging in customization on Prevention.com.

Experiment

We conducted an experiment to assess the use and effectiveness of customization tools in a controlled site dedicated to prevention of colorectal cancer. We constructed three versions of the site, with one serving as an electronic leaflet, being purely informational. This was our control condition. We also had a tailoring version wherein the site would provide recommendations for diet and exercise based on the subject's demographics and health history. Our third condition was a customizable version wherein subjects would enter their daily diet and exercise activities on the site and obtain highly individualized feedback from the site.

Healthy individuals over the age of 50 (n=33) were randomly assigned to one of these three conditions and instructed to log into the dedicated site every day for one week. While there were no main effects, we found that subject involvement (in the site and the designated activity) significantly moderated the relationship between customization and intention to follow preventive health behaviors. The positive health benefit of customization was clearly contingent upon user involvement, whereas involvement did not matter in the control and personalization conditions.

Discussion

Results from these studies suggest that although customization promises agency and a sense of control to users, and although these attributes positively impact health outcomes, the mere availability of customization features is not sufficient to promote healthy lifestyles. It seems that we need technologies to motivate use of customization in the first place.

What are some solutions? How can we motivate users to customize more actively in interactive health systems? Perhaps we could develop a suite of scaffolding devices to help users realize the autonomy and control afforded by these tools and therefore engage in customization more widely. Another strategy would be to identify drivers of intrinsic motivation and accordingly target users who are likely to score high on autonomy, competence and relatedness, the three predictors of self-determination. Alternately, we could design tools that serve to enhance these motivational drives. At WISH, we hope to brainstorm these and other approaches to designing effective interactive tools for enhancing user agency *en route* to adopting and maintaining healthy behaviors.

Citations

[1] Blom, J. Personalization - a taxonomy, Extended abstracts of the CHI 2000 Conference on Human Factors in Computing Systems. New York: ACM, 2000.

[2] Fox, S. Online health search 2006. PEW Internet and American Life Project. http://www.pewinternet.org/Reports/2006/Online-Health-Search-2006.aspx

[3] Hawn, C. Take two aspirin and tweet me in the morning: How Twitter, Facebook, and other social media are reshaping health care. *Health Affairs 28*, 2 (2009), 361-368.

[4] Hong, T. The Internet and tobacco cessation: The roles of Internet self-efficacy and search task on the information-seeking process. *Journal of Computer-Mediated Communication 11,* 2 (2006), article 8. http://jcmc.indiana.edu/vol11/issue2/hong.html

[5] Rice, R. E., and Katz, J. E. Internet use in physician practice and patient interaction.In M. Murero & R. E. Rice (Eds.), *The Internet and health care: Theory, research and practice* (pp. 149-176). Mahwah, NJ: Lawrence Erlbaum Associates (2006).

[6] Rimal, R. N., and Adkins, A. D. Using computers to narrowcast health messages: The role of audience segmentation, targeting, and tailoring in health promotion. In T. L. Thompson, A. M. Dorsey, K. I. Miller, & R. Parrott (Eds.), *Handbook of health communication* (pp. 497-513). Mahwah, NJ: Lawrence Erlbaum Associates, (2003).

[7] Sundar, S. S. Self as source: Agency and customization in interactive media. In E. Konijn, S. Utz, M. Tanis & S. Barnes (Eds.), Mediated interpersonal communication (pp. 58-74). New York: Routledge, (2008).

[8] Sundar, S. S. and Marathe, S. S. Is it tailoring or is it agency? Unpacking the psychological appeal of customized news. Paper presented at the Annual Conference of the Association for Education for Journalism and Mass Communication (AEJMC2006), San Francisco, CA, 2006.

[9] Sundar, S. S., Marathe, S. S., and Kang, H. Beyond tailoring: Customization in health websites. Paper presented at the Annual Conference of the National Communication Association (NCA2009), Chicago, IL, 2009.

Sentient displays to connect elders with cognitive disabilities to the digital era of social interaction

Monica Tentori
UABC, School of Computer Science
UCI, Department of Informatics
mtentori@uabc.mx

Raymundo Cornejo
CICESE, Computer Science Department
rcornejo@cicese.mx

Jesus Favela
CICESE, Computer Science Department
favela@cicese.mx

Introduction

Social ties and social integration often play a beneficial role in the maintenance of psychological well-being and to a better state of mental health [1, 2]. Alzheimer's disease (AD) are considered by many the fastest growing intellectual disabilities that can be affected by the accompanying challenges to establishing long lasting social ties [3, 4]. For instance, an elder with AD might be physically aggressive, even pushing away all their love ones. Social interaction may be even harder for these populations as the new spectrum of digital technologies evolve. These new tools include everything from the use of Social Networks Sites (SNS) to personal devices for communication such as IM.

Although there are obviously many advantages to the availability of these services, they paradoxically, are limited in their potential for non-technical users to socialize through them. Moreover, these less technically inclined individual may even feel like outsiders in their off-line social networks or families, contributing to further cognitive decline and isolation. To fully support these populations, then, we require a new computing paradigm: one capable of seamless integration of both traditional and digital social communication tools.

In this paper, by binding the ideas of sentient computing [5] and ambient displays [6], we explore a new way to augment everyday objects as digital artifacts acting as a natural interface for people to interact with an ubiquitous computing environment. To demonstrate the feasibility and applicability of our approach, we describe a sentient display capable of monitoring elders' context and providing them with continuous information in a subtle, peripheral and expressive manner about their social network.

Related work

Similar studies have explored ambient displays to keep elders in touch with people they care about. For instance, the CareNet display [7] and the Family Digital

---

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Figure 1. Participants of our study during one of the day of observation (a) Elders with cognitive decline that live in a nursing home (b) Elders living with their relatives or independently and elders participating in a social network site (SNS)

Portrait [8] are digital frames augmented with elders' information such as patterns of communication or information about the ADLs being conducted to inform relatives about sensitive data facilitating day to day care. In contrast other have explore mechanisms that allow relatives to send relevant information to the elder. For example, the Epigraph [9] is a screen divided into a number of channels, one representing each family member. Channels can be updated via email, text or picture message.

Understanding social ties: A case study

For a period of four months, we studied the social ties of elders in three conditions: (a) elders with cognitive decline that live in a private nursing home (b) elders living with their relatives or independently and (c) elders participating in a social network site (SNS) (Figure 1). A total of 9 elders, 32 of their relatives and the nursing manager participated in the study.

Information shared and communication patterns

The information shared is highly varied, including everything from merely shallow interactions, such as jokes to information that include emotional elements, such as problems or feelings. During this study, participants shared mostly shallow information when they were face-to-face. This could be partially explained, because they interact quite often. Furthermore, the time they spend together is used as gateway to escape from their problems and their everyday routines, aiming instead at having a playful, nice and relax time. In contrast, the type of information shared in a SNS is very explicit and frequently includes information about feelings and moods such as detail about participants' location, activity or status. Patterns of communication depended on the time people spent together, their proximity and the stage in their lives.

Becoming an outsider due technology usage

One of biggest barriers of maintaining a strong emotional tie uncovered in this work was the disassociation of the elders with those relevant events that arose in the everyday lives of their relatives, such as a grandson's soccer game or daughter's problems at work. As a result, elders' conversations often remained superficial, making it difficult to preserve long-lasting deep personal relationships. To cope with this emotional detachment, photos can be shared between elders and their relatives. In addition, families used SNS to maintain communication with other relatives, coworkers or friends. However, these individuals did use these sites to connect with their non-technical elderly relatives. Thus, the elders sometimes described feeling disconnected with such community and even feeling like "outsiders" in their own families.

A sentient display to connect people to SNS

The study findings motivated the development of a sentient display to integrate elders with cognitive decline into SNS. We defined a *sentient display* as an everyday artifact augmented with digital services capable of perceiving information from the environment to then offer continuous awareness or allow users to change the ubiquitous environment [10]. This sentient display is a digital frame –the ePortrait (Figure 2)- that works in pair with a decorative bowl –the eBowl (Figure 3)- to provide elders with everyday knowledge about their relatives and feedback to the SNS.

The ePortrait collects ten new photos uploaded by each member to Facebook (Figure 2). The system then edits the photo's content by adding a caption at the bottom of each photo and the owner's image at the left side (Figure 2a). Next, it publishes the downloaded photos in a RSS file to be read by the digital frame.

Figure 2. The ePortrait (a) The digital photo modified to be displayed in the digital frame (b) An elder using the ePortrait (c) The ePortrait placed in the TV room

The eBowl is a bowl decorated with an array of leds that emit derided light patterns as virtual laughter from relatives and within the bowl aesthetically pleasant vine balls containing RFID tags are used to control the information in the ePortrait (Figure 3). The bowl lies on a wooden base that contains a Phidget RFID reader to monitor the RFID tags, a PhidgetLED to control the array of LEDs and a netbook, which controls both phidget boards. The eBowl allows the elder to share the current joke displayed in the digital frame by placing a unique sharing vine ball inside the eBowl. Once the joke is sent, every family member has the opportunity to read and rate the joke from one to five stars whether they like or dislike the joke. At a given time, the ejoke service collects the rates of the current joke and displays a light pattern on the elder's eBowl as an indication of the family members laughs. In addition, the eBowl is used to notify relatives whether the elder is home. When the elder places her home keys inside the eBowl, her status in the social networking system changes to "at home"; when the keys are removed, her status change to "outside".

Evaluation

We conducted a preliminary field trial of our prototype system with one family. From the elders who participated in the original fieldwork, we selected Dana[1], an 88 year-old grandmother whose family members are geographically distributed, many of whom have been using Facebook at least two years. Her family members include 18 adults across two generations. Both sentient displays were deployed in the grandmother's house (Figure 2b,c and Figure 3c). Dana rapidly adopted the sentient display and described it as pleasant and attractive. She stated that it was a way to keep up with family events:

> *"to see if there is something new, to be informed…".*

Pathways and communication routines

Dana changed her daily routine to include viewing the photos every morning for around 30 minutes. The sentient display acted as a communication enhancer by providing awareness of her relatives' activities and generating new topics of conversation. The system also provided relatives opportunities of knowing when the grandmother is "at home" to choose a good time to call her. Throughout the pilot study, family members demonstrated new patterns of use of the SNS. For instance, one son joined Facebook motivated by the opportunity of sharing photographs with her mother. Moreover, we observed a change in the content of the photographs and an increment in some activities in the family social network like tagging the grandmother when she appeared in a photograph.

Acting as a virtual entity and communication enhancer

Dana used the ePortrait as a virtual entity of the family members in the SNS to induce a sense of presence. She described feeling emotionally connected with her loved ones even if they could not visit or call her. In general, photographs helped the grandmother feel in contact with her relatives even when they cannot visit:

> *"I keep seeing them… as when they come to visit me […] and I realized that we have more topics to talk about".*

Digital social interaction engagement

Relatives' activity in the SNS was rather heterogeneous—largely due to similarly heterogeneous computer usage patterns, but overall, they described being pleased with the participation of their

---

[1] All names have been changed to protect the privacy of our informants.

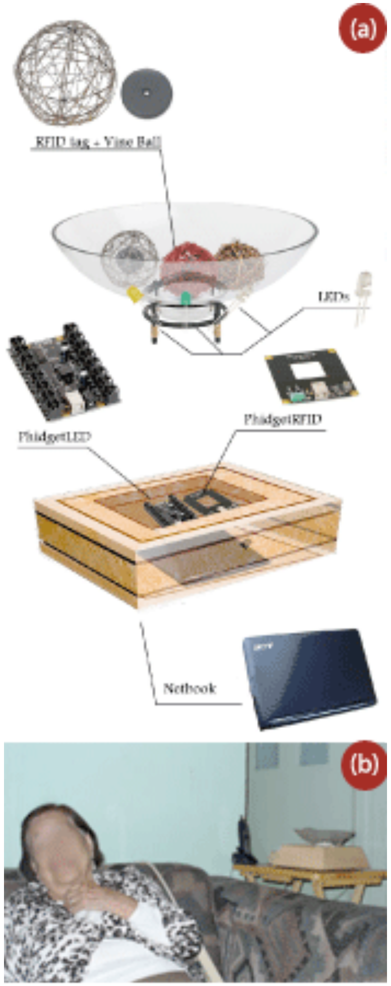


Figure 3. The eJoke (a) Component of the eJoke and (b) An elder using the eJoke

grandmother in the SNS. As a result, they incorporated several strategies to involve her. For instance, more photographs with family content were uploaded Facebook with the aim of increasing the probability that share them with their grandmother. Another strategy was to tag the grandmother when photographs so she can see them more quickly. Consequently, Dana began using digital information as an information source when socializing with their love ones. For instance, an elder explained:

> *"I told them last night a joke about a photo. I like it because now I know about what can I talk to them".*

Conclusions and implications of our work

Sentient displays offer a new type of interaction, helping elders to connect with SNS while avoiding the high cognitive load present in the standard interfaces of these systems. ePortrait is an affective digital frame that allows an elder to become part of a social virtual network and keep in touch with her relatives' life. Evaluation results highlight the importance of providing feedback so that a bidirectional sense of presence in the social network can be established. This research will contribute to new opportunities of use of the online communities by giving new ways of interaction to the elderly. We plan to investigating the advantages and problems of using ambient information systems to integrate the elders to these online communities will provide feedback into the design of these systems and might help prevent isolation, disassociation and enhance their quality of life.

References

1. Sheldon, C., *Social Relationships and Health.* American Psychologist, 2004. 59(8): p. 676-684.
2. Morris, M., J. Lundell, E. Dishman, and B. Needham. *New perspectives on ubiquitous computing from ethnographic study of elders with cognitive decline*. in *UbiComp 2003* Seattle, WA, USA: LNCS 2864 Springer.
3. Bennett, D., J. Schneider, Y. Tang, S. Arnold, and R. Wilson, *The effect of social networks on the relation between Alzheimer's disease pathology and level of cognitive function in old people: a longitudinal cohort study.* The Lancet Neurology, 2006. 5(5): p. 406-412.
4. Pillai, J.A. and J. Verghese, *Social networks and their role in preventing dementia.* Indian J Psychiatry, 2009. 51(5): p. 22-28.
5. Hopper, A., *The Royal Society Clifford Paterson Lecture, 1999 - Sentient Computing. .* Philosophical Transactions, 2000. 358: p. 2349-2358.
6. Mankoff , j., A.K. Dey, G. Hsieh, J. Kientz, S. Lederer, and M. Ames. *Heuristic Evaluation of Ambient Displays*. in *Conference on Human Factors in Computing System*. 2003. Ft. Lauderdale, Florida, USA.
7. Consolvo, S., P. Roessler, and B.E. Shelton. *The CareNet Display: Lessons Learned from an In Home Evaluation of an Ambient Display*. in *Ubicomp*. 2004. Notingham, England: Springer.
8. Mynatt, E.D. and J. Rowan. *Digital Family Portrait Field Trial: Support for Aging in Place*. in *Conference on Human Factors in Computing Systems*. 2005. Portland, Oregon.
9. Lindley, S.E., R. Harper, and A. Sellen. *Desiring to be in touch in a changing communications landscape: attitudes of older adults*. in *Human factors in computing systems*. 2009. Boston, MA, USA.
10. Favela, J., M. Tentori, D. Segura, and G. Berzunza, *Adaptive awareness of hospital patient information through multiple sentient displays.* International Journal of Ambient Computing and Intelligence, 2009. 1(1): p. 27-38

Reducing Health Disparities in End Stage Renal Disease: An Online Peer Mentoring Approach

Tiffany Veinot
School of Information
University of Michigan
1085 South University Ave.
303B West Hall
Ann Arbor, MI 48109-1107
tveinot@umich.edu

Kai Zheng
School of Public Health
University of Michigan
M3531 SPH II
109 South Observatory St
Ann Arbor, MI 48109-2029
kzheng@umich.edu

Mark W. Newman
School of Information
University of Michigan
2222 SI North, 1075 Beal Ave.
Ann Arbor, MI 48104
mwnewman@umich.edu

Erica E. Perry
National Kidney Foundation of Michigan
1169 Oak Valley Drive
Ann Arbor, MI 48108
eperry@nkfm.org

Chrysta Meadowbrooke
School of Information
University of Michigan
1085 South University Ave.
304 West Hall
Ann Arbor, MI 48109-1107
cmeadow@umich.edu

CHI 2010, April 10–15, 2010, Atlanta, Georgia, USA.

Abstract

Chronic kidney disease (CKD) is the ninth leading cause of death in the United States. The final stage of CKD is end-stage renal disease (ESRD), where people require dialysis or transplantation in order to stay alive. Rural dwellers and young adults (YAs) with ESRD face increased morbidity and worsened quality of life when compared to the general population of ESRD patients. Peer mentoring among adult, urban ESRD patients has been shown to be an effective way of enhancing communication and patient education. However, there are unique challenges in offering face-to-face peer mentoring for YA and rural ESRD patients. We report preliminary findings from a research program to design and evaluate online peer mentoring programs with these vulnerable groups, including results from a pilot peer mentoring website for YAs and ethnographic observations in a dialysis clinic.

Keywords

Peer mentoring, online communities, kidney failure, dialysis, rural, young adult, health disparities

ACM Classification Keywords

J3. Computing applications: Life and Medical Sciences: Medical information systems.

Introduction

Chronic kidney disease (CKD) is the ninth leading cause of death in the United States [1]. CKD is a progressive, permanent condition in which kidneys are damaged and gradually lose their function. The final stage of CKD is end-stage renal disease (ESRD), where people require dialysis or transplantation in order to stay alive. ESRD is thus a demanding and life-threatening disease; indeed, 17% of all ESRD patients in 2006 died [7].

ESRD is also a disease characterized by health disparities. Specific groups experience higher rates of disease, as well as disproportionately poor health-related outcomes. Young adults (YAs) and rural dwellers are two groups which experience such disparities. YAs are less likely to adhere to ESRD treatment, thus increasing their morbidity and mortality risks [6]. Similarly, rural dwellers who live a greater distance from renal health care services experience worse quality of life and higher mortality rates [4].

Peer mentoring—training selected patients to listen to, empathize with, role model for, and empower other patients—is an effective approach to enhancing communication and patient education [3]. The National Kidney Foundation of Michigan (NKFM), our partner in this research, has achieved success with an adult-focused, peer mentoring program [5]; yet, challenges exist when extending this model to certain populations.

Because YAs constitute only 2.7% of dialysis patients in the US [7], they are often the only young person in their dialysis unit. Consequently, YAs may feel alienated from other patients, who tend to be 65 or older [7]. In a similar manner, rural residents with serious illnesses have limited access to peer support groups [2], and may have more difficulty meeting peers than urban residents.

We report here the pilot results of a research program which aims to extend the reach of peer mentoring to YAs and rural dwellers, two groups with fewer opportunities to meet peers. Through three pilot studies, we investigate the potential of offering online peer mentoring for both groups by examining their experiences and needs. Findings reveal much promise for online peer mentoring, but suggest that very different approaches are appropriate for each group.

Three Studies

Study 1: Key Informant Interviews

We conducted key informant interviews with eight NKFM staff and volunteers. The interviews lasted from one to two hours, and focused on the experiences of ESRD patients and their needs for, and experiences with, peer mentoring. The interviews were audio taped, transcribed, and analyzed using a constant comparison approach. We also conducted informal interviews with 18 renal health care providers to learn about YA needs.

From these interviews, we learned that rural ESRD patients experience *difficulties with transportation* to hemodialysis treatments three times a week. Such problems may be associated with insufficient financial resources, winter weather, and a lack of local transportation services. Consequences of transportation issues are serious; for example, they may result in missed or shortened dialysis sessions that could be life-threatening to the patient. Rural dwellers, who are disproportionately elderly and poor, may also experience greater *challenges in obtaining information,* particularly due to lack of Internet access and computer competency. However, we found that the time spent at dialysis could be an *opportunity* to provide peer-based education and support, given that patients must spend a long period of time at clinics while dialyzing.

We also learned that renal health care providers are concerned about YA non-compliance with treatment. For example, they expressed sentiments such as "they [YAs] think they are invincible," "they don't listen," "their priorities are all mixed up," "they don't tell us what they are really doing," and "I worry myself sick about them." Because of their challenges in dealing with YA patients, these providers expressed enthusiasm at the idea of online peer mentoring for YAs.

Study 2: Ethnographic Observation in a Dialysis Clinic
Based on results from our key informant interviews, we conducted ethnographic observations to investigate whether dialysis clinics might be an opportune location for providing peer mentoring. We conducted 40 hours of ethnographic observations in an urban dialysis clinic in order to understand: 1) whether, and how, ESRD patients currently exchange information and support in this setting; and 2) current technology use in clinics.

We observed many instances of patients offering support and encouragement to each other, but this primarily took place in the clinic waiting room. Patients often inquired after each others' health and recent experiences, medical or otherwise. Several told each other to "have a good run" and to keep sticking with treatment for its benefits, even if some days were tough. Some patients also shared information related to ESRD, such as what happened with procedures they underwent or how they got help resolving difficult financial aspects of their healthcare. However, many patients who interacted in the waiting room did not continue conversing once seated for dialysis. This was likely due to the physical layout of the clinic, which created large distances between patients, and background noise from dialysis machines, televisions, and staff calling out to each other while working.

Based on these observations, we concluded that interaction between patients may be further facilitated through use of laptop computers in the dialysis clinic, to help patients "speak to" each other—for example, through real-time chat. Moreover, interview data revealed that providing Internet access may be appropriate for rural dwellers, since they are less likely to have connectivity at home. However, YAs require a different approach. Our observations revealed that YAs who struggle with compliance often miss dialysis treatment. Since YAs are also more likely to have Internet access outside the clinic, a more distributed (e.g., web-based) approach seems suited to them.

Study 3: Pilot Peer Mentoring Intervention with YAs
In a third effort, we created a DVD of interviews with YA peer mentors that included YAs discussing the effect of ESRD on their lives. In addition, based on participatory design sessions with YA peer mentors, we developed an online patient community website, *ktalk.org*. On *ktalk.org*, YAs can interact with those featured on the DVD, who act as peer mentors on the website, as well as other YAs who join the community. This hybrid intervention was deployed in a preliminary trial with 39 YA dialysis patients who viewed the DVD and were given a registration code for *ktalk.org*.

We found that the *ktalk.org* site garnered interest from YA participants, with 15 of 39 (39%) of those invited joining the site. The majority of the conversation on *ktalk.org* took place on the individual profiles, rather than in online forums. While young people expressed enthusiasm about the site in their online posts, we found that the small numbers on the site meant that discussions often petered out after a few responses. As such, the majority of the content on *ktalk.org* involved personal introductions. Anecdotally, however, some YAs indicated that *ktalk.org* had helped them, such as when making treatment decisions. The authors were further encouraged that eight months after the launch, YA participants were still communicating on *ktalk.org*.

Implications and Recommendations

Findings from our research confirm the initial premise that online peer mentoring is a promising strategy for addressing challenges facing YAs and rural dwellers. However, this study also reveals the necessity of utilizing different design and implementation strategies based on the unique needs of each group. Next steps in this research program include further development and evaluation of separate rural and YA online peer mentoring models. Our rural research will involve observations and interviews in rural dialysis clinics in order to look for uniquely rural features. We will then conduct participatory design sessions with rural ESRD patients, deploy laptops in dialysis clinics and work with NKFM to train rural peer mentors. Further, we will deploy and evaluate the intervention on a pilot basis.

As for the YA model, we will continue to offer the YA website, *ktalk.org*, to the YA participants of the study as well as other YAs with ESRD. In so doing, we plan to work with NKFM to increase the number and scope of participants. We will also study activities on *ktalk.org* to shed light on the online behavior of this group.

As we move forward with this research, we plan to investigate our hypothesis that online peer mentoring can improve the quality of life of YAs and rural dwellers with ESRD, while addressing factors which contribute to the health disparities that they confront.

This work was supported in part by Grant # UL1RR024986 received from the National Center for Research Resources.

References

[1] Heron, M., Hoyert, D. L., Murphy, S. L., Xu, J., Kochanek, K. D. and Tejada-Vera, B. Deaths: Final data for 2006. *Natl Health Stat Report 57*, 14 (August 17, 2009 2009), 1-135.
[2] Institute of Medicine *Quality Through Collaboration: The Future of Rural Health*. National Academies Press, Washington, D.C., 2005.
[3] Kapron, K., Perry, E., Bowman, T. and Swartz, R. D. Peer resource consulting: Redesigning a new future. *Adv Ren Replace Ther 4*, 3 (1997), 267-274.
[4] Moist, L. M., Bragg-Gresham, J. L., Pisoni, R. L., Saran, R., Akiba, T., Jacobson, S. H., Fukuhara, S., Mapes, D. L., Rayner, H. C., Saito, A. and Port, F. K. Travel time to dialysis as a predictor of health-related quality of life, adherence, and mortality: The Dialysis Outcomes and Practice Patterns Study (DOPPS). *Am J Kidney Dis 51*, 4 (Apr 2008), 641-650.
[5] Perry, E., Swartz, J., Brown, S., Smith, D., Kelly, G. and Swartz, R. Peer mentoring: A culturally sensitive approach to end-of-life planning for long-term dialysis patients. *Am J Kidney Dis 46*, 1 (Jul 2005), 111-119.
[6] Saran, R., Bragg-Gresham, J. L., Rayner, H. C., Goodkin, D. A., Keen, M. L., Van Dijk, P. C., Kurokawa, K., Piera, L., Saito, A., Fukuhara, S., Young, E. W., Held, P. J. and Port, F. K. Nonadherence in hemodialysis: Associations with mortality, hospitalization, and practice patterns in the DOPPS. *Kidney Int 64*, 1 (2003), 254-262.
[7] United States Renal Data System (USRDS). *The 2008 USRDS Annual Data Report (ADR) Reference Tables*. The National Institute of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD., 2009.

Using the Electronic Medical Record to Keep Hospital Patients Informed

Lauren Wilcox
Columbia University
Dept of Computer Science
wilcox@cs.columbia.edu

Dan Morris
Microsoft Research
dan@microsoft.com

Desney Tan
Microsoft Research
desney@microsoft.com

Justin Gatewood
Dept of Emergency Medicine
Washington Hospital Center

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Abstract

The increasing availability of electronic hospital records has already improved hospital process and provided indirect benefits to patients through increased provider efficiency. However, to date, electronic medical records are typically not presented to patients during hospital visits, and are not structured to be accessible to patients. We suggest that the lack of patient-friendly views into the medical record represents a missed opportunity to keep patients more informed about their own care, more engaged in dialog with physicians, and ultimately more compliant with medical instructions when they leave the hospital. In this position paper, we describe the basis for this perspective, we summarize our own results from a study exploring patient and provider responses to real-time, patient-facing views into a hospital's electronic medical record (EMR), and we propose future work regarding the automation of such displays.

Keywords

Electronic medical records, hospital patients, information displays

ACM Classification Keywords

J.3 [Computer Applications] Life and Medical Sciences – Health.

Introduction: Patient-Facing EMR Systems

Electronic medical records are gaining traction in both hospitals and private-practice clinics, and numerous nation-scale efforts are presently attempting to make electronic medical records ubiquitous. [2] and [3] discuss the tangible benefits of EMR adoption. Reasons frequently cited for the value of the EMR transition are efficiency of information transfer among providers, comprehensive record-keeping for liability mitigation, and accurate and efficient record-keeping for streamlined billing. Anecdotally, providers rarely cite "keeping patients more informed" as a primary benefit of electronic record-keeping.

In parallel, however, medicine is seeing a philosophical shift toward patient ownership of information. The Health Information Portability and Accountability Act (HIPAA), passed in 1996, provides a legal foundation for this trend, guaranteeing patients in the U.S. access to their medical records. The emergence of personal health record (PHR) systems and their (slow but promising) connection to electronic medical records offers a realistic path for convenient access to the records promised to patients under HIPAA.

However, the *availability* of medical records is just the first step in making those records *useful* to patients and their families. By necessity, EMR systems are structured to be practical for their primary consumers: physicians, nurses, lawyers, and hospital administrators. Patients are rarely (if ever) taken into account when considering the language and user interface built into an EMR. The information at the core of the EMR – diagnoses, test results, tests ordered, medications, etc. – is similarly written by providers for providers, in language that is accurate and efficient for inter-provider communication.

Furthermore, this may be an inevitable condition within EMR systems: it is likely not possible in the foreseeable future for providers to craft every medical note to be patient-friendly, nor would we want this at the expense of accuracy and efficiency in patient care.

We thus postulate that EMR systems will offer significant direct benefit to patients, but that significant research is necessary in finding the right analysis, translation, and presentation techniques for automatically building practical *patient-facing* interfaces to modern EMR systems.

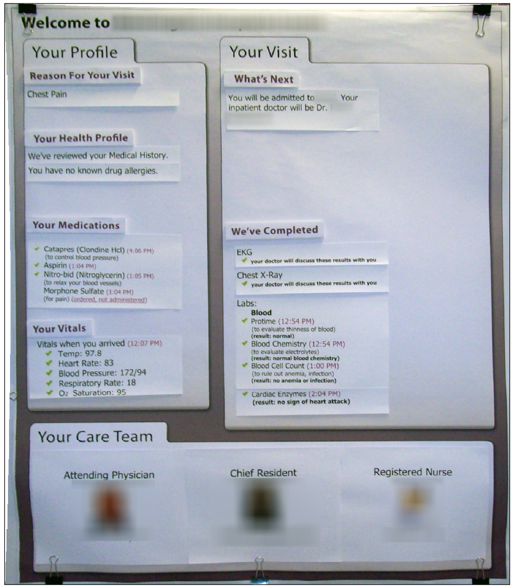
The Real-Time, Patient-Facing EMR

While there are numerous scenarios in which automatic analysis of EMR content could produce useful patient-facing materials, we focus on a particular scenario in our own work. Specifically, we examine the practicality of using the EMR to keep *emergency department* (ED) patients more informed about their care in *real-time* through *in-room displays*.

We note that large displays and diverse input systems are becoming so ubiquitous and affordable that – particularly given that the cost of such items in a medical context can be amortized over many patients – it is reasonable to propose that such technologies can be made available to patients in a wide array of hospitals. We further note that the emergency department is particularly well-suited to this type of information presentation, since (1) the temporal density of medical events is extremely high, (2) the chaos of the ED environment often prevents providers from spending extensive time communicating with each patient, and (3) patients often drift rapidly and unpredictably among states of awareness, suggesting that a persistent information display might be especially valuable (so that information can be available whenever a patient is prepared to consume it).

Patient-Facing Displays: Initial Study

In [1], we present the results of our initial exploration into the methods, benefits, and limitations of patient-facing, in-room displays in an urban emergency department. This study was conducted using a real-time Wizard-of-Oz technique, in which paper prototypes were prepared using information gathered from the EMR used within the ED. Patients received either large-format (3′ × 4′) posters (13 patients) or letter-sized handouts (5 patients). Examples of each prototype form factor are presented in Figures 1 and 2.



Welcome to [redacted]

Your Profile

Reason For Your Visit

Chest Pain

Your Health Profile

We've reviewed your Medical History.

You have no known drug allergies.

Your Medications

- ✓ Catapres (Clondine Hcl) (4:06 PM) (to control blood pressure)
- ✓ Aspirin (1:04 PM)
- ✓ Nitro-bid (Nitroglycerin) (1:05 PM) (to relax your blood vessels)
- Morphone Sulfate (1:04 PM) (for pain) (ordered, not administered)

Your Vitals

Vitals when you arrived (12:07 PM)

- ✓ Temp: 97.8
- ✓ Heart Rate: 83
- ✓ Blood Pressure: 172/94
- ✓ Respiratory Rate: 18
- ✓ O_2 Saturation: 95

Your Visit

What's Next

You will be admitted to [redacted]. Your inpatient doctor will be Dr. [redacted]

We've Completed

EKG

✓ **your doctor will discuss these results with you**

Chest X-Ray

✓ **your doctor will discuss these results with you**

Labs:

Blood

- ✓ Protime (12:54 PM) (to evaluate thinness of blood) **(result: normal)**
- ✓ Blood Chemistry (12:54 PM) (to evaluate electrolytes) **(result: normal blood chemistry)**
- ✓ Blood Cell Count (1:00 PM) (to rule out anemia, infection) **(result: no anemia or infection)**
- ✓ Cardiac Enzymes (2:04 PM) **(result: no sign of heart attack)**

Your Care Team

Attending Physician [redacted]

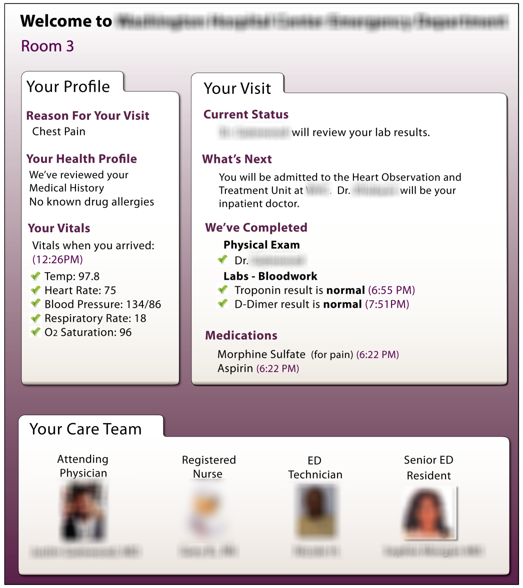
Chief Resident [redacted]

Registered Nurse [redacted]

Figure 1. Display prototype prepared as a 3′x4′ poster.

We designed our prototypes to contain several information categories, allowing us to explore patient responses and preferences, provider responses, and preparation challenges associated with each. We specifically aimed to include the following categories on each poster:

1) Reason for present visit
2) Vital signs
3) Care team (including names and photos)
4) "What's Next" (pending steps in the care process)
5) "We've Completed" (previous steps in the care process)
6) Medications administered in the ED



Welcome to [redacted]

Room 3

Your Profile

Reason For Your Visit

Chest Pain

Your Health Profile

We've reviewed your Medical History

No known drug allergies

Your Vitals

Vitals when you arrived: (12:26PM)

- ✓ Temp: 97.8
- ✓ Heart Rate: 75
- ✓ Blood Pressure: 134/86
- ✓ Respiratory Rate: 18
- ✓ O_2 Saturation: 96

Your Visit

Current Status

[redacted] will review your lab results.

What's Next

You will be admitted to the Heart Observation and Treatment Unit at [redacted]. Dr. [redacted] will be your inpatient doctor.

We've Completed

Physical Exam

✓ Dr. [redacted]

Labs - Bloodwork

- ✓ Troponin result is **normal** (6:55 PM)
- ✓ D-Dimer result is **normal** (7:51PM)

Medications

Morphine Sulfate (for pain) (6:22 PM)

Aspirin (6:22 PM)

Your Care Team

Attending Physician [redacted]

Registered Nurse [redacted]

ED Technician [redacted]

Senior ED Resident [redacted]

Figure 2. Display prototype prepared as an 8.5″x11″ handout.

We point readers to our paper for a full description of our prototypes and the results of semi-structured interviews with patients and providers, but we briefly summarize our results here:

1) Overall, "What's Next" is the perceived by patients as the most useful display component, with some dissenters.
2) Patients liked the information display in general, *even patients who already felt well-informed*.
3) Privacy was much less of an issue than we expected, with a few important caveats.
4) Patient displays facilitate within-visit information sharing among patients and visitors.
5) Patient displays will likely facilitate post-visit information sharing with family and other providers.
6) Patient displays provide memory aids in the ED.
7) Providers were generally supportive of an in-room information display.
8) Most of the information necessary to prepare an effective information display *can* be extracted from an EMR, but there are still important gaps that need to be filled in by physicians.

Future Work

Our initial study looked only at a paper prototype, deployed in a single emergency department. We propose two major avenues of future work:

1) Our initial study was based on a paper prototype. While some of the information transfer from EMR to poster was straightforward, a significant amount of manual translation, interpretation, and physician consultation went into this process. Future work will focus on the automatic extraction of relevant data from the EMR and the adaptation of that information for patient viewing, using natural language generation, machine learning techniques, and heuristics that we have built from our initial experiences in the ED.
2) Our initial study looked only at a small deployment in a single emergency department. However, we propose that the principles gleaned from our initial work and the technical developments discussed in (1) will apply to a variety of display types (in-room displays, discharge materials, online viewing of EMR data at home, etc.) and a variety of clinical environments. Further work is necessary to evaluate the appropriateness of patient-facing views on the EMR for other scenarios.

Supplementary Materials

The full set of display prototypes used in our study is available in the supplementary Web page prepared to accompany our paper:

http://research.microsoft.com/cue/patientdisplays

References

[1] Wilcox, L., Morris, D., Tan, D., and Gatewood, J. Designing Patient-Centric Information Displays for Hospitals. Proceedings of ACM CHI 2010.

[2] Wang S.J., et al. A cost-benefit analysis of electronic medical records in primary care. Am J Med. 2003 Apr 1;114(5):397-403.

[3] Hillestad, R., et al. Can Electronic Medical Record Systems Transform Health Care? Potential Health Benefits, Savings, And Costs. Health Affairs, 24, no. 5 (2005): 1103-111.

Healthcare Consumers' Needs for Interactions with Personal Health Records

Barbara M. Wildemuth
School of Information & Library Science
University of North Carolina at Chapel Hill
100 Manning Hall, CB #3360
Chapel Hill, NC 27599-3360
wildem@ils.unc.edu

Abstract

Personal health records (PHRs), under the control of healthcare consumers, can help them more fully participate in the management of their health care. Forty-three interviews were conducted with people that are likely to be early adopters of PHRs. The interviews revealed that healthcare consumers want to share responsibility for maintaining their health records with their healthcare providers. They want to be able to filter and sort their records based on time, disease or condition, and physician, and to be able to generate personalized displays that are understandable. Such input from potential users of PHRs can inform their design.

Keywords

Personal health records, Usability

ACM Classification Keywords

H5.2. Information interfaces and presentation (e.g., HCI): User interfaces.

General Terms

Human Factors, Design

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Introduction and Background

Personal health records (PHRs) contain the information that individuals need to make decisions about their health and are owned and managed by the individuals they describe [1]. Thus, they are distinct from and complementary to the electronic medical records held by healthcare providers. PHRs also include software tools that allow healthcare consumers to interact with them [5]. PHRs have the potential to empower people to participate more fully in their healthcare management [4]. However, designing PHRs so that they are usable by healthcare consumers presents a variety of challenges.

Based on previous studies, healthcare consumers can be expected to use their PHRs for a variety of purposes, from reviewing lab results, to monitoring trends in their health status over time, to making an appointment to see a physician [2,6]. While people can envision many possible uses for PHRs and over 150 different PHR systems are now available [3], it is not clear that a PHR can be designed that will be usable by the intended audience. PHR usability considerations need to take into account PHR functionality (e.g., entering and sharing data), the data to be stored (e.g., lab test results and physician appointments), and specific usability issues (e.g., complexity, flexibility, and user control) [3]. Results from this study provide the basis for concrete recommendations for designing usable PHRs.

Methods

The study was intended to be diverse, including four specific groups of healthcare consumers that are likely to be early adopters and heavy PHR users: parents with young children, adults with chronic diseases requiring self-management (e.g., diabetes), adults caring for older parents, and older adults. Forty-three semi-structured interviews were conducted with this sample during April-May 2006. Each interview covered the participant's current health records and how they are used; the types of data they would like to keep; the circumstances under which they would create, maintain, and use a PHR; and the usability, privacy, and security of PHRs. The interview transcripts were inductively coded and analyzed further using Nvivo (v.7).

Results and Discussion

Study participants raised and discussed a number of issues in relation to their possible interactions with a PHR. Results related to the ways in which users might add/edit and use their PHRs are briefly summarized and discussed here, including issues related to *who* will be able to view and edit the PHR.

Creating and editing the PHR

A core aspect of the definition of a PHR is the control that the healthcare consumer (rather than the healthcare provider) has over the content of the record. Many of the study participants recognized the advantages provided by such control, such as the integration of data from their medical records and their personal experiences. For instance, participants noted their desire to be able to annotate their existing medical records with notes about specific symptoms or their reactions to a doctor visit. As Edouard[1] said, "If I were to have symptoms, let's say I'm feeling dizzy someday, I might want to just enter it. I would say it is not worth calling a doctor. At the same time, I might want to enter this in case it proves significant." Sandy wanted to ensure that her own knowledge was included in the

---

[1] Pseudonyms are used for all participant names.

record, pointing out that, "The doctor has a lot more knowledge about anatomy and physiology, but sometimes a doctor, even if they listen very well, just doesn't get what you're saying or doesn't understand you."

While most people believed that their health care providers should be allowed to view their PHR (even records aggregated from several providers), some expressed reservations about allowing complete access, particularly to their personal annotations. At the same time, a few of the participants expressed no interest in controlling their own records. They believed that their doctors could and should maintain all the information needed. Jack summed up this perspective: "We don't worry about [our health information]. The doctors… keep it. Our house can burn down faster than the [doctor's office]. They have computers. They can put it on their computers."

A few respondents had concerns about whether they were qualified to maintain a PHR, stating that they would be more comfortable with the accuracy of the records if professionals were responsible. They were particularly interested in having their healthcare providers be responsible for entering technical information, such as lab results. As Evelyn suggested, "I guess, results of tests, it might be nice to have him or her do it rather than me, because they apparently understand the medical terminology better."

Given these results, it seems most workable to allow the healthcare consumer to download records from the provider's system and to augment them with personal notes. Some of the participants suggested that a Q&A dialogue might aid in the addition of content, pointing to *Quicken* personal finance software as an example of the type of interaction desired.

Using the PHR

The study participants expected that a PHR would provide assistance to them in understanding and interpreting the data stored in it. They wanted to know such things as what test results mean and whether they're in a normal range or not, how their health conditions have been changing over a period of time, and whether they've been successful in managing a chronic disease. Thus, the design of the PHR display must include mechanisms for both general and personalized assistance in interpreting the data.

Participants would also like to be able to filter and sort the entries in their PHRs. They would like to be able to filter the entries based on time period (e.g., date range or seasons), condition/disease or body part/system (e.g., heart/cardiac condition), and physician. They would like to be able to sort the entries based on these same attributes: date, condition/disease, physician.

Many of the participants' comments focused on displaying data/trends over time. For example, Judy wanted to see, "If I had problem with my blood pressure. Just to notice if there is a pattern or general variations in my health, trying to figure out what it is impacting." Similarly, Evelyn said, "It would be cool to plot out from a 10-year period or whatever, things like cholesterol level, the IDL and HDLs. And blood pressure. The kind of things that matter. Bone density. See it on a plot – that would be cool." From these example comments, it's also clear that PHR users would like to have a fair amount of control over the displays they received, adjusting the time periods and the content of the displays through easy-to-use tools.

Participants also spoke about the usability criteria to be applied to a PHR. While most of these comments were quite general (asking that the PHR be convenient, easy to use, or user friendly), others were more specific. For example, Margaret mentioned accessibility issues: "Is there a way to do voice recognition, for people who have visual impairments or for people who may have literacy issues?" Sandy was concerned about errors in the data: "I have no concerns other than, possibly, someone entering the data might make an error. The doctor may make an error in computerized entry. Anyone can make an error." From these comments, we can conclude that certain aspects of usability are particularly important for PHR design.

Conclusion

While PHRs are already available to healthcare consumers, their form is not yet established and we have the opportunity to incorporate users' perspectives into their design. Findings from this study of the behaviors and opinions of a variety of people likely to need PHRs can be used to improve PHR usability. They promote a vision of a PHR that is collaboratively created from electronic medical records, patient/user notes, and healthcare provider notes. Such a PHR can be used by healthcare consumers to understand their own health status more completely – by understanding their current health status and being able to track trends in their health indicators over time. With an accessible and understandable view of information about their health, people will be able to participate more fully in managing their health care.

Acknowledgements

This paper is based on interviews conducted by Catherine L. Blake, Kristina Spurgin, Sanghee Oh, Yan Zhang, and myself. Financial support for this research was provided by a grant from the National Cancer Institute ("Evidence Base for Personal Health Record Usability," PI Gary Marchionini, 2006 Supplement to grant, "M.I.N.C. for Mammography Maintenance," CA 105786, PI Barbara Rimer).

References

[1] Burrington-Brown, J., Fishel, J., Fox, L., Friedman, B.,et al. Defining the personal health record. *J. of the Am. Health Info. Mgmt. Assoc. 76* (2005), 24-25.

[2] Cimino, J.J., Patel, V.L., & Kushniruk, A.W. The patient clinical information system (PatCIS): Technical solutions for and experience with giving patients access to their electronic medical records. *Int. J. of Med. Informatics 68*, 1-3 (2002), 113-127.

[3] Marchionini, G., Rimer, B., & Wildemuth, B.M. Evidence base for personal health record usability: Final report to the National Cancer Institute. (2007). http://ils.unc.edu/phr/files/final%20report%20010307.pdf.

[4] Ueckert, F., Goerz, M., Ataian, M., Tessmann, S., & Prokosch, H.U. Empowerment of patients and communication with health care professionals through an electronic health record. *Int. J. of Med. Informatics 70* (2003), 99-108.

[5] Vincent, A., Kaelber, D.C., Pan, E., Shah, S., Johnston, D., & Middleton, D. A patient-centric taxonomy for personal health records (PHRs). *AMIA Annual Symposium Proc.* (2008), 763-767.

Wildemuth, B.M., Blake, C.L., Spurgin, K., Oh, S., & Zhang, Y. Patients' perspectives on personal health records: An assessment of needs and concerns. Poster presented at "Critical Issues in eHealth Research 2006," Bethesda, MD, Sep. 11-12, 2006. http://ils.unc.edu/~wildem/EducatingInformationists/PHRposter2006.pdf.

PaperChain: A Collaborative Healthcare System Grounded in Field Study Work

Stephanie Wilson
Centre for HCI Design
City University London
Northampton Square
London EC1V 0HB, UK
steph@soi.city.ac.uk

Peter Woodward
Centre for HCI Design
City University London
Northampton Square
London EC1V 0HB, UK
peter.woodward.1@soi.city.ac.uk

Rebecca Randell
Centre for HCI Design
City University London
Northampton Square
London EC1V 0HB, UK
rebecca.randell.1@soi.city.ac.uk

WISH 2010 April 11, 2010, Atlanta, Georgia, USA.

Abstract

In this extended abstract we summarise our recent experiences of designing and deploying PaperChain, a system to support real-time information sharing in healthcare work. A guiding principle has been the development of a deep understanding of the work as the foundation for effective system design. We summarise the field work that motivated the development of PaperChain, some of the key findings and the resulting system. We briefly reflect on the benefits gained from undertaking substantial HCI work in the design of a healthcare system.

Keywords

Collaborative work, healthcare systems, digital pen

ACM Classification Keywords

H.5.3. [Information interfaces and presentation (e.g. HCI)]: Group and Organization Interfaces – *computer-supported cooperative work.*

Introduction

In a world where healthcare work is increasingly complex and collaborative, and where healthcare systems and organizations face significant challenges in managing huge volumes of information, there are interesting opportunities for new technologies to facilitate and enhance the effectiveness and safety of the work. Yet in spite of this, studies of healthcare work reveal a continuing reliance on artefacts such as informal paper notes, forms and status boards and there have been several notable failures of Information and Communication Technologies (ICTs) introduced in clinical settings. One reason for this has been a failure to take adequate account of the situated clinical work. In response, there is now a greater appreciation of the important contribution that many disciplines, including human-computer interaction, can make to the design of healthcare ICT systems. This view has underpinned recent work that we have undertaken in the development of PaperChain, a novel system to support one specific form of collaborative healthcare work known as clinical handover. The design of PaperChain was user-centered and participatory; it was motivated and inspired by workplace studies of handover. In this paper, we briefly summarise our studies and the resulting PaperChain system. Our aim is to exemplify the rich insights we gained from a strong focus on the work and the benefit this brought to the design.

Background

Clinical handover is the process by which responsibility for patient care is transferred from one healthcare practitioner or group of practitioners to another and in which relevant information may be shared between the two parties [3]. We have been investigating clinical handover for a number of years and one of our interests has been the potential role of information technology in supporting effective handover.

To understand this role, where technology may be useful and where it may be less so (e.g. see [2]), we have undertaken substantial field studies of handover. These studies were located within a variety of hospital settings [3] and focused primarily on nursing shift handovers, medical shift handovers, temporary delegations of responsibility and transfers between settings (e.g. from an Accident and Emergency department to an admitting ward). The studies took the form of non-participant observations recorded as field notes, audio recording of verbal communications and informal interviews with staff. We have spent over 700 hours in the field undertaking these studies and have acquired a rich set of data.

Handover has tended to be regarded as a baton-passing activity, in which there is a single point of transfer of responsibility and information. Based on our field studies, we have suggested that it may instead be fruitful to view handover as a process and the attendant information sharing as on-going activity (rather than a single transition) that promotes good clinical situation awareness [3]. This reframing of handover motivated and has grounded the development of PaperChain, a system designed to support the real-time sharing of clinical information for one of our field study sites, a paediatric ambulance transport service in London, UK.

Workplace Studies

The ambulance service transports critically ill children from regional hospitals that do not have intensive care facilities to the paediatric intensive care units (PICUs) of major London hospitals. It also provides advice on the treatment of children either prior to transporting them or instead of doing so, in situations where transport is deemed inappropriate. The service is staffed by doctors and nurses, and the transport or “retrieval” of each child is a collaborative activity involving multiple healthcare professionals.

We spent 111 hours at the ambulance service as part of our initial field studies (and many more hours since then). We observed the work at the base office, travelled on retrievals, and conducted informal interviews with the staff. The retrieval of a child starts when a regional hospital phones the office of the transport service. At the time of the field studies, details of the case were then recorded on a multi-page paper form by an administrator and a trainee doctor known as a “fellow”. If the decision was made to retrieve the child, a team consisting of the fellow, a nurse and an ambulance driver would be mobilized and would travel to the regional hospital taking the paper form with them to record further clinical details. Senior physicians, who generally remained at the base office, did not have access to the information on the form and had to rely on a telephone handover from the fellow prior to authorizing transport of the child.

Based on the field studies, we set out with the goal of developing a system to support better real-time information sharing between the clinical staff, thereby taking the pressure off “baton-passing” handovers. Specifically, the aim was to improve information sharing between the team who travelled to the regional hospital to stabilise and transfer the child, the senior physicians and others at the base office and the PICU staff. The field studies yielded valuable information about handovers, how they happened, what information was communicated etc, and this informed the design of PaperChain. However, some of the most valuable insights were not about the functionality of the system but about the nature of the work and the circumstances in which it was conducted. For example:

The fiction of a normal course of events
Healthcare work is well-known for its contingent and responsive nature. When we spoke to the staff about their work they gave us a high-level, process-oriented description of how the service operated and what happened on a retrieval. This was very valuable but with the field studies it rapidly became apparent that retrievals rarely (or never) conformed to this idealized description. Instead, they varied in myriad ways that we could not have anticipated and which the staff would not have been able to articulate easily. It became clear that our system should not be constrained by a strong, process-oriented view of the work but instead should acknowledge the non-normal courses of events, allowing staff to flexibly capture and view relevant clinical information irrespective of what happened in practice.

Benefit without pain
The priority for the doctors and nurses on a retrieval is looking after the patient. They are working in high-pressure, sometimes life-critical circumstances. When dealing with a critically ill patient they have no capacity or motivation to use a system that adds to their work or removes their attention from the patient unless there is some immediate benefit to be gained. For us, this was an imperative for truly lightweight data capture and an argument against the perhaps obvious solutions of a PDA or tablet PC-based system. Similarly, staff at the base office are busy and perhaps unlikely to access a display that requires effort on their part. We needed a display paradigm where information was “pushed” not “pulled”.

PaperChain

PaperChain uses a novel combination of digital pens/paper and shared displays to provide light-weight capture and sharing of information in (almost) real-time. Digital pen and paper is a relatively new technology. Anything written on digital paper with a digital pen is captured electronically and can be immediately transferred to a central server via the mobile phone network.

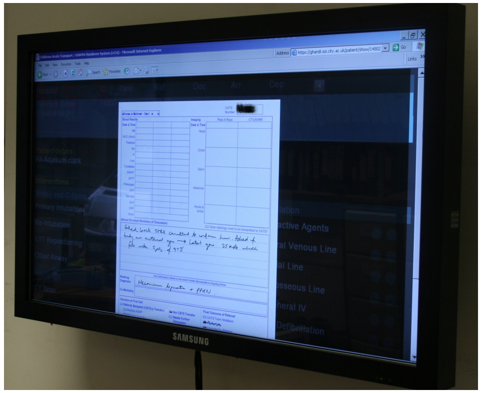


Figure 1: Shared display with one page of the clinical form overlaid on summary information

We replaced the existing paper forms used by the ambulance service with digital pens and paper so that all written information about a retrieval is now automatically captured in electronic form. Hence, with minimal change to the work of the ambulance team, we are able to capture information about a retrieval while it is in progress. This information is then transmitted to base office and the PICU where shared displays make it readily available. A large shared touchscreen display in the base office acts as an "awareness display" [1], providing a continuously updated view of current cases and giving staff access to the digital form (Figure 1).

Status and Brief Reflection

PaperChain is a robust research prototype. It has now been deployed for several months and is in routine everyday use. We are currently evaluating its impact through post-deployment field studies using multiple evaluation methods. While there have inevitably been some practical problems, our experiences thus far, and the enthusiasm with which the clinical staff have embraced PaperChain, suggest that this combination of technologies has much promise. The strong focus on the work provided by the detailed workplace studies was invaluable and demonstrates (yet again) the benefit of multidisciplinary approaches in healthcare ICT design. The value of the studies was not just what they revealed about the tasks and the information flow, but what they told us about the many ways in which work routinely varied from the norm and which had to be accommodated in a flexible design.

Acknowledgements

This work was funded by the UK Engineering and Physical Sciences Research Council (EPSRC), grant EP/D078636/1. Thanks to all the staff at the ambulance service and to Digital Field Solutions for sponsoring and providing the digital pen technology and services.

References

[1] Bardram, J.E., Hansen, T.R. & Soegaard, M., AwareMedia: A Shared Interactive Display Supporting Social, Temporal, and Spatial Awareness in Surgery, *Proc. CSCW 2006*, ACM Press (2006), 109-118.

[2] Wilson, S, Galliers, J. & Fone, J. Medical Handover: A Study and Implications for Information Technology. *Proc HEPS 2005*, 2005.

[3] Wilson, S., Randell, R., Galliers, J. & Woodward, P., Reconceptualising Clinical Handover: Information Sharing for Situation Awareness, *Proc. ECCE 2009.*

Designing for Adoption: A Living Laboratory for Health IT

Lena Mamykina
Dept. of Biomedical Informatics
Columbia University
lena.mamykina@dbmi.columbia.edu

Lauren Wilcox
Dept. of Computer Science
Columbia University
wilcox@cs.columbia.edu

David Vawdrey
Dept. of Biomedical Informatics
Columbia University
david.vawdrey@dbmi.columbia.edu

Daniel Stein
Sarah Collins
Stewin Camargo
Matt Fred
George Hripcsak
Dept. of Biomedical Informatics
Columbia University
{dan.stein, sarah.collins}
@dbmi.columbia.edu;
sc2689@columbia.edu;
mrf2004@nyp.org;
hripscak@columbia.edu

Steven Feiner
Dept. of Computer Science
Columbia University
1214 Amsterdam Avenue
New York, NY 10027-7003
feiner@cs.columbia.edu

Abstract

We describe how an interdisciplinary collaboration has created a "living laboratory" in which researchers maintain a direct and ongoing loop between innovation and production and study true adoption of technology in real world settings. The collaborators include the Department of Biomedical Informatics and the Department of Computer Science at Columbia University, industrial partners developing commercial health IT applications, and New York-Presbyterian Hospital's Columbia University Medical Center. In this paper we discuss our current projects, and mention some of the unique benefits and challenges of building a living laboratory for health information technology.

Keywords

Health information technology, living laboratory, design, evaluation

ACM Classification Keywords

J.3 Life and Medical Sciences: Medical Information Systems.

General Terms

Design

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Introduction

The health care industry maintains tight connections with research communities in such areas such as Computer Science (CS), Human-Computer Interaction (HCI), and Biomedical Informatics, among many others. Traditionally, researchers investigate problems experienced by health care professionals and identify opportunities to enhance work practices with novel technologies. Oftentimes, especially in the field of HCI, researchers work with potential users of new technologies through formative studies, user-centered design approaches and evaluation studies, often leading to prototypes. Occasionally, these prototypes inspire new commercial products that are adopted by health care professionals and shape the way health care is delivered. In many cases, however, the engagement of research does not extend beyond the initial investigation and prototyping phases, and opportunities to study adoption of innovations and incorporate lessons learned into the design of new technologies are limited.

In contrast to this approach, the New York-Presbyterian (NYP) Hospital's Columbia University Medical Center, jointly with the Department of Biomedical Informatics and the Department of Computer Science, have cultivated a "living laboratory" environment in which technological innovations can be deployed for use in real clinical settings. Throughout the years, these innovations included complete Electronic Health Record (EHR) systems for the hospital and a number of novel applications that have enhanced commercial health information technology (IT) applications used by the hospital [2].

Current Collaborative Projects

We are applying our experience with system integration, patient-centered design, computerized provider order entry, and electronic documentation to design clinical innovations focusing on quality, safety, and effectiveness. Below, we outline current projects on which we are collaborating.

Including patients and their loved ones as part of the inpatient care team.

This project focuses on the design of patient-centered, bedside information technology, linking the inpatient EHR with the hospital's personal health record (PHR) system. We build on previous work on collaborative communication among the care team, including studies of patient handoff, goal-setting, and task coordination to answer the question: how can we include patients and their family members in the care team?

Achieving effective medication reconciliation across care settings.

We are conducting a formal study of the paperless medication reconciliation process at NYP that uses a medication list based on discrete, coded elements to bridge ambulatory and inpatient care settings.

Improving electronic documentation tools and assessing their use.

We are currently evaluating the impact of electronic documentation at NYP (over 100,000 clinical notes are entered each month into the EHR). Through commercial systems that we have augmented and deployed [6], and research prototypes used in design explorations [7], we are investigating new approaches to information retrieval for documentation and content management. We are beginning to answer questions such as: How can technology enable relevant information retrieval from unstructured documents? How can technology better enable clinical notes to serve as effective communication artifacts?

Extending the reach of the EHR using mobile devices to support task management for clinicians.

For this project, we are developing technology to support the delivery of subscriptions to messages originating in the EHR (e.g., laboratory results and task reminders) to care team members, via mobile devices such as the Apple iPhone. This project explores questions such as: how can mobile technologies better enable care team members to coordinate tasks and share information? What types of interaction and presentation techniques can permit clinicians to view and manage notifications and alerts in the context of care delivery?

Our particular approaches to these and former projects point to a number of unique benefits for the researchers in HCI, CS, Biomedical Informatics and related fields. However, they also face a number of challenges. Next, we discuss these challenges in the context of design, implementation, and evaluation of technology. The list presented here is far from exhaustive; our hope is to highlight some salient points that could inspire a discussion within the community.

Design Challenges

Health and medical care are extremely expertise-heavy domains. Medical professionals undergo years of intensive training and continue to refine their expertise throughout their practice. This limits the designers' ability to become domain experts. At the same time, medical professionals are some of the busiest people, leaving little opportunity for traditional user-centered design processes, such as interviews, observations, and participatory design [1,5]. These challenges present a need for different approaches to engaging users in research and design. We found that short but intense feedback sessions (e.g., 30 minutes [7]) can save clinicians' time and provide sufficient information to inform ongoing research and design. We also found that it was effective to include a feedback mechanism to capture clinician feedback, not as a bug reporting utility or service function, but as a way to record frustrations and ideas for improvement.

Practicing medicine as part of a living laboratory often leads to cautious attitudes to novel designs and solutions. This presents a need to balance innovation and familiarity and places particular importance on achieving the right tradeoff between longer-term benefits and immediate adoption costs. Also, new technologies require adjustments to work practices that could lead to initial inefficiencies. This is especially true in cases when new technology initially co-exists with older technology rather than replacing it, which often leads to duplication of work.

Modern medicine relies heavily on computing technology. The information technology presents a complex ecosystem of infrastructures and applications designed for interdisciplinary teams, as well as individual clinicians. Each new application needs to be designed with respect to this ecology and each new design needs to be considered in context of its implications for the overall system.

Implementation Challenges

Information technology in health care industry is slow to change. Many clinical centers, small and large, continue using outdated technology, often decades after its prime. Novel technologies typically need to be integrated with legacy applications, infrastructures, data storage and communication standards.

Health care is an intensely regulated industry, with various standards controlling many aspects of care itself, as well as information technology supporting care practices. Controlled vocabularies, information exchange protocols and data structures are a necessary component for each new application.

The existing ecology of computing systems and infrastructures impacts both implementation and design of new applications. Each new innovation needs to co-exist with existing systems.

Evaluation Challenges

The living laboratory presents an opportunity to go beyond usability studies and small-scale deployment studies to study true adoption (or lack thereof) of computing technologies. At the same time, it presents a need for new metrics for evaluating the long-term impact of technology and its adoption by users. This integrated view of a computing system as an ecology makes it difficult to separate the effectiveness of its components.

The complex and mission-critical nature of health care settings makes it difficult to run rigorous controlled experiments. Often, researchers have limited impact on the consistency of usage, or it is hard to isolate and control variables; In these cases, it may be impossible or impractical to include a control condition. Moreover, clinical tasks are often interdependent and not clearly defined, further complicating experimental design.

Any health care IT should be evaluated on clinical outcomes, such as improved quality of care or on improved efficiency and cost-saving. However, these measures require extensive longitudinal studies, presenting the need to introduce intermediate outcomes. For example, for applications specifically targeting improved clinical documentation, there are no existing gold standards that could be used for comparison. One approach is to invite experts to judge the quality of work mediated by novel technology [3]; however these approaches tend to be costly and time-consuming.

Finally, the years of collective expertise in conducting usability studies has allowed the HCI community to formulate a number of heuristics that allow experts to predict usability of computing systems with a certain level of confidence [4]. There is a need for a set of heuristics that can allow experts to anticipate the likelihood of adoption of computing systems. Longitudinal studies of health IT adoption, which are possible in living laboratories, should make it possible to formulate such heuristics.

Conclusions

In this paper, we discussed some of our current collaborative projects, and our experiences designing novel computing technologies that support clinical work in a living laboratory. We also discuss some key challenges associated with conducting research in this unique setting.

References

[1] Beyer, H., Holzblatt K. Contextual Design, Kaufmann 1998.

[2] Hripcsak, G., Cimino, J., Sengupta, S. Webcis: Large scale deployment of a web-based clinical information system. Proc. AMIA. 1999 Nov.

[3] Jordan, D., McKeown, K., Concepcion, K., Feiner, S., Hatzivassiloglou. Generation and evaluation of intraoperative inferences for automated health care briefings on patient status after bypass surgery. Jnl. AMIA, 8(3), May/June 2001, 267–280.

[4] Nielsen J., and Mack R.L. Usability Inspection Methods, John Wiley & Sons, New York, NY, 1994.

[5] Schuler & Namioka 1993, Participatory Design, Lawrence Erlbaum

[6] Vawdrey, D.K. Assessing usage patterns of electronic clinical documentation templates. Proc AMIA. 2008 Nov 6:758-62.

[7] Wilcox, L., Lu, L., Lai, J., Feiner, S. Physician-driven management of patient progress notes in an intensive care unit. Proc. CHI 2010, Atlanta, GA, April 10-15, 2010.

Cultural and Linguistic Adaptation of Relational Agents for Health Counseling

Langxuan Yin
Timothy Bickmore
Donna Byron
Northeastern University
360 Huntington Ave, WVH
Boston, MA 02115 USA
{yinlx,bickmore,dbyron}@ccs.neu.edu

Dharma E. Cortés
Cambridge Hospital
Harvard Medical School
Cambridge, MA
dharma_cortes@hms.harvard.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

Computer-based systems for health education and behavior change are becoming widely used in health care, but systems targeting specific cultures other than Anglo-Americans are few. We describe our methodology and experiences adapting a conversational health counseling agent for older Latino adults, the implications for automated patient-facing health systems, and directions of future research.

ACM Classification Keywords

H5.2. Information interfaces and presentation: user interfaces – Graphical user interfaces (GUI), natural language, user-centered design

Introduction

Culture is important in health education and behavior change interventions. In face-to-face interactions, many studies have demonstrated the importance of cultural congruity between health providers and their patients. For example, health counselors from a patient's own culture are usually "deemed more desirable because of their presumed familiarity with the cultural values" [2]. Culture is also important in print-based interventions, with several studies showing that

Figure 1. The interactive interface of the system featuring Carmen

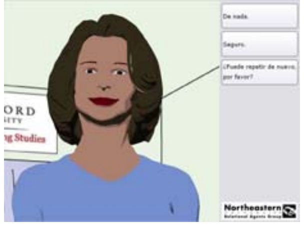


Figure 2. A close-up look of Carmen

health-related content tailored to a particular user is more effective than standard materials in promoting behavior change [3]. Although culture is becoming an increasingly important research focus in HCI, little work has been done on cultural adaptation of computerized patient health interventions, and particularly those delivered by conversational agents.

In this work, we present our experience in adapting a relational exercise promotion agent originally designed for older Anglo adults [4] for a population of older Latino adults. Relational agents are conversational agents designed to build and maintain long-term social-emotional relationships with their users, and, in the healthcare context, leverage these relationships to increase adherence to health regimens.

A relational agent to promote walking among older Latino adults

In collaboration with Dr. Abby King at the Stanford School of Medicine we developed "Carmen" as a relational agent that promotes walking among older Latino adults (Figures 1 & 2). Carmen runs in a kiosk in a community center in San Jose, and is designed to talk to people several times per week about their walking behavior, measured by pedometers. In a typical ten-minute conversation, Carmen greets the user, follows up with brief social chat, then uploads the user's walking steps from their pedometer and discusses their walking goals. At the end of the session, Carmen says goodbye and walks off the screen. Carmen can talk with users in either English or Spanish.

LINGUISTIC ADAPTATION

Since most members of the development team did not speak Spanish, the dialogue content of the system was first developed in English and thoroughly tested before translation into Spanish. As the target population is one with low health literacy, literal or "word-for-word" translation of the dialogue was avoided, and complex terms were broken down to simpler but longer phrases in order to convey the sense and meaning of the dialogue originally developed in English. When the translation was complete and implemented in the dialogue system, both versions were placed in parallel in the system so that the agent could switch between the languages based on user preference.

Prior to the development of Carmen, we conducted literature reviews on nonverbal behaviors of Latinos and analyzed videos of a Spanish-speaking Latino researcher counseling members of the target population about their exercise behavior. After detailed analyses of several dialogues and accompanying nonverbal behavior, we concluded that the rules used to generate nonverbal behavior for our Anglo English-speaking agent did not need to be modified. This decision was confirmed by having several Spanish speakers review the conversational behavior of the agent. There were, however, some behaviors that we observed that could not be implemented in our system, including touching.

CULTURAL ADAPTATION

Hofstede's cultural dimensions research shows the Latino culture is high in power distance and collectivism [1]. Much of the dialogue content from the original project that Carmen is based on was adapted to match the Latino culture on these dimensions. For instance, Carmen's coaching strategy puts an emphasis on walking with friends or with other walking partners (emphasizing collectivism). Also, appeals to authority, such as healthy behavior recommendations framed with "experts say" in the English system, were reworded or removed to increase the counselor's affinity (emphasizing power distance) [2]. Latino music well-known to the community, such as "El electricista" and "Pasito Tun Tun", is also played when Carmen walks on and off the screen, as well as at other appropriate points.

RELATIONAL ADAPTATION

Having the agent demonstrate cultural congruity [6], through any means, improves solidarity and like-mindedness, which should boost rapport and trust with users. In addition, we extended the system so that limited information about users' lifestyles (e.g., culturally appropriate leisure time activites) and social networks (e.g., names of friends and family members) could be input to the system at enrollment time, enabling the agent to refer to these in dialogue. Reference to social networks is especially important in collectivist cultures. Reference to this information by the agent demonstrates mutual knowledge, knowledge of users' personal lives, and integration into users' social networks, which should all serve to decrease social distance with users

PILOT STUDY

An evaluation study has just been completed with forty participants aged 55 and over. Those in the intervention group were asked to wear pedometers daily and check in three times a week for four months with Carmen. Half of participants chose to conduct their counseling sessions in Spanish.

Preliminary results indicate that intervention group participants talked to the counseling agent an average of 1.1 times per week, and retention in the intervention group over the four months was 95%. Anecdotal feedback about the agent and the walking intervention was very positive. Intervention participants increased their step counts by an average of 1,276 steps per day over their baseline at enrollment. Comparisons to the control group are still underway.

LESSONS LEARNED

Cultural differences can be very subtle and difficult for non-members of a culture to even perceive, thus increasing the importance of participatory design with members of the target population. Two obstacles prevented us from using these methods as much as we would have liked in our development: lack of access to the user population due to geographic constraints, and the fact that most of our development team did not speak Spanish. Future efforts should take care to address both of these issues.

Holding off the translation until the system is completely tested in one language turns out to be a successful approach. However, the translation process required several iterations. Since most users in the target population have low health literacy, some of the original Spanish translation had to be revised to improve readability, generally by breaking complex wordings into longer phrases. According to one of our translators, it would be helpful if translators could review the scripts to spot discrepancies before the English system is finalized.

User feedback in the study shows that participants felt sad when Carmen joked about herself being trapped "in the box" (of the computer), and when she says she is staying "in the box" over the weekend. The participants expected Carmen to be able to walk freely, and have friends to hang out with during the weekend. We initially restricted Carmen to talking about herself as a computer since we were worried about the potential dishonesty perceived by the participants, but a recent experiment shows that in this context, first-person human autobiographical stories can in fact increase engagement without users feeling deceived [5].

Future work

As an initial attempt at the cultural-specific design of health counseling systems, we integrated counseling strategies based on Hofstede's theory. Two of the five dimensions defined by Hofstede, namely power distance and individualism vs. collectivism [1], were explored in this system, although power distance plays less of a role due to the specific context of the dialogue. One direction of future work is to develop guidelines for cultural adaptation of a counseling agent between any two cultures, by identifying the modifications require for movement along any of Hofstede's five axes.

Another important research question is the individual impacts of language and cultural congruity on outcomes for health counseling systems. Cultural congruity, defined by Luna [6], is "the agreement of the cultural manifestations expressed … with the cultural manifestations of" the users of a computer system. In the system presented in this paper, language is chosen by the user, and the congruity level of the system does not vary between languages, thus we cannot tell whether language or cultural congruity, or both, have an impact on the participants' attitude towards the system, and on their health behavior outcomes. We plan to conduct a study that teases apart the impact of these factors to provide further insights into the design of culture-specific systems.

Acknowledgements

Thanks to our collaborators at Stanford: Abby King, Ines Campero, and Leslie Pruitt. This work was funded by NIH National Cancer Institute grant 5R21CA127511.

Citations

[1] Hofstede, G. Culture's Consequences: Comparing Values, Behaviors, Institutions and Organizations across Nations. Sage Publications, Thousand Oaks, (2001)

[2] Sue, D.W., Ivey, A., Pederson, P. Theory of Multicultural Counseling & Therapy, Thomson Brooks/Cole, (2007).

[3] Campbell, M.K., DeVellis, B.M., Strecher, V.J., Ammerman, A.S., DeVellis, R.F., and Sandler, R.S. Improving dietary behavior: the effectiveness of tailored messages in primary care settings. American Journal of Public Health, 84(5), (1994), 783-7.

[4] Bickmore, T., Caruso, L., Clough-Gorr, K., and Heeren, T. "It's just like you talk to a friend" – Relational Agents for Older Adults. Interaction with Computers, 17(6), (2005), 711-735.

[5] Bickmore, T., Schulman, D. and Yin, L. Engagement vs. Deceit: Virtual Humans with Human Autobiographies. Intelligent Virtual Agents, LNAI 5773, (2009), 6-19.

[6] Luna, D., Peracchio, L., and Dolores de Juan, M. The Impact of Language and Congruity on Persuasion in Multicultural E –Marketing. Journal of Consumer Psychology, 13(1&2), (2003), 41-50.

Clinician Workarounds in Use of Computerized Prescriber Order Entry

Xiaomu Zhou
University of Michigan
1075 Beal Ave.
Ann Arbor, MI 48109 USA
xmzhou@umich.edu

Kai Zheng
University of Michigan
109 Observatory St.
Ann Arbor, MI 48109 USA
kzheng@umich.edu

Mark S. Ackerman
University of Michigan
1075 Beal Ave.
Ann Arbor, MI 48109 USA
ackerm@umich.edu

WISH 2010, April 11, 2010, Atlanta, Georgia, USA.

Abstract

A workaround is a user-initiated alternative means of accomplishing a task that bypasses intentionally or unintentionally introduced obstacles. Through a qualitative investigation, we studied causes of and reasons for clinician workarounds in their day-to-day interaction with a computerized prescriber order entry (CPOE) system. We found that clinician workarounds for the CPOE were pervasive in the clinical environment we studied. By examining their distinct purposes and potential consequences, we conclude that tolerating maleficent workarounds may compromise patient safety; however, dismissing those beneficent ones could forgo opportunities for organizational learning and improvement.

Keywords

Workarounds, computerized prescriber order entry, CPOE, organizational routine

ACM Classification Keywords

H H.0 [information systems]; K.4.3 [organizational impacts]: Computer-supported cooperative work.

Introduction

As estimated by the Institute of Medicine, preventable medical errors are responsible for 44,000 to 98,000 patient deaths annually in the United States [1]. Computerized prescriber order entry (CPOE) is generally regarded as a promising tool for reducing medication errors through its ability to eliminate illegible handwritten prescriptions and common human omissions (e.g., decimal point errors). Despite the great potential, introduction of CPOE has been slower and more problematic than anticipated. This is partially due to the overly simplistic models underlying current CPOE designs that are not well aligned with clinical workflow and clinicians' tasks, cognitive limitations, and established practice styles [2].

Workarounds is a consequential, end-user response to this technology-task misalignment [3]. Workarounds occurs when a clinician's usual work routine is 'blocked' by certain obstacles introduced by CPOE. Some of these 'blocks' are intended (e.g., to comply with regulatory requirement); some are unintended, such as those used to address design deficiencies of a CPOE system. To better understand this dichotomized nature of clinician workarounds of CPOE, we conducted a qualitative study to investigate clinicians' working-around behaviors in their day-to-day clinical practice *before*, *during*, and *after* a CPOE implementation.

Methods and data collection

The empirical study was conducted at a large academic medical center. From January to August 2008, the first author conducted an ethnographic study in an inpatient unit, where a commercially purchased CPOE system was introduced in April 2008. Informed by the findings from the ethnographic observations, we subsequently conducted semi-structured interviews with 18 nurses, 6 clerical staff, and 6 physicians to solicit additional working-around tactics they adopted as well as their explanations of and attitudes toward the behavior.

Results

Five major types of workarounds of CPOE emerged from the qualitative analysis. They were created to: (1) accommodate new patterns of team communication and coordination; (2) shift workload and responsibility to others; (3) address issues from inadequate system integration; (4) improve technology affordance; and (5) avoid undesirable information sharing. Below we describe each with an example, respectively.

Team communication and coordination

Prior to the CPOE implementation, physicians had to physically present themselves at the nursing station to write orders. While inefficient, it provided an opportunity for them to meet nurses regularly to discuss patient conditions and unclear orders. After the CPOE implementation, this routine communication channel was no longer available. Nurses had to log into a computer terminal periodically to find out whether there were pending orders that needed their immediate attention. As a result, orders that should have been administered in a timely manner were often delayed or missed. Because requiring nurses to closely monitor patient orders *at all times* was unrealistic, a working-around solution was created, which became a regular practice across all units at the medical center: clerical staff were assigned a new duty to constantly monitor order status for all patients and notify the nurses when actions were needed.

Shifting workload and responsibility

Depending on a patient's progress, physicians often need to prescribe a new order for the same drug, but with a new dosage and usage, while the old order is still in place. In the old paper-order operation, nurses understood that an order with an updated dosage and usage would overwrite an existing order. After the CPOE implementation, a number of extra and time-consuming steps were required for physicians to modify an order, including locating the old (existing) prescription from a large volume of orders that can not be easily searched or sorted, discontinuing it, and then placing a new order with updated dosage and usage. Hence, physicians often chose to start a new prescription without discontinuing the previous one, hoping the issue of duplication will be subsequently taken care of by the nursing team. This working around behavior of physicians shifted the workload and responsibility to nurses, who were extremely unhappy because the volume of duplicated orders was overwhelming and they needed to take on additional responsibilities which were originally not part of their work.

System integration issues

The medical center has a wide range of heterogeneous hospital information systems in use because of legacy reasons. Many are not well integrated and do not allow for seamless data interoperability. For example, the emergency department and the pharmacy department have their own specialized software applications that have limited data exchange with the CPOE system. As a work-around solution to assembling essential patient care information residing in multiple systems, nurses often manually transferred patient data to their personal sheets and then sometimes voluntarily typed them into the CPOE system.

Affordance of technology

To avoid waiting in line for CPOE workstations during peak time to prepare medication, some nurses chose to transfer patients' medication information onto their personal sheets in advance. Clearly, this extra step was not only time-consuming, but could cause errors in transferring patient data, missing new orders, or missing modifications to existing orders. Similarly, using paper artifacts as a temporary recording media became a common working-around approach to address the need for conveniently accessing information. For example, in order to catch a physician in the hallway to clarify unclear orders, many nurses chose to print out *all* orders so as to present the patient case to the physician.

Unintended information sharing

Implementation of the CPOE system, by design, eliminated most of the paper forms. However, some of these forms were utilized by nurses in subtle ways that could not be fully replicated in the CPOE system. For example, nurses used to maintain temporary, working documents where sensitive psychosocial information was recorded. These working documents would be tossed away following the patient's discharge. Forcing nurses to document such information in the CPOE system raised great concerns among nurses, as electronic documentation would become part of the patients' permanent legal medical records. Additionally, it increased the visibility of information. The sensitive psychosocial information, which often conveys a nurse's judgmental words about the patient's behavior, could now be easily accessed by anybody across the institution. As a result, instead of recording the information in the CPOE system as instructed, nurses started passing it on through verbal communications. However, the oral information relay was only effective from one shift to the next. Important information could be diluted or lost *across* multiple nursing shifts [4].

Discussion and implications

Clinician workarounds of the CPOE pervaded the clinical environment we studied. They represent clinicians' first-order problem-solving tactics for addressing the immediate symptom of a problem without treating its cause. Further, workarounds can be studied to reflect clinicians' thought process leading to the perception that working around an obstacle is a more preferred method. For example, clinicians may have applied decision-making heuristics, or 'rules of thumb,' in order to arrive at a solution rapidly with minimal cognitive efforts. Clearly, working around a problem without initiating the effort to learn from the problem will not lead to informed and improved practice. However, certain workarounds, such as those created to remedy technology deficiencies, could sustain, propagate, and eventually become new organizational routines.

Treating workarounds differently according to their distinct nature could inform more realistic CPOE policies and more useful and usable CPOE designs. In this study, we differentiated the workarounds discovered based their varying purposes and potential consequences. We also differentiated them based on their distinct lifespan: temporary fixes employed shortly after the CPOE implementation, versus long-term solutions institutionalized as new organizational routines. Transferring patients' medication information in advance to reduce waiting time, for example, is a temporary workarounds that was used only initially after the CPOE implementation. This working-around behavior was gradually abandoned when nurses learned better ways to manage their work processes. On the contrary, several other workarounds reported in this paper, such as assigning clerks to monitor the orders have become institutionalized as new ways of work. Furthermore, passing sensitive psychosocial information verbally rather than recording it in the CPOE system as required represents a workaround that was socially accepted (even though it was problematic) as a norm among the nurses.

Conclusion and future work

By differentiating clinician workarounds of CPOE based on their distinct purposes and potential consequences, we concluded that while tolerating maleficent workarounds may compromise patient safety, dismissing beneficent ones could forgo opportunities for organizational learning and improvement. In our future work, we will seek to understand the psychological and social underpinnings of clinicians' working-around behaviors by answering: "What leads to clinicians' judgment that working around an obstacle is a more preferable option as compared to the prescribed means?" and "What stops clinicians from expending additional resources to solve any blocking condition so that it will not occur again?" Further, we will interview additional types of clinicians to learn about their perspectives regarding workarounds of CPOE.

References and Citations

[1] Institute of Medicine. *To Err is Human: Building a Safer Health System*. National Academy Press; 1999.

[2] Niazkhani, Z. et al. The impact of computerized provider order entry (CPOE) systems on inpatient clinical workflow: A literature review. *J Am Med Inform Assoc.*16, 4(2009), 539-549.

[3] Pollock N. When is a work-around? Conflict & negotiation in computer systems development. *Sci Technol Hum Val.* 2005;30(4):496-514.

[4] Zhou, X., Ackerman, M., and Zheng, K. I just don't know why it's gone: maintaining informal information use in inpatient care, *Proc. CHI2009*, ACM Press (2009), 2061-2070.