Incorporating Participatory Action Design into Research and Education

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Abstract - **Technology plays a pivotal role in transforming lives of people with reduced functional capabilities due to aging or disability. The Quality of Life Technology Engineering Research Center (QoLT ERC) supported by the National Science Foundation is dedicated to create smart devices, systems, and environment adaptations to enhance the quality of life of this population. The context in which QoLT systems are to be deployed consist of multifaceted dimensions including real-life experiences from the end-users or their family members and caregivers, technical competence, clinical expertise, social-behavior knowledge, and industrial and marketing issues. So in the center, students from multiple disciplines such as engineering, rehabilitation science, and social science work together in the classroom and research laboratories to jointly create QoLT systems. The participatory action design (PAD) model, emphasizing the involvement of end-users along the entire product development process, has been applied to the research and educational programs within the center. Two examples are particularly discussed to show the application of the PAD model in our Research Experiences for Undergraduates (REU) program, and in planning a new course 'Quality of Life Ethnography'.**

Index Terms – Curriculum, Participatory action design, Quality of Life Technology Engineering Research Center, Research experiences for undergraduates.

INTRODUCTION

Technology plays a pivotal role in transforming lives of people with reduced functional capabilities due to aging or disability. The Quality of Life Technology Engineering Research Center (QoLT ERC, www.qolt.org) supported by the National Science Foundation (NSF) is dedicated to create pervasive and smart devices, systems, and environment adaptations that can know and respond to individual functional needs in order to maximize self-determination and community living among this population. The context in which QoLT systems are to be deployed consist of multifaceted dimensions including real-life experiences from the end-users or their family members and caregivers, technical competence, clinical expertise, and social-economic knowledge, and industrial and marketing issues. Thus in the center, faculty and students from multiple disciplines such as engineering, rehabilitation science, and social science work together in the classroom and research laboratories to jointly create QoLT systems. Four research thrusts have been established including Perception and Awareness, Mobility and Manipulation, Human Interface Interaction, and Person and Society. The first three thrusts are structured along main engineering disciplines for developing fundamental knowledge and applications in QoLT, and the fourth relates the three engineering thrusts to the individual person and society along the dimensions of adoption, evaluation, and socio-economic impact.

The vision requires relating human physiological, physical, and cognitive function to the design of intelligent systems, and creating technologies that make measurable positive impact on quality of life, so working closely with user groups throughout design, development, testing, and deployment phases for adoption, evaluation, and privacy concerns is the focus of the education and research agenda. Neither the experts including engineers, clinicians, and social scientists, nor the users possess the complete knowledge. A systematic mapping is required of the opinions and viewpoints of the different interested stakeholders, their experiences and requirements that can contribute to developing successful QoLT systems. Thus Participatory Action Design (PAD) approach was adopted, which is a process of developing QoLT systems that involve end-users in every aspect of the research and development from setting the research agenda, developing research questions, participating in the research as researchers, advisors, and consultants, testing research ideas, and most importantly, evaluating the results of the research.

In this paper, the PAD approach and its application to the educational programs within the QoLT center will be discussed. Two examples where the PAD approach is adopted in a student project in the Research Experiences for Undergraduates (REU) program, and in planning a new course 'Quality of Life Technology Ethnography' were particularly discussed.

PARTICIPATORY ACTION DESIGN

Participatory action design is an approach to the design, development, and assessment of technology that places an emphasis on the active involvement of the intended users in the design and decision-making process [1]. The field of participatory design grew out of the work beginning in the early 1970s in Norway, when computer professionals worked with members of the Iron and Metal workers Union to enable the workers to have more influence on the design and introduction of computer systems into the workplace. The workers were considered equal members of the design team, and they participated from the start of a project through its completion [2]. Since then, the PAD approach has been widely adopted in different fields such as urban design, landscape planning, and human computer interaction. Surprisingly, it is not frequently used in developing engineering systems for those with reduced capabilities due to disability and aging. A few exceptions were found [1], [3]-[6]. Fischer et al. [3] reported using a participatory approach to design transportation systems for persons with cognitive disabilities. The research methodology involved conducting field studies that examine socio-technical solutions in light of real world constraints and cognitive issues. Though the design team was composed of individuals from a diverse set of stakeholder communities, they didn't include any person who had cognitive impairments. Wu et al. [4] presented experiences and insights into participatory design with individuals with amnesia. They particularly discussed a case study of developing a memory aid for this population with a focus on the techniques and methodologies that they employed during the participatory design process. Seale et al. [5] described a focus group methodology used to help older people identify and describe the nature of the mobility-related problems that they encounter. Davies et al. [6] conducted an ethnographic study with one participant to learn about communication strategies used by people with aphasia, and to observe how a Personal Digital Assistant (PDA) is incorporated into those strategies.

Implementing participatory action design in the domain of improving the quality of life of a population with special needs can be challenging. Muller [7] noted that the visual and hands-on nature of most participatory design practices are in direct conflict with the universal usability needs of individuals with visual and motor disabilities. In addition, the variability of impairments and the variability of the attitudes towards modern technology are usually wide-ranging among the elderly and individuals with disabilities, thereby making the PAD implementation within a group of participants difficult to manage and operate. Figure 1 describes the PAD model that was adapted to develop quality of life technology in the center.

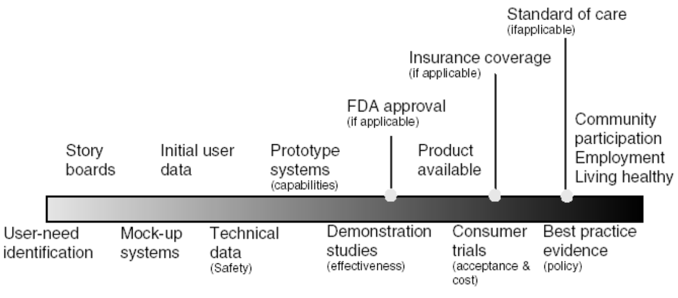

FIGURE 1
ILLUSTRATION OF THE PAD PROCESS

The process starts with identification of the users' needs. There are several ways of doing this: through focus groups, where an open-ended discussion is moderated by a person from a design team, or by getting feedback from users through surveys and questionnaires about specific requirements and possible solutions. All of this information is assembled, which helps to identify desirable features for prospective products. These data are helpful in comparing alternatives for a product and determining advantages or disadvantages of each. The next step includes development of a mock-up system, in which the devices' key features are incorporated on the way to a product design. All the features of the product are then compared to the benchmarks available, ensuring that the designed features are at par with industry standards. The prototype is constructed after this step, and it includes as many of the features as are feasible. With the prototype completed, a comparison is made with the standards for the product. Product efficacy is determined with appropriate tests. Product durability and reliability are often key aspects of consumers' desires. Durability testing typically determines the ability of individual components of a particular device to withstand repeated use by the end user. On incorporating the changes suggested by the efficacy testing, the results for medical devices, which include a range of QoLT devices and systems, are submitted to the Food and Drug Administration (FDA) for approval. The FDA approval process is an extensive procedure, with emphasis on ensuring safety to the end users. Clinical effectiveness of these devices is best established in several phases. Typically, there are four phases of testing involved in determining clinical effectiveness. The first phase involves conducting a focus group of clinicians, end users, and manufacturers. These individuals provide their feedback on the benefits and disadvantages of the product. The second phase involves testing the product using an unimpaired population when appropriate. The third phase includes case studies, in which a small number of potential end users get tested on the device. The outcomes of determining clinical effectiveness could include physical capacity measures and/or functional performance measures. The fourth phase consists of testing a large group of potential end users, so that generalization can be made to the entire population, which will eventually be using the device. The most intricate step in this entire process is establishing insurance coverage, where potentially eligible, for a particular product. This involves identification or formulation of a common code for the device and establishing a fee schedule for the device. If the product meets the needs of end users and the approval of clinicians, it should become a part of the arsenal to ameliorate disability. With further clinical studies, the product may be incorporated into a clinical practice guideline.

In general, employment of the PAD process in the domain of developing QoLT for those in special needs requires:

- Rapid cycling from laboratory to clinical study, observation, and feedback
- Diverse environment from skilled-care institutions to independent home living and to community environments
- Broad range of participants, ranging from children to older adults, at home, school, and work throughout the community, and across a broad range of conditions and impairments
- Robust and expeditious regulatory training and review processes to be in place

The PAD model throughout the entire product development process has been a focus in our educational program in the center. The multifaceted dimensions of the PAD model allow us to integrate humanistic, social, and economical elements into the engineering curriculum and train students from traditional engineering, clinical science, and social science to form effective and functional interdisciplinary teams. Students may still focus a majority of their efforts on the technology component of the product development process, but they will not work in the vacuum of unjustified homework or course projects, instead, they will begin with exposure to a particular device's design cycle, learning about participatory design, ethnography and evaluation metrics. Two examples where the PAD model is employed will be discussed in the following section.

EXAMPLES

I. Research Experiences for Undergraduates (REU)

The REU program supports undergraduate interns for 10 weeks of research practice. Due to the short period of time, it is difficult to expose the student to the PAD process throughout the entire product development period. Instead, a selected portion of the process for the undergraduate research project was chosen to amplify while keeping the students informed of the long-term plan and vision.

An example REU project is described as follows. During the 10-week program, one of the undergraduate interns who had a background of bioengineering worked on a large-scale user-need identification study for an international collaboration project that aims to develop low-cost yet high-quality power wheelchairs for India. Before the REU stduent started, the project crew visited Inida where they conducted initial small-scale focus group with local wheelchair users. The first prototype power wheelchair was then designed and constructed. They visited India again with the first prototype and conducted another focus group with local clinicians, manufacturers and wheelchair users to solicit feedback on design improvement. They also realized that a larger-scale user-need identification study is needed to inform them about the diverse environments where wheelchair users live in India and gather design improvement ideas to ensure the prototype design meets the needs of the users in their environment. Thus a novel methodology of collecting users' needs became the project of a REU student [8].

Wheelchair users in India were given a disposable camera with self-addressed envelopes and paid shipping. They were instructed to take pictures in and around their house, work, and neighborhoods where they encountered accessibility barriers. They were also asked to have another person take a picture of them in their wheelchair while performing tasks that were difficult for them. For each photo, they were asked to write down a description of what they were photographing [9]. About 500 photos were de-identified and screened, and then posted on a web-based online survey that the REU student developed. A diverse group of stakeholders including wheelchair users and their family members, rehabilitation engineers, service providers (e.g., physical and occupational therapists), and architects who have experience in design and/or modification of environments to make them accessible were recruited to rate these photos. Each image is presented with an interactive survey (Figure 2) regarding the accessibility with questions based on the American Disabilities Act Accessibility Checklist, covering issues of steps, rough terrain, doorway widths, ramps, etc. They were asked to choose the accessibility issue portrayed in the photo (13 possibilities), and the severity of the accessibility issue (1- 10 in order of least-to-most severe). The survey included comment boxes for the subject to describe the power wheelchair design features that would allow the device to accommodate the accessibility barriers portrayed in the photo and/or the changes to the environment that should be made to allow for accessibility.

Based on the results from this REU project and the second focus group conducted in India, the second generation prototype taking the physical, cultural, technological, and economic constraints into account was designed and constructed. The prototype wheelchair is currently in India and one of our graduate students is conducting field tests and usability studies with the local wheelchair users to identify final design modifications. The long-term goal of this project is to transfer the design to a local manufacturer for production.

FIGURE 2
WEB-BASED ONLINE SURVEY
DEVELOPED BY AN REU STUDENT

There are also other REU projects in the center where students focus on different components along the PAD process during their 10-week research practice. Our strategy is to teach and demonstrate not a single line of technology development, but the process whereby the students work closely with the end-users and other stakeholders to jointly create socially positive products.

II. New Course Development

Another example of the PAD application is the development of a new graduate-level course 'Quality of Life Technology Ethnography'. The course is still in the process of being developed, and will be launched in the fall of 2008. At this point, only the concept and plan for the course development will be discussed, and more detailed information and results will be followed at a later time.

Ethnography is a descriptive research methodology that attempts to provide a detailed understanding of how subjects interact within their natural environment and culture [10]. Ethnography and related qualitative research approaches are important across the social sciences and related disciplines, such as education and development studies, however, they are rarely seen in the engineering curricula [11].

In order for the QoLT systems to have truly measurable impact on those with reduced capabilities due to aging or disability, students need to have a deep understanding of the complete life context surrounding the implementation of those technologies. We increasingly realize that social scientists and clinical professionals can contribute to the development of more usable technical tools by providing useful answers to the context related questions, and engineers should be exposed to a broader context and learn to incorporate non-technical elements into the design such as connection with end-users and understanding of their lifestyle, emotion, and culture [12]. So this immersive course on Quality of Life Technology Ethnography was proposed where ethnographic methodology as applied to understanding context in the lives of individuals with disabilities and older adults is to be taught and demonstrated.

Two instructors specialized in clinical rehabilitation and design respectively, will be teaching this course. The course has four main goals:

- Understand how technology might assist people with reduced capabilities due to aging or disability, helping them to stay independent and active longer.
- Learn different ethnographic methods and the selectivity and interpretation of ethnographic data.
- Learn how to work in diverse but integrated teams.
- Learn how to effectively communicate with end-users.

Students will be assigned readings on ethnographic analysis in areas as diverse as demographics, health care trends, and assisted living analyses, etc. They will also work in teams to conduct field trips to local facilities such as nursing homes, long-term care facilities, and rehabilitation hospitals to evaluate actual conditions. They will practice principal ethnographic methods in these settings with real clients such as participant observation, key informant interviews, and questionnaire surveys, and learn to identify and problematize things that the participants being observed or interviewed usually take for granted. Finally, student teams will complete a term project in which they characterize specific opportunities for technological intervention in the facility they visited. Summative pre/post evaluations will be conducted to assess the course effectiveness, and reported in future papers.

CONCLUSIONS

Historically, engineers have worked somewhat in isolation, producing artifacts that subsequently became the subject of individual, policy, and social studies. Post-production feedback occurred too late in the process. It is believed that this conventional technically-oriented approach is inherently incomplete for developing QoLT systems that will truly impact the lives of those with special needs. By incorporating the PAD model into research and educational programs, we are able to identify, translate, and integrate contextual constraints into the conception and development of QoLT system. Most importantly, we are producing future engineers who have a better understanding and association with a broader context of their discipline. We will share more insights and results with the projects moving along.

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