
HCIxDementia Workshop: The Role of Technology and Design in Dementia

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Abstract

With an increasing amount of work within HCI targeting people who have dementia, it is important to understand the ways that various factors influence the technology that is designed for people with dementia, and the way individuals adopt and use (or don't use) this technology. A nuanced understanding of this is especially important given the ethical and logistical issues of designing for and with a population that still faces significant marginalization, and who (along with family, carers, and clinicians) are managing a condition as complex as dementia. This two-day workshop aims to bring together HCI researchers and members from the dementia care community, to explore three subthemes of cross-cultural and local experiences of dementia, creativity and dementia, and personhood & citizenship in dementia.

Author Keywords

Dementia; participatory design; ethics of participation; agenda-building; cross-cultural dementia; creativity; personhood; citizenship; intersectionality.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

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Background

As our population ages, dementia is increasingly a focus of researchers, policy makers, and the healthcare system. Dementia involves changes in short-term memory, executive functioning, communication, and can also bring about significant changes in personality and mood. There are over 100 types of dementia, with Alzheimer's type dementia being most prevalent; however, dementia can be difficult to diagnose, and frequently co-occurs with other conditions and illnesses that are more common towards the end of our lives.

In HCI research, dementia has often been conceptualized as a series of cognitive deficits that can be 'solved' through the introduction of a technology – for example, gaps in remembering faces can be solved with the use of a prospective memory aid (such as a wearable which recognizes and 'prompts', i.e., Google Glass [10]), or difficulty in recalling everyday activities can be supported by the wearing of a life-logging camera [4]. Beyond this, much HCI research in dementia has focused on safety of people with dementia, involving the deployment and use of GPS technologies to ameliorate issues such as wayfinding and wandering. Another thread of HCI research in dementia has attempted to engage with the social worlds of people with dementia to envision new ways of communicating with individuals whose communication styles have changed. Such research has focused on topics such as community reminiscence [6, 15], digital jewellery and personhood [16], music and participative performance [11, 7], and artistic expression [9].

Given the increasing depth and breadth of HCI work on dementia, we believe it is time to pause and take stock of the work that has been carried out within the field so

far. As a part of this, the field can benefit from the inclusion of perspectives from those outside the field of HCI, and in particular, from close contact with those living with dementia in different capacities. This workshop provides an opportunity for researchers working within the field of dementia and HCI research to come together with experts from Denver-based dementia groups (Seniors' Resource Centre, Alzheimer's Association, Access Gallery, and Dementia-Friendly Denver) who have committed to participating in the workshop. The overarching goal of this workshop is to co-create, with researchers, clinicians, advocacy groups, family caregivers and people with dementia themselves, a research agenda that builds on what has been done in order to envision a new future for dementia and HCI.

We will achieve this overarching goal via the investigation of dementia through three workshop topics: 1) Dementia across cultures and the role of local knowledge; 2) Creativity and dementia, and; 3) Personhood vs citizenship. These topics respond to themes within the HCI and dementia research literature [1, 3, 13], and are central to understanding and addressing current challenges posed by policy, health and social care systems around the world. Through these topics, we will identify stereotypes and stigmas that block progress of HCI work, explore the diverse situations of people living with dementia, and build a new agenda for HCI work pertaining to dementia.

Dementia across cultures and the role of local knowledge

It can be tempting to treat dementia as a series of cognitive symptoms, which are then addressed in modular ways. However, this approach ignores the role

of cultural context and local knowledge. One aim of the workshop will be to uncover how dementia is constructed and experienced differently across different cultures and other intersections of experience, and explore ramifications for HCI. The international perspectives of the workshop attendees will be complemented by diversity and inclusion officers from the Alzheimer's Association (Colorado Chapter), who have agreed to participate in our workshop to guide a new, sensitive set of research directions. These directions will pay close attention to the ways in which a diagnosis of dementia impacts people based on their gender, race, sex, sexuality, location, religion, and socio-economic status; and how this impact can be made more complex by the changing nature of the condition itself. Although it is impossible to design for 'everyone', HCI research in dementia so far has generally not taken stock of these intersectional experiences.

Beyond this, having been guided from conversations with our community partners, we will also explore the role of service and technology design in facilitating empathy and co-learning between people with dementia and a) professional carers, a body of employees which is increasingly made up of people from cultures other than the one in which they are caring, and b) family members, for whom shifts in living standards, general culture, and generational differences may mean that communication with loved ones can be complex.

Creativity and dementia

A burgeoning body of work in HCI attests to the role of creativity in dementia care – from approaches and designs that are therapeutic, assistive, meaningful, or

simply enjoyable for people with dementia. Given the predominant focus on cognitive deficits in dementia, for many researchers, creativity in dementia can be valuable in negotiating new ways of communicating and learning about and with the person with dementia. In talking about music in particular, Killick and Craig give the example of a care resident who sang what seemed to them to be a 'nonsense' song:

"I had recorded her and I played the recording back to her. To my surprise she sang along to the tape, reproducing the exact sounds she had made the first time. Although the words made no sense to me, they clearly did to Ella. ... [W]e have to find what process suits the person, however unconventional it may seem." [5, p. 31]

Despite its apparent value, approaches to designing creatively for and with people with dementia have varied in HCI, and so this workshop will explore differing approaches to designing creatively with people with dementia in a way that will help to classify and continue future work. To aid in guiding this, one of our community group members is a professional who facilitates therapeutic writing classes for carers and people with dementia.

Beyond this, the workshop will discuss how we might reconcile literature which varyingly reports the benefits of creative activities in dementia with design approaches that in the literature have been indicated to be useful or fruitful. In this way, we will address the intersection of research in HCI and clinical research, a set of points which can often be disparate, contradictory, or not investigated to the fullest extent.

Personhood and citizenship

Person-centred care has often been heralded as the best approach to caring for people with dementia, with the central notion of personhood conceptualizing the perseverance of a self in dementia despite other associated (e.g., cognitive) decline. The approach was revolutionary when it was suggested and then deployed in the 1990s by researcher-practitioners such as John Kitwood and Dawn Brooker, and has contributed to an increasingly common view of people with dementia as ‘people’, rather than ‘patients’ or ‘sufferers’.

However, recent critiques of the notion of personhood question its emphasis on individuality [5], rather than on a more ecological approach to personhood, which takes into account the cooperative construction of personhood by outside social positioning forces. These critiques ask: is it enough to be a person? Can people with dementia (and their carers) be citizens as well? This may mean having their voices heard effectively in matters which pertain to their futures, knowing how to access services (which are often quite disparate and poorly advertised) meant for them, and being treated as a valued member of society with much to offer, rather than a ‘bed blocker’ [14] or as a non-person entirely.

In 2015, Olivier and Wright [12] positioned digital civics as a) giving people a “voice in the commissioning of services that local government or the National Health Service provided to them”, b) offering “alternatives to traditional top-down consultation mechanisms”, and c) providing “support for people to deliberate on matters of concern, express their collective views, or instill in people confidence that their voices would be listened to.” This is a complex enough task in carrying out HCI

research with more typical participants – is it possible to do within a context of dementia care? In Denver, where a ‘dementia-friendly Denver’ initiative is just about to begin, the notion of citizenship is on the minds of many of our community partners. These concerns extend also beyond the context of dementia to additional areas of concern within HCI in which the nature of participatory design and related methodologies can become problematic, such as with vulnerable populations, populations that are traditionally difficult to study, and populations in which participants’ citizenship and care needs can be difficult to understand.

Organizers

Kellie Morrissey completed her PhD in University College Cork’s School of Applied Psychology in 2016. She now works at Open Lab, Newcastle University, where she is primarily involved in exploring the role of technology and service design for dementia-friendly community initiatives.

Amanda Lazar is a postdoctoral scholar at Northwestern University. She completed her PhD at the University of Washington in 2015. Her research has focused on the ways that technologies designed for health and wellbeing position and support individuals as they age.

Jen Boger is an Assistant Professor in the Department of Systems Design Engineering at the University of Waterloo, Canada and the Schlegel Research Chair in Technology for Independent Living. Her research investigates the development of intelligent technologies that support aging and wellbeing, with a focus on people with dementia and their circle of care.

Austin Toombs completed his PhD in Indiana University's School of Informatics and Computing in 2016. His research has focused on maker and hacker communities, and how the development of a maker identity relates to conceptions of care and community relationships. He now works at Open Lab, Newcastle University, exploring the intersections of various kinds of community and social care in the context of digital civics and computing technologies.

Larger committee

Our workshop will be buoyed by a larger committee of researchers across the world who have a) committed to providing guidance on the workshop's activities and outcomes, b) committed to reviewing participants' position papers, and c) agreed to attend the workshop, to have their PhD students to attend, and to promote the workshop to a larger community. These researchers include Jayne Wallace (*Northumbria University*), Stephen Lindsay (*Swansea University*), Claire Craig (*Sheffield Hallam University*), Claudia Muller (*University of Siegen*), John McCarthy (*University College Cork*), Patrick Olivier (*Newcastle University*), Kristine Holbo (*SINTEF Oslo*), Anne-Marie Piper (*Northwestern University*), Niels Hendriks (*LUCA School of Arts*), and Frank Vetere (*University of Melbourne*).

Community group partners

We have engaged personally with partners in Denver who have committed to act as sponsors for this workshop, having travelled to Denver in September 2016 in order to engage these groups more directly. As a result, these groups will be attending the workshop to share their experiences, concerns and help us to shape our research agenda. 1-2 members of these communities will attend and help direct the whole

workshop; up to 10 others will join only temporarily, at different points, and so this should not inflate our workshop size considerably.

The Alzheimer's Association – Colorado Chapter:

the AA is the largest non-profit funder of Alzheimer's disease research; its local chapters seeks to increase awareness and offer resources for those affected by the disease;

Senior's Resource Center: the SRC is a non-profit provider of information, services and advocacy for seniors in the Metro Denver area and surrounding communities. Their programs and services are designed to help seniors remain independent, living in their own homes.

Access Gallery: the Denver Access Gallery is an inclusive nonprofit organization that engages the community by opening doors to creative and educational opportunities for people with disabilities to access and experience the arts. It has recently pioneered a series of community arts projects with people with dementia entitled "Granny Does Graffiti".

Dementia-Friendly Denver: Dementia-Friendly Denver is a working group across the Denver Metro area, which aims to help make Denver a dementia-friendly community. Attendees from this group will primarily include business people who are interested in ways of ensuring that dementia-friendly businesses can be affordable, profitable, and engaging for communities.

Pre-Workshop Plans

In the months preceding the workshop, we will promote the workshop through our experienced committee members' own networks; we will also advertise the workshop through the network recently created by the DementiaLab event (<http://www.dementialab.com/The-Role-of-Design-2016>), at which Morrissey was a participant. We will populate our website (<https://openlab.ncl.ac.uk/dementiahci>) with a workshop structure, call for papers, and sensitizing material taken from a) our community partners (e.g., testimonials, videos, news articles) and b) key ideas from our own research and extant HCI research we have found illuminating. We will work continuously with our community partners to ensure the workshop structure is appropriate for their needs (e.g., activities may need to be structured in open ways to allow for the comfortable participation of people with dementia), and to arrange a suitable venue.

We will solicit position papers from participants shortly after notification in order to comply with early acceptance dates (21st December), and will post a second deadline in mid January of 2017, to ensure the review process is completed in advance of the 24th of February deadline.

Workshop Structure

The workshop will be scheduled as follows:

Day 1

09:00- 09:15 Welcome and introductions

09:15- 10:30 Participant introductions: identify and briefly present (5 mins) a paper within HCI or dementia research which they feel speaks to workshop goals (organisers to later collect & disseminate)

10:30- 11:00 Coffee break

11:00- 12:30 Dementia across cultures and the role of local knowledge in designing for and with people with dementia and their carers (brief lightning talk and group work)

12:30- 13:00 Feedback to larger group & bringing together of important points; identification of sub-goals within theme

13:00- 14:30 Workshop lunch

14:30- 16:00 Dementia and creativity: how can creative approaches help us to design for/with people whose communicative abilities are changing? (brief lightning talk and group work)

16:00- 16:30 Coffee break

16:30- 17:00 Feedback to larger group & bringing together of important points; identification of sub-goals within theme

Day 2

09:00- 09:15 Brief summary of previous day

09:15- 10:45 Citizenship and dementia: how can we work with people with dementia and their carers to help position them as citizens rather than consumers/users of technology?

10:30- 11:00 Coffee break

11:00- 12:00 Feedback to larger group & bringing together of important points; identification of sub-goals within theme

12:00- 13:30 Workshop lunch; additional members of community groups arrive

13:30- 14:00 Welcome for community groups and summary of workshop so far; community group introductions

14:00- 15:00 Community groups review participants' position papers/pick out 'highlights'

15:00- 15:30 Coffee break

15:30- 16:45 Three rotating table discussions with members of community groups discussing their experiences pertaining to workshop themes

16:45- 17.15 Summary and wrap-up

17:15- 21:00 Pizza, pop & demonstration from Granny Does Graffiti project (optional)

Post-Workshop Plans

The primary output from this workshop will be a co-created research agenda which will be informed by a) critical examination of extant research literature, b) discussions centred around the three workshop themes, and c) documentation of concerns from community members “on the ground” with specific regard to their work that has already been done. This will be disseminated in a special issue of a journal, where the agenda from this workshop will foreground individual submissions from workshop attendees, as well as from a wider research community. We are also keen to ensure that our community partners mutually benefit from their participation in the workshop. With this in mind, we have begun discussions with them concerning a co-creation of a resource which responds to discussions to be held as part of the workshop.

Call for Participation

Although dementia has been a topic of interest for the HCI community for many years now, HCI work on the topic is typically scattered and often neglects to consider multiple perspectives, including the sensitive inclusion of the lived experience of having, or caring for, dementia. This two-day workshop brings together HCI researchers with several dementia-focused community groups (Very Special Arts, Alzheimer’s Association, Senior’s Resource Centre, and Dementia-Friendly Denver) in order to discuss extant research on

dementia under the themes of *dementia across cultures and the role of local knowledge*, *creative approaches to working with dementia*, and *citizenship and personhood in dementia*. The goal of this workshop is to consolidate existing research within the area in order to co-create – with community members – a research agenda for the future which responds to real life challenges and opportunities brought about by a diagnosis of dementia. More details regarding the workshop can be found at [our website](#).

We invite researchers interested in participating to submit 4-6 page position papers (ACM [Extended Abstract](#) format). Papers should critically reflect on how the researchers’ research/interest addresses challenges but also opportunities which are faced by people who are affected by dementia, and should respond to at least one of the themes of the workshop in some way. Submissions should be sent to kellie.morrissey@ncl.ac.uk in .pdf format. Position papers will be reviewed based on relevance to the workshop and the potential for contributing to discussions on the research agenda to be developed during the workshop. At least one co-author of each accepted paper should attend the workshop and one day of the conference.

Important Dates:

Early Submission Deadline: 14th December 2016

Early Notification: 21st December 2016

Final Submission Deadline: 20th January 2017

Final Notification: 24th February 2017

Workshop Dates: 6th-7th May 2017

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