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# Understanding the Occupational Therapists Method to Inform the Design of Technologies for People with Dementia

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## ABSTRACT

This paper describes a PhD research project involving people with dementia and practitioners who work primarily with people with dementia to support engagement in meaningful activities and activities of everyday living. The aim of this work is to develop a technology which adapts to changing cognitive demands of people with dementia in order to facilitate continuous engagement in meaningful activities. In depth, semi-structured interviews were conducted with practitioners to understand their methods for personalization of activities and the implications for design of future adaptive technologies. Preliminary results from interviews with Occupational Therapists are presented.

## 1 INTRODUCTION

Tom Kitwood once famously said, “When you’ve met one person with dementia, you’ve met one person with dementia”. His life’s research in social psychology focused on personhood theory as related to people with dementia and the uniqueness of each individual’s experience with the disease [1]. This uniqueness makes designing technologies for people with dementia more difficult as there is no universal design to fit all potential symptoms [2].

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*CHI’19 Extended Abstracts, May 4–9, 2019, Glasgow, Scotland UK*

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ACM ISBN 978-1-4503-5971-9/19/05.

<https://doi.org/10.1145/3290607.3308453>

**KEYWORDS**

User-Centered Design; Occupational Therapy;  
Dementia; Individualized Design;  
Adaptive Technologies

**DEFINITIONS:**

Pluralism: to design artifacts that resist a single point of view, or universal point of view [3].

Ecology: to design artifacts with the awareness of how it may affect all stakeholders in an environment [3].

Occupational Therapists (OT) help people of all ages to maintain or regain skills by engaging them in everyday activities. OTs rely on individualized, pluralistic modifications to activities and environments in order to successfully complete sessions with their patients with dementia. The role of OTs is to modify the environment in which people with dementia function without requiring the individuals to change [5]. These modifications are based on the study of the ecologies in which people with dementia live, focusing on retention of capabilities and adapting existing behaviors for long-term sustainability [6]. The individualized and adaptive methods of OT have potential to inform the design of adaptive technologies for people with dementia. To identify the design implications, this work aims to answer the following research questions:

- What is the OT method to develop sustainable personalized activities for people with dementia as they experience cognitive changes?
- How can the OT method inform the design of future technologies to aid people with dementia?

Therefore, technologies developed for people with dementia should consider pluralism<sup>1</sup> and ecology<sup>2</sup> as major design considerations [3]. Additionally, the progressive loss of cognitive ability intensifies the need for technologies to self-adapt to the changing cognitive ability of individuals with dementia, otherwise the technology becomes obsolete [4].

**2 BACKGROUND AND RELATED WORK**

Past work has often examined the approach of adaptive interfaces to accommodate changes that people with dementia experience. Tsiakas et. al, developed an adaptive robot to engage people with dementia in musical games [7]. Their robot monitors and adjusts to the user's cognitive ability with the goal of encouraging task improvement, reduced negative behaviors and attention training. The results showed a reduction in negative behaviors in the short-term, however in the long-term the device became less impactful. Other reactive technologies designed for reducing negative behaviors in people with dementia have been created such as Paro and Robocat for sensory therapy [8, 9]. These technologies focus on stopping behaviors, primarily viewed by others as negative, through redirection of attention.

Rowles, an OT researcher, argues habits and routine behaviors become ingrained in people lives, making changes in ability that come with age or loss of cognitive ability hard to cope with [6]. This inability to cope can result in what many view as negative behaviors. Therefore, by viewing technology through the OT method, technology should be working with the behaviors of people with dementia; only stopping behaviors when they become harmful to the individual's well-being and no other alternative is present [5]. The OTs role is to reinforce habits which can be sustained, modify habits that can no longer be sustained, and introduce new habits which may enrich the individuals sense of being [6]. This viewpoint is compatible with recent work in HCI on dementia that calls for epistemological shifts in how we think about dementia [10].

Therefore, there is a need to design adaptive technologies using the OT method, in order for the adaptive technology to have sustained impact on habits.

**3 METHODOLOGY**

This research will use a combination of observation and semi-structured in-depth interviews of people with dementia and their caregivers to obtain feedback from their use of prototype adaptive computer applications. To inform the design of the computer application, the user-centered design process will be used, including: 1) identifying needs through semi-structured interviews with people with dementia, caregivers, and practitioners; 2) specifying design requirements using the identified needs; 3) prototyping potential applications; 4) evaluating prototypes using ethnographic research methods.

A total of four OT interviews were analyzed using a Grounded Theory Approach [11]. Each interview was audio-recorded, transcribed, and line-by-line coded using an inductive content analysis method to develop theory and identify major themes. This paper includes only initial findings from the practitioner interviews. Participants were recruited from online practitioner groups, such as the American Occupational Therapist Association, and through word of mouth. The OTs interviewed to date have experience ranging from 4 to 8 years working primarily with people with dementia. Two of the OTs work in nursing homes and assisted living environments the other two work as in home consultants to support people with dementia aging in place. The interview process for practitioners is ongoing and will include more OTs, activities directors, and speech language pathologists. The next phase of interviews will include people with dementia and their caregivers to understand their needs for adaptive technologies. The results reported here are, therefore, initial findings that will be expanded upon after all interviews have been completed. Where relevant, anonymized interview transcript quotes have been included.

#### **4 RESULTS OF INTERVIEWS WITH OCCUPATIONAL THERAPISTS**

##### **4.1 Justification for Applying OT Methods to the Design of Personalized Technology**

OTs act as the guide, helping people with dementia continue to engage in enjoyable activities with their changing cognitive ability. This is done by personalizing activities to engage their interests, participant three (P03) states, “My strategies are honestly different for every single person, but I guess you could say the umbrella strategy is again reaching them on some sort of level that is important and meaningful to them”. These interviews have shown the parallel between the design of personalized technologies and the OT methods as P01 stated, “Each activity is tailored, it’s selected specifically for that individual”, highlighting the potential usefulness of their approach in HCI, which has long been concerned with personalization and tailoring.

Even with the vast difference in personal interests and symptoms of dementia, OTs are able to modify activities to fit the needs and desires of each of their patients. It is recognized by OTs that activities must be adjustable to cognitive changes as the person with dementia progresses in the disease.

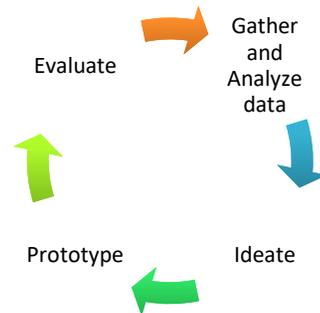
P01 stated, “Sometimes the individual over the course of two months, three months can change”. These cognitive changes are completely dependent on the individual person. Additionally, unpredictable cognitive carryover – the retention of an OTs lesson over a period of time – makes it hard to teach new strategies to engage in meaningful activities. P02 stated, “You don’t want to expect someone is going to consistently complete something you’ve trained them on because with dementia the memory just isn’t there to have that carryover”.

Even with this known lack of cognitive carryover, OTs continue to successfully modifying activities and environments to allow people with dementia to engage with them. Below I describe the OTs method, surfacing throughout the interviews, which gives insight into how they create lasting cognitive carryover of activities.

#### 4.2 OTs Method for Personalization of Activities

Three major steps were discussed by all four OTs. The first step was to understand the individual ecologies of each person with dementia [6] using ethnographic methods. P03 describes this by stating, “For someone with dementia, it could take me several sessions before I fully understand how to reach that person. For me, it takes a long time. A lot of time spent with that person, understanding what triggers them, understanding what they’re going to respond too. I like the approach if I have the time to do it is spending just time with that person where like I’m kind of a fly in the wall”. While observing the ecology of the person with dementia the OT is looking for how they interact with their environment in order to emulate that interaction to facilitate carryover. P03 describes what type of interactions to emulate; “Do they interact with their caregivers through music, through Bible verses, through stories told about when they were younger like how do they interact with the world around them and then I’m going to present my teachings in the same manner”. Contact with caregivers and family members helps OTs get an idea of the person with dementia’s background, who they are and where they’re coming from. P04 even mentions the importance of understanding the individual’s former occupation, “if they were a pharmacist or if they were a doctor or if they worked as a receptionist, and the things that they’re interested in, it’s very hard to kind of engage to what they like to do and what they’re capable of doing. So you really have to again, kind of build a rapport and know who they are”.

Figure 1: User-Centered Design Process



The second step is trial and error, an iterative process, which closely resembles the user-centered design process (Figure 1). OTs test out the same ideas, gathering and analyzing data as they go, ideating when necessary. P02 stated, “As an occupational therapist you have to decide what is the most successful way of helping someone”. Then they prototype activities and evaluate them as P03 stated, “I’m going in, I’m seeing them in their environment and then I’m making recommendations for modifications to their home. Then I go back and check the modifications and see if the person is interacting with it the way I kind of initially intended”. Even with frequent modification and testing of methods, P01 remarks on the importance of fluidness and flexibility in the OT role because “you never know what’s going to happen during the course of that session. Always have back up plans you know back up activities in case something bounces out. Or you know ways to switch things up and also where to find resources”.

The third step is to make the activities sustainable, even with the loss of cognitive ability with the progression of dementia. This often requires training caregivers, facilities staff and family members to think like an OT and continue to modify activities after the OT has finished consulting.

According to P01 this training is done by, “brainstorming with caregivers so the caregiver would learn sort of that thought process. So ok this isn't working so do you reduce the amount of time, do you reduce the complexity, do you go from 100 piece puzzle down to a 50 piece puzzle.

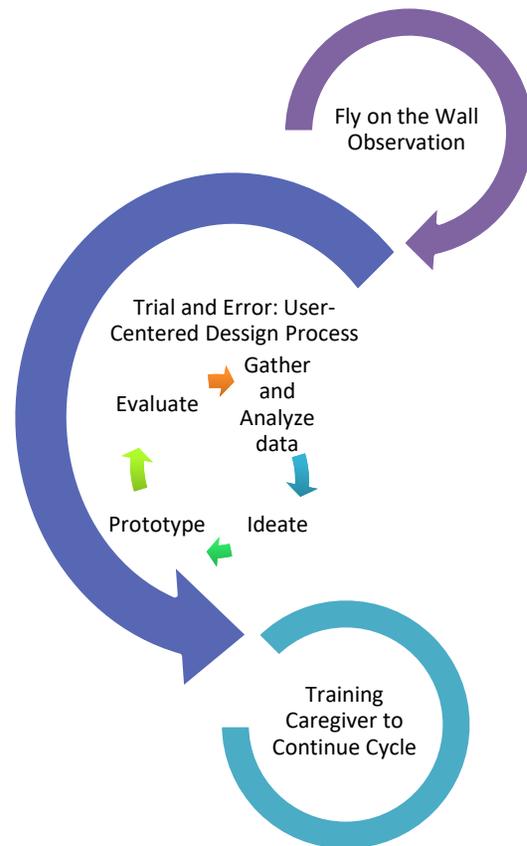
So talking through that out loud with the caregivers”. P02 also supported family training as a method to sustain activities; as P02 stated, “you don't want to expect someone is going to consistently complete something you've trained them on because with dementia the memory just isn't there to have that carryover”. OTs even train other practitioners such as facilities staff to carryover certain methods to engage individuals with dementia. For example, P02 stated, “The only way I could get her to engage with it is I had to play like oldies music while we were doing anything and then I trained the nursing staff to carry that over when I had discontinued with her”. Training others to modify environments is essential to the sustainability of activities for people with dementia. Without the sustainability mindset, people with dementia would be unable to engage in meaningful activities after a certain point in the progression of the disease.

## 5 DISCUSSION

An open research challenge in HCI is tailoring and personalizing technologies to individual's ability, particularly for individuals with cognitive impairments. This work has the potential to impact HCI by emphasizing the understanding of the ecologies in which individuals with dementia interact. My findings support the approach involving ethnographic work in order to understand individual ecologies [12]. My findings also align with the current user-centered design process with the exception of the added fly on the wall and training steps (Figure 2). Future research to design adaptive technologies for people with dementia should consider incorporating the OTs method in order to create technologies which interact with individuals in ways they will respond to. Therefore, making adaptive technology easily understandable by people with dementia throughout the progression of their cognitive impairment. Adaptive technologies have already been designed for people with dementia [7,8,9], however, none have been able to demonstrate a lasting impact on negative behaviors. While HCI researchers excel at the initial data gathering and the UCD process, what is missing is an understanding of how to train people to use technologies after the researchers are gone. By following the OTs method it may be possible to develop technologies that have sustainable impact on negative behaviors.

Much of the sustainability aspect of the OTs role is to train caregivers to think like an OT. Current work in HCI, involving caregiver training, focuses on creating empathy using virtual reality (VR) [13,14]. This type of training, although valuable, does not contribute in the same practical way as OT training. OTs focus more on modifications of environments and activities to aid people with dementia to sustain their current functionalities. Future research should consider incorporating OT training into VR simulations for caregivers, focusing more on problem solving to give people with dementia the highest functionality possible.

Figure 2: User-Centered Design Process for People with Dementia; Adaptations from Occupational Therapists Method



## ACKNOWLEDGMENTS

We would like to thank the occupational therapists who agreed to participate in these research interviews. This publication was supported, in part, by grant 90REGE0008, U.S. Admin. for Community Living, Dept. of Health & Human Services. Opinions expressed do not necessarily represent official policy of the Federal government.

## 6 CONCLUSION

These preliminary findings support the use of the OTs method for creating personalized adaptive technologies. It furthers existing work by providing an OTs method of adaptations to activities for people with dementia. These insights can be used to specialize the user-centered design process to develop more sustainable, adaptive technologies that adjusts to changes in cognitive ability.

This is an on-going project, the next interviews will include: activities directors, speech pathologists, art therapists, as well as people with dementia and their caregivers to understand what technologies they currently use to support enjoyment and everyday activities. Findings from all interviews will then be used to inform the design of prototype adaptive applications to support engagement in meaningful activities for people with dementia. These prototypes will be tested by people with dementia in their home environment using user-centered design methods and analyzed using an ethnographic approach.

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