

RESEARCH STUDY

1. What is the name of the study?
The COACH: An automated task guidance system for older adults with dementia
2. When does the recruitment start and finish?
Recruitment of caregivers for the questionnaire has already begun and finishes at the end of March, 2010. Recruitment of caregivers for the focus groups and interviews starts in March, 2010 and finishes at the end of April, 2010.
3. How is the study being funded?
This study is funded through research grants from CIHR and the American Alzheimer Association
4. What is being investigated?
We are using a participatory design strategy to develop intelligent technology that is able to assist people with dementia with daily activity completion. In participatory design end-users cooperate with researchers and developers during an innovation process. Our current study is looking to learn from caregivers of people with dementia through an online questionnaire, focus groups and interviews.
5. Why is the study important?
The main benefits of the study and any developed intelligent technology are:
 - i. Increase quality of life for older adults with dementia and their caregivers
 - ii. Reduce caregiver burden
 - iii. Promote aging-in-place
6. Who can participate?
Participants will be restricted to caregivers of people with dementia who:
 - i. Must be a family caregiver (i.e. not a professional caregiver)
 - ii. Have at least 2 years care-giving experience
 - iii. Are fluent in English
 - iv. Have read, understand and sign the University of Toronto REB information and consent form
7. Who cannot participate?
Anyone not meeting the inclusion criteria
8. What is required of the participants?
The participants will be asked to complete the questionnaire, either online, in person or via a paper copy. Following the questionnaire participants will be asked to join semi-structured focus groups of 5-7 caregivers, and subsequent follow-up interviews.
9. What are the potential benefits and limitations of participating?
Benefits: Through participation in the study, the participants will gain knowledge of various technologies available to assist in caring for a person with dementia. Additionally, their voluntary participation in subsequent phases of the project (design and testing exercises) will allow firsthand experience with a modern assistive device. Finally, participants of the focus group studies will have the chance to speak first-hand with other people in a similar position to their own; an opportunity to talk, learn and get support that may otherwise be unavailable to them.

Limitations: Caring for a family member can be a very personal and sensitive subject. With elderly cognitively impaired individuals, care decisions may be challenging because the elderly person was once self-sufficient and independent. Every care situation is unique and caregivers will often employ different care strategies. While the intention of the focus group is to elicit general information, the process will require the participants to volunteer their personal views on the caring process. This might expose some participants to feelings of anxiety, stress or insecurity.

10. Has the study been approved by an ethics committee? (please provide details)

The study has been approved by the University of Toronto Research Ethics Board (REB #24637)

11. How large is the study?

The study requires approximately 100 respondents for the questionnaire and 15-20 participants for the focus groups and interviews.

12. Where are the study sites?

The study will take place at the University of Toronto and in the GTA community as required for focus groups and interviews.

13. Where can one obtain more information?

Information can be obtained through the following methods:

- i. PH: (416) 946-8565
- ii. E-mail: alex.mihailidis@utoronto.ca
- iii. www.iatsl.org

14. Any additional comments?

The contents of this document are provided for information purposes only by the Alzheimer Society of Toronto and do not represent an endorsement or a recommendation with respect to the research study and/or the claims and properties thereof.

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