
Lessons Learned Conducting User Studies in a Dialysis Ward

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Abstract

In this paper, we describe lessons learned while conducting user studies in a dialysis ward. We learned that we must be more aware of environmental factors, participants' abilities, and time management. We will continue conducting studies in a dialysis ward to help us develop an assistive system for dialysis patients to monitor their nutritional intake.

Keywords

Non-Traditional Environments, Evaluation Techniques, Ubiquitous Computing, Health Informatics

ACM Classification Keywords

H.5.2 [User Interface]: Evaluating/Methodology

Introduction

Traditional food diary methods of monitoring intake fail in 80% of dialysis patients [1]. Fortunately, studies have shown that compliance rates of electronic diaries are as high as 94% [2]. We are developing an electronic assistive system called the Dietary Intake Monitoring Application (DIMA) to help dialysis patients monitor their sodium and fluid intake [3]. Assistive systems pair human computer interaction techniques and technology to enhance the quality of life for people with various special needs.

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Computerizing fluid and sodium intake for dialysis patients has many benefits. We chose to develop DIMA for a PDA because it has sufficient computational power and memory to create an application that can automatically compute and record dietary intake; easily show non-textual information; provide real-time feedback to patients to make improved decisions about diet on a prospective basis; and allow patients to record information anywhere. Patients can input food items into DIMA by scanning barcodes or selecting food icons from the touch-sensitive PDA screen. We emphasize easy input mechanisms (e.g. scanning and non-textual food icons) because our user group gets treatment at an urban, public facility where the patient literacy rate is low.

In this paper, we discuss the studies we conduct in the dialysis ward to develop DIMA and lessons learned along the way. We begin with a description of the user study environment – the dialysis ward. The three studies we have conducted are discussed in the following section. We conclude our paper with our lessons learned.

User Study Environment – The Dialysis Ward

User studies are conducted during dialysis sessions because this is the most convenient for patients. The user study space is small and stressful. Each patient sits in a recliner chair and has access to a small television and side table. The patients have limited mobility because the fistula¹ in their arm or catheter in their clavicle is attached to the dialyzer machine. If the patient moves too much, the tubing from the patient to

the dialyzer machine is cut off and clinicians must come over to check the patient and reset the dialyzer machine. There is only space for one researcher to stand while conducting studies. The Health Insurance Portability and Accountability Act (HIPAA) limit the amount of recording equipment.

Overview of the Studies Completed

We have completed three independent studies in the dialysis ward – interviewing patients about technology views; determining the feasibility of dialysis patients using PDAs; and learning how dialysis patients think about food categorizations and initial interface design concepts. For each study, one researcher conducted interviews or studies with 8-10 dialysis patients who were receiving treatment at the time.

For the first study, patients were asked about what kind of technology they used (e.g. cell phone, computer) and their feelings about technology. We found a majority of the participants used computers for playing games and owned a cell phone for emergency purposes only. Participants thought DIMA could be useful, but only half of the participants trusted technology [4, 5].

We were primarily concerned with how dialysis patients completed conventional PDA-based tasks (e.g. pressing buttons, viewing icons, voice recording) and non-conventional tasks (e.g. scanning barcodes) for the second study. Each dialysis patient used a PDA to complete the tasks while leaning on their personal side table. Overall, dialysis patients found all of the PDA tasks easy to complete suggesting that use of technology to self-monitor dietary and fluid intake would be feasible in this patient population [4].

¹ A fistula is surgically created by joining an artery and vein.

In our third study, we learned how dialysis patients categorized food items and interpret icons. During our low fidelity, paper prototype study, patients were shown pictures of food items or interfaces and asked relevant questions. Our findings helped us in designing DIMA's interface [5].

Lessons Learned

Each study we conducted proposed its own unique set of challenges that are not covered in traditional user study methodology [6, 7]. For example, during our interviews, the researcher had to stand the entire time and take notes about what the participant said. Since some of the PDA tasks in our second study required the use of two hands, patients routinely made their machine alarm sound because blood flow had been cut off from the machine causing the study to be paused while clinicians checked on the patients and machines. Clinicians asked us to sterilize our paper prototypes for the third study because they did not want germs spread between patients.

We can broadly categorize the lessons learned during our studies into three groups:

- Environmental Factors
- Participants Ability
- Time Management

Environmental Factors

Environmental factors encompass everything from rules and regulations to what the study space looks like/provides. Here we briefly list lessons learned and experiences leading to the lessons.

Lesson 1: Researchers must know the rules and regulations of the facility and adapt the study appropriately. For example, video and audio recording equipment is prohibited, thus we had to use alternative recording mechanisms, such as shorthand. Our shorthand sheets had most of the study information printed on it so researchers could easily follow it and take appropriate notes.

Lesson 2: Researchers should visit the study site before conducting their investigation and takes notes on what is available for them to use. In the dialysis ward, patients only have a small side table measuring approximately 10"x13" (25.4cm x 33.02cm). When conducting user studies, the researcher had to wear clothing with lots of pockets or hold a multi-pocket folder to hold the various technology, food items, and paper prototypes used during the study to ensure the participants' table workspace was free of distractions.

Lesson 3: Researchers should be mindful of the study environment and keep the health/safety of all parties involved in mind. Since we were working in a hospital environment, we had to minimize the passing of germs between patients and researchers. We laminated our paper prototypes and cleaned them with disinfectant between studies.

Participants Ability

Researchers must always be aware of participants' abilities. These abilities can range from what they are capable of completing at a specific time during the study because of fatigue to their education level.

Lesson 4: Researchers must be aware of the participant's comfort. Since dialysis patients experience

cramping after two hours of treatment, we had to be aware of patients' unspoken signs that patients were not feeling well enough to participate.

Lesson 5: Researchers must take into account the sensitivities of their participants. For example, my user group has varying literacy levels, thus we had to avoid situations that may embarrass patients by exposing their literacy levels.

Lesson 6: Researchers should dress appropriately and define their role to the participants. Our user group was accustomed to meeting with clinicians and dieticians often. When we dressed professionally, patients worried we were clinicians and were not as honest with us when answering questions. When we wore street clothes, they were more comfortable speaking candidly with us.

Time Management

Time management is important in all user studies because participants have busy schedules and can only concentrate for limited amounts of time. However, in non-traditional environments, researchers must be prepared for the unexpected.

Lesson 7: Researchers must design adaptable studies. For example, patients may need immediate medical treatment during the study. Our studies are modular and have short sub-tasks so that we can stop and restart a study with little review and time loss.

Lesson 8: Researchers must learn how to multi-task during user studies. When patients require medical attention during a study for an extended period of time, we visited other patients and asked if they would be interested in participating in the study soon.

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Katie's research interests focus on integrating technologies into healthcare environments and user study methodology.

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