Designing a Health Sharing System for Families

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BIOGRAPHY

Carolyn Pang is a Master of Science student in the School of Interactive Arts and Technology at Simon Fraser University where she studies design and human-computer interaction (HCI), with a particular interest in health information sharing. Her thesis research explores the design of an electronic health system for patients, caregivers, and remote family members to remain connected during the diagnosis and treatment of chronic illnesses. Along with a BTech degree that specialized in HCI, her extensive background includes ten years of professional experience delivering design projects spanning the arts, service, and public sector industries. Carolyn's previous research explored the design of interactive environments for government bodies to promote civic engagement. To date, she has begun exploring literature in the areas of family communication, interpersonal awareness, the role of caregivers with chronically-ill patients, and evaluations of existing personal health record systems. She is planning to conduct studies in 2012 that explore patient-generated information, and the channels in which such information is shared with and received by loved ones. Further exploration will then consider methods of depicting health information within a system that supports feelings of connectedness between patients and remote family members.

Dr. Carman Neustaedter is an Assistant Professor in the School of Interactive Arts and Technology at Simon Fraser University. Dr. Neustaedter specializes in the areas of human-computer interaction, domestic computing, and computer-supported collaboration. He is the director of the Connections Lab, an interdisciplinary research group focused on the design and use of technologies for connecting people who are separated by distance or time (http://clab.iat.sfu.ca). This includes design for families and friends, support for workplace collaboration, and bringing people together through pervasive games. Dr. Neustaedter has designed and studied numerous systems that allow family members to share information about their everyday experiences with one another, including health-related information. This includes family calendars, family messaging systems, video conferencing systems and media spaces, and photo sharing applications. Dr. Neustaedter was formerly a Research Scientist at Kodak Research Labs and Adjunct Professor in the Department of Computer Science at the University of Rochester, NY. He received his BSc, MSc, and PhD degrees from the University of Calgary, Canada.

INTERESTS TO THE WORKSHOP

We are interested in the workshop because we feel it will be an invaluable opportunity to connect with other researchers and hope to establish potential ties for collaboration. We also feel that we will bring a fresh perspective to the workshop with a focus on *designing a space for patient health information sharing for distributed families*. We believe this broadens the workshop's focus in an important and underexplored direction. We will also bring an understanding of background research in the areas of health sharing tools and patient communication of health data. Four of the workshop's design challenges relate to our research:

[1] Methods for processing narrative versus numeric data. Our research considers how patients' experiences may be shared with remote family members; specifically, it explores how such narrative data can be displayed within a system that is accessible by distributed families.

[2] Depicting a diversity of opinions and experiences embedded within patient-generated information. With each diagnosis, patients face decisions surrounding the granularity of information to share and with which social groups (e.g., immediate family members, friends, coworkers) to share it with. Our research explores how to design a system that manages the diversity of opinions and contributions from each social group to support a patient during the ongoing treatment of his or her illness.

[3] Working with 'lay' concepts and language and their alignment with complex medical issues. An immediate reaction following a diagnosis is often to learn about the disease by obtaining facts about the condition and by seeking expert medical advice. This information must then be translated into a simple language comprehensible for remote family members. In the design of a health sharing space, our research will consider how to combine and display user-generated data and expert opinions.

[4] Being mindful with privacy-enhancing methods for data handling. Our interest in this challenge comes from a different perspective. In many cases, a family member may take on a caring role to support the sick person, with an added responsibility of channeling health updates to other family members who may be either co-located within a city or distributed over distance or time. We are exploring the mechanisms required to support patient and caregiver decisions to share certain personal health information with particular social groups.