Tracking Observations of Everyday Living with Smart Phones

Michelle Rogers

The iSchool at Drexel University,
3141 Chestnut Street,
Philadelphia, PA 19104-2875 USA
mrogers@drexel.edu

Abstract. Reports of health information systems failures identified the guilty parties laying with issues around social, technical, and organizational factors. The reason so many systems fail may lie in the socio-cultural fit of e-Health systems. We do not understand how to deliver information to providers when they need it, in a usable format, and in a way that fits transparently into their workflow and into the daily lives of patients. In addition to understanding how clinicians use HIT in order to promote health behavior change, it is necessary to consider patient goals, preferences and capacities. Patients with multiple diagnoses are often complex to manage because so much of their experiences happen in between clinical visits. Information and communication technologies (ICT) can play an important role in assisting patients managing personal health information. The key question is how do we take advantage of the power of low-cost ICTs to extend care?

Keywords: Information and communication technologies, Socio-technical systems, consumer health, usability, human-computer interaction.

1 Introduction

The shortcomings of healthcare information and communication technology implementations have been well documented [1-4] and identified the guilty parties laying with issues around social, technical, and organizational factors [5-9]. The reason that so many systems fail may lie in the socio-cultural fit of these systems. Often health information technology (HIT) are poorly automated [1,9,10]; slow [11, 12]; insensitive to human factors engineering principles [13], introduce unanticipated workflow concerns [14-15] and often deliver non-computable data. We do not understand how to deliver information to health care providers when they need it, in a format they can use, and in a way that fits transparently into their workflow and into the daily lives of patients. This is crucial to understand given the significant health improvements there have been demonstrated using HIT that utilize concepts of patient involvement in the documentation of health outcomes, increased patient-provider communication and patient engagement [16].

C. Stephanidis (Ed.): Universal Access in HCI, Part III, HCII 2011, LNCS 6767, pp. 76–83, 2011.

In addition to understanding how clinicians use HIT in order to promote health behavior change [17], it is necessary to consider patient needs, goals, preferences and capacities [18-20]. Patients with multiple diagnoses are the most difficult and complex patients to manage because so much of their experiences happen in between clinical visits. Research shows that the collection of data in between clinical visits is a key way to manage patient health information and empower patients to be an active part of their care [21,16]. Some would have you believe that the organization of the paper medical record is driven by billing concerns and only tracks discrete clinical data. Upon further consideration, the health record also contains information that is not all quantitative; it often captures qualitative information obtained at the clinical encounter. Personal health records (PHRs) in particular, are demonstrating new ways of collecting, organizing, displaying and using that information. The ultimate goal being to use data from everyday life to understand how personal choices affect one's health. Information and communication technologies (ICT) can play an important role in assisting patients managing personal health information [16] which has been shown to be a tool to improve care for complex patients [5,6,22].

Broad acceptance of "Medicine 2.0" technologies will continue to provide an avenue for the education and communication of patients and clinicians. Hornik [23], Napoli [24], and others think that the use of innovative ICT applications can take advantage of mobile applications needed to effect change. Research on the use of low-cost ICT's with medically underserved populations is sparse despite the expressed need for tools that are affordable and effective [16]. Harnessing the power of "smart" technology can be a bridge that crosses the "digital divide" to support general patient well-being given the prevalence of mobile technology use in underserved populations [25]. In the past, use of ICTs has been hindered because of costs, access and cultural relevance. Medically underserved being defined by a population that faces economic barriers (low-income or Medicaid-eligible populations), or cultural and/or linguistic access barriers to primary medical care services as defined by the Index of Medical Underservice [26]. Reports have shown that mobile technology is ubiquitous in these communities and patients are willing to use them for managing their health [16]. However, healthcare has not capitalized on the capabilities of low cost (ICT)'s and their potential to bring ICT's to different populations. The key question is how do we take advantage of the power of low-cost (ICT) to extend e-health/medicine 2.0 to underserved communities?

2 Observations of Everyday Living

The Robert Wood Johnson foundation has led the way in funding efforts to understand how personal health records can be enhanced by collecting data generated between clinical visits. Five grantee teams are currently working to demonstrate how to improve the health and well-being of people with two or more chronic diseases by helping them capture, understand, interpret and act on information gathered from their observations of daily living [27-28]. The research teams are currently working with clinical partners and patients to identify, capture and store several types of observations. The long-term goal is to enable patients to share this information with members

of their clinical care team in a way that can easily integrate into their clinical work flow, ultimately impacting policymakers and clinical leaders.

Tracking observations of everyday living allow for behavioral observations to be captured on a commonly used device to capitalize on patients' ability to easily document activities. They build an ability to record thoughts and feelings and associate them with patients' activities. Table 1 contains a short list of less obvious observations of everyday life that could be tracked.

Table 1. Observations of Daily Living

Observations of daily living	**Meaningfulness for Individuals**	**Meaningfulness for care providers**
Self rewards	Understanding how self-rewards move patients toward or away from their goals can provide insight into self-care and coping.	Individuals use self rewards often. Differentiating between positive and negative rewards can shed light on activities that impact health
Stress	Identifying causes and effects of stress can be the first step toward recovery	Identifying the causes and incidents of stress can assist can direct care plans
Pain	Identifying the sources and incidents of pain can assist in isolating the source and possible solutions	Identifying the sources and incidents of pain can assist in isolating the source and possible solutions
Impact of spirituality	Spirituality is a source of support and comfort in this population.	Awareness of how and when that support is present assist in identification of possible care strategies

The novelty of the range of observations of everyday life is exemplified by the expectation that the data analysis will reveal patterns of daily living across a variety of behaviors in chronic disease management. Not only can observations of everyday life change patients and their relationship to their own health care, but they may allow providers the chance to see a fuller picture of their patients. This comprehensive view of care by definition lends itself to more complete and accurate care.

3 Health Information Management and ICT's

Health behavior change requires a highly sophisticated understanding of the dynamic social practices that occur [29]. ICTs must be designed to work in many settings with a broad range of different consumers and providers [30-32]. While health communication generally has been "person-directed," the process of initiating and maintaining

a life change is made in the context of family, community, and other cultural factors [30-32].

3.1 Previous Uses of ICT's in Healthcare

Three landmark studies have examined how web-based information and support systems affect patient care. First, the Comprehensive Health Enhancement Support System (CHESS) serves several diverse patient populations (Breast cancer, prostate cancer, HIV/AIDS, heart disease, asthma, caregiving and dementia, and menopause), providing information, decision support and connection with medical experts and other patients [33-35]. Secondly, Brennan and colleagues [36,37] developed and evaluated Heartcare, an Internet-based information and support system for patient home recovery after coronary artery bypass graft surgery. HeartCare matched recovery resources with patient needs by providing individually tailored recovery information, peer support and nurse-patient communication. The HeartCare system used WebTV (now MSN TV) and was designed to be an enhancement and extension of traditional nursing services. This randomized trial significantly improved symptom management, reduced depression and physical dysfunction in the HeartCare group as compared to the "lower tech" comparison intervention. Finally, Columbia University's Informatics for Diabetes Education and Telemedicine (IDEATel) project [38,39] is a demonstration project of the Centers for Medicare and Medicaid Services to evaluate the feasibility, acceptability, effectiveness and cost effectiveness of advanced computer and telecommunication technology to manage the care of persons with diabetes. These studies were pioneers in the field in demonstrating that low income users will utilize technology to improve their healthcare. However, the studies were completed before the emergence of Web 2.0 interactive tools that allow for multiple avenues for data collection, social support and information sharing. In addition, each gave participants specialized tools to complete the intervention, which has been shown to not be a preference of underserved users [16].

3.2 Usability of ICT's in Healthcare

Initial studies using ICTs for supporting patient information management have used devices that were often designed specifically for this function [40]. Recent studies have shown that underserved patients would prefer if such systems were available on devices they already use [16,21]. Until recently, most software products being tested were desktop based. Moving the user interfaces of HIT systems on to mobile devices creates new challenges for system design and usability evaluation [41]. From a usability perspective, the main difference between desktop-based and mobile computing is related to the environment of use. For desktop-based applications, use typically involved a stationary user using a keyboard and a mouse. Mobile technology, on the other hand, is embedded into the user's physical and social life, referred to as embodied interaction by Dourish [42]. Embodied interaction is characterized by presence and participation in the world [42]. As such, interaction with mobile technology is fundamentally different from the interaction with desktop-based systems, because of the switching between being at the focus of the user's attention and residing in the background of their work/life [43]. Prior studies conducted by the author indicate that usability testing and evaluation can offer only incremental improvements in health

information technology (HIT) use and success is contingent upon integration with clinician's workflow and the patient's lifestyle.

4 Future Research and Development

As observations of everyday life enhance patients' understanding of themselves and their relationship to their health care, it is anticipated that clinical practice will change as providers are given a more complete view of patient status. Clinical use of observations of everyday life can allow for timely feedback to patients as data is received and analyzed. In addition, the provider will be able to engage patients in their own care by reflecting the data about daily activities back to patients and incorporate new connections between activities, feelings and well-being into their treatment plan. For example, parents who track their children's eating habits gain insight into their own food choices, particularly since it is unlikely that they prepare separate meals. Once patient data is analyzed, the clinician will be able to incorporate this data into treatment plans that are based on evidence-based practices. The outcomes will bring awareness to the individual patient and to providers that can lead to changes in how individuals manage their chronic conditions and how care is delivered, enabling clinicians, public health professionals and medical caregivers to better understand patterns of health behaviors within this population. Most studies of patient behavior look to what causes people to not follow their recommended regimen. Observations of everyday life offer a window into what helps people make good choices and how they reward themselves.

5 Summary

If we can understand how collecting data from patient's everyday life can be successfully used by clinicians, we can provide designers with the basis for impact on workflow. Current implementation studies often only focus on one-time IT use with no consideration for integration into the clinical workflow and use for improving health outcomes. As we think about new research questions, studies should investigate how to capture and process observations of everyday living made by patients and clinic staff. This understanding will enable healthcare providers to engage patients in their own care by establishing connections between activities, feelings and well-being into their treatment plan (e.g. high blood pressure readings after eating salty foods). A new theory of HIT design is essential for this to succeed. This work has the potential to impact not only information technology design approaches and methods but to discover design requirements for technologies to support patients from diverse and underserved populations.

References

1. Cook, R.I., Woods, D.D.: Adapting to New Technology in the Operating Room. Human Factors 38(4), 593–613 (1996)
2. Koppel, R., Wetterneck, T.B., Telles, J.L., Karsh, B.: Workarounds to barcode medication administration systems: occurrences, causes and threats to patient safety. J. Am. Med. Inform. Assoc. 15, 408–428 (2008)

3. Bates, D.W., Cohen, M., Leape, L.L., Overhage, J.M., Shabot, M.M., Sheridan, T.: Reducing the frequency of errors in medicine using information technology. J. Am. Med. Inform. Assoc. 8(4), 299–308 (2001)
4. Karsh, B.-T.: Beyond usability: designing effective technology implementation systems to promote patient safety. Quality & Safety in Health Care 13(5), 388–394 (2004)
5. Bates, D.W.: Using information technology to reduce rates of medication errors in hospitals. BMJ 320, 788–791 (2000)
6. Sobol, M.G., Alverson, M., Lei, D.: Barriers to the adoption of computerized technology in health care systems. Topics in Health Information Management 19(4), 1–19 (1999)
7. Poissant, L., Pereira, J., Tamblyn, R., Kawasumi, Y.: The Impact of Electronic Health Records on Time Efficiency of Physicians and Nurses: A Systematic Review. Journal of the American Medical Informatics Association 12(5), 505–516 (2005)
8. Poon, E., Blumenthal, D., Jaggi, T., Honour, M., Bates, D., Kaushal, R.: Overcoming the barriers to the implementing computerized physician order entry systems in US hospitals: perspectives from senior management. In: AMIA Annual Symp. Proc., p. 975 (2003)
9. Lucas, H.C.: Why Information systems fail. Columbia University Press, New York (1975)
10. Chan, W.: Increasing the Success of Physician Order Entry through Human Factors Engineering. Journal of Heathcare Information Management 16(1), 71–79 (2002)
11. Berger, R., Kichak, J.: Computerized physician order entry: helpful or harmful. J. Am. Med. Inform. Assoc. 11(2), 100–103 (2004)
12. Valdez, R.S., Ramly, E., Brennan, P.F.: Industrial and Systems Engineering and Health Care: Critical Areas of Research—Final Report. (Prepared by Professional and Scientific Associates under Contract No. 2900900027U). AHRQ Publication No. 10-0079-EF. Rockville, MD: Agency for Healthcare Research and Quality (May 2010)
13. Patterson, E.S., Cook, R.I., Render, M.L.: Improving patient safety by identifying side effects from introducing bar coding in medication administration. Journal of the American Medical Informatics Association 9(5), 540–553 (2002)
14. Harrison, M.I., Koppel, R., Bar-Lev, S.: Unintended Consequences of Information Technologies in Health Care—An Interactive Sociotechnical Analysis. Journal of the American Medical Informatics Association 14(5), 542–549 (2007)
15. Bates, D.W.: Using information technology to reduce rates of medication errors in hospitals. BMJ 320, 788–791 (2000)
16. Jimison, H., Gorman, P., Woods, S., Nygren, P., Walker, M., Norris, S., Hersh, W.: Barriers and Drivers of Health Information Technology Use for the Elderly, Chronically Ill, and Underserved. Evidence Report/Technology Assessment No. 175 (Prepared by the Oregon Evidence-based Practice Center under Contract No. 290-02-0024). AHRQ Publication No. 09-E004. Rockville, MD: Agency for Healthcare Research and Quality (November 2008)
17. Webb, T.L., Joseph, J., Yardley, L., Michie, S.: Using the Internet to Promote Health Behavior Change: A Systematic Review and Meta-analysis of the Impact of Theoretical Basis, Use of Behavior Change Techniques, and Mode of Delivery on Efficacy. Journal of Medical Internet Research 12(1), e4 (2010)
18. Murray, E., Khadjesari, Z., White, I.R., Kalaitzaki, E., Godfrey, C., McCambridge, J., Thompson, S.G., Wallace, P.: Methodological challenges in online trials. Journal of Medical Internet Research 11(2), e9 (2009)
19. Abraham, C., Michie, S.: A taxonomy of behavior change techniques used in interventions. Health Psychol. 27(3), 379–387 (2008)
20. Cifuentes, M., Fernald, D.H., Green, L.A., et al.: Prescription for health: changing primary care practice to foster healthy behaviors. Ann. Fam. Med. 3(2S), S4–S12 (2005)

21. Schneider, S.J.: Personal Health Information and the design of consumer health information technology: Secondary analysis of Data from the medical expenditure panel survey (Prepared by Insight Policy Research, under Contract No. HHSA290200710072T). AHRQ Publication No. 09-0090-EF. Rockville, MD: Agency for Healthcare Research and Quality (July 2009)
22. Shojania, K.G., Duncan, B.W., McDonald, K.M., Wachter, R.M. (eds.): Making Health Care Safer: A Critical Analysis of Patient Safety Practices. Rockville, MD: Agency for Healthcare Research and Quality. Evidence Report/Technology Assessment No. 43; AHRQ publication 01-E058 (2001), http://www.ahrq.gov/clinic/ptsafety/index.html
23. Hornik, R.C.: Public health communication: evidence for behavior change. Lawrence Erlbaum Associates, Mahwah (2002)
24. Napoli, Q.M.: Consumer use of medical information from electronic and paper media. In: Rice, R.E., Katz, J.E. (eds.) The Internet and Health communication. Sage, Thousand Oaks (2001)
25. Dias, M.B., Brewer, E.: How computer science serves the developing world. Communications of the ACM 52(6), 74–80 (2009)
26. Health Resources and Services Administration (HRSA) Shortage Designation: Medically Underserved Areas & Populations (1976), Retrieved from http://bhpr.hrsa.gov/shortage/muaguide.htm (accessed on June 1, 2010)
27. Project Health Design (2010) Current Projects, Retrieved from http://www.projecthealthdesign.org/projects/current_projects (accessed on 5/1/2010)
28. Brennan, P., Casper, G., Downs, S., Aulahk, V.: Project Health Design: enhancing action through information. Studies in Health Technologies and Informatics 146, 214–218 (2009)
29. Renders, C.M., Valk, G.D., Griffin, S.J., Wagner, E.H., Eijk Van, J.T., Assendelft, W.J.: Interventions to improve the management of diabetes in primary care, outpatient, and community settings: a systematic review. Diabetes Care 24(10), 1821–1833 (2001)
30. Wilcox, A.B., Jones, S.S., Dorr, D.A., Cannon, W., Burns, L., Radican, K., et al.: Use and impact of a computer-generated patient summary worksheet for primary care. In: AMIA Annu. Symp. Proc., pp. 824–828 (2005)
31. Brennan, P.F., Norcross, N., Grindrod, D., Sopher, M.: Community-wide Information Systems Design: Concepts and an Illustration. Medinfo 2004 11(Pt. 1), 192–196 (2004)
32. Civan, A., Skeels, M.M., Stolyar, A., Pratt, W.: Personal health information management: consumers' perspectives. In: Proceedings of the American Medical Informatics Association Fall Symposium, pp. 156–160 (2006)
33. Gustafson, D., McTavish, F., Boberg, E., Owens, B., Sherbeck, C., Wise, M., Pingree, S., Hawkins, R.: Empowering Patients Using Computer-Based Support Systems. Quality in Health Care 8, 49–56 (1999)
34. Gustafson, D., Hawkins, R., Boberg, E., McTavish, F., Owens, B., Wise, M., Berhe, H., Pingree, S.: CHESS: 10 years of research and development in consumer health informatics for broad populations, including the underserved. International Journal of Medical Informatics 65(3), 169–177 (2002)
35. Gustafson, D., Hawkins, R., Boberg, E., Pingree, S., Serlin, R., Graziano, F., Chen, C.: Impact of Patient Centered Computer-based Health Information and Support System. American Journal of Preventive Medicine (Spring 1999)

36. Brennan, P.F., Moore, S.M., Bjornsdottir, G., Jones, J., Visovsky, C., Rogers, M.: HeartCare: An Internet-based Information and Support System for Patient Home Recovery after Coronary Artery Bypass Graft (CABG) Surgery. Journal of Advanced Nursing 35(5), 699–708 (2001)
37. Brennan, P.F.: Computer network home care demonstration: a randomized trial in persons living with AIDS. Computers in Biology and Medicine 28, 489–508 (1998)
38. Starren, J., Hripcsak, G., Sengupta, S., Abbruscato, C.R., Knudson, P.E., Weinstock, R.S., Shea, S.: Columbia University's Informatics for Diabetes Education and Telemedicine (IDEATel) Project: Technical Implementation. Journal of the American Medical Informatics Association 9(1), 25–36 (2002)
39. Shea, S., Starren, J., Weinstock, R.S., Knudson, P.E., Teresi, J., Holmes, D., Palmas, W., Field, L., Goland, R., Tuck, C., Hripcsak, G., Capps, L., Liss, D.: Columbia University's Informatics for Diabetes Education and Telemedicine (IDEATel) Project: Rationale and Design. Journal of the American Medical Informatics Association 9(1), 49–62 (2002)
40. Glasgow, R.E., Bull, S.S.: Making a Difference With Interactive Technology: Considerations in Using and Evaluating Computerized Aids for Diabetes Self-Management Education. Diabetes Spectrum 14(2), 99–106 (2001)
41. Chapman, R.J., Rogers, M.L., Render, M.: The tradeoffs and side-effects of migrating from wireless computer to PDA-based support for medication administration. In: Proceedings of the Human Factors and Ergonomics Society 48th Annual Meeting, New Orleans, LA, September 20-24, pp. 1638–1642 (2004)
42. Dourish, P.: Where the action is: the foundations of embodied interaction. MIT Press, Cambridge (2001)
43. Svanæsa, D., Alsosa, O.A., Dahl, D.: Usability testing of mobile ICT for clinical settings: Methodological and practical challenges. International Journal of Medical Informatics 79(4), 24–34 (2010)