Dementia Ambient Care: Ethical Issues Encountered during the Pilot of a Home-Based Multi-sensor Support System

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BACKGROUND

- With the worldwide increase in dementia prevalance acceptable and cost-effective home-based solutions are needed to support people with dementia to live well in the community for as long as possible and to delay institutionalisation.
- Ambient Assistive Technologies represent a way of enabling independence and facilitating "ageing in place", by supporting the health, lifestyle, and safety of people with dementia in an unobtrusive manner. However, ethical issues associated with their use remain under-reported; issues of safety, security, and privacy are most common.[1]
- The Dem@Care project aims to provide multi-parametric remote monitoring and enablement for people with dementia living in the community. We report ethical challenges and recommendations from our initial home-based pilot studies.

METHODS

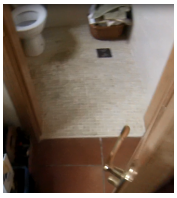
- The @Home Dem@Care Toolbox uses a variety of ambient and wearable sensors to provide individualised, person-centred support in five domains: physical activity, sleep, activities of daily living, social interaction and mood.[2]
- Multiple case study design (initial pilot, *n*=2), purposive sampling of people with dementia
- R&D is carried out as a user-driven co-design process with people with dementia, informal and formal caregivers, and clinicians.
- Informed consent from the person with dementia and the carer required for sensor use.
- Participants are asked not to wear cameras in settings where photography is prohibited.

Figure 1. Dem@Care system and sensors

RESULTS

PRIVACY

Participant forgets to turn the camera off in situations where their privacy should be respected.



Recommendation: Develop integrated sensors that automatically stop recording when entering potentially sensitive areas.

ANXIETY

- New learning Is often required for people with dementia and caregivers. Adequate training periods and support are required.
- Sensor synchronisation, data capture, and data processing need to be fully automated.
- Prototype sensors can malfunction and these issues can cause distress.
- Prototype sensors are often not market-ready and may have usability and acceptability issues to begin with.

SURVEILLANCE

Carers wish to use the ambient cameras as 'surveillance' tools to monitor the activities of the person with dementia.

Debate Needed: Contrary to Dem@Care ethical guidelines BUT these 'Nanny Cams' do exist. Often carers are not aware of the ethical implications of their use.

THIRD PARTY CONSENT

Challenge of determining how to obtain third party consent (family members, friends, acquaintances..) for ambient recordings in the home.[3]

One suggestion: Less invasive modes for obtaining (at least) implicit) consent; for example, an information sheet on entry to the room.

But: this discriminates against the rights of the person with dementia not to disclose their diagnosis

CONCLUSIONS

- Ambient assistive technologies are potentially beneficial and generally acceptable to people with dementia and to their informal caregivers.
- Given the difficulties with new learning and remembering to use options such as privacy buttons, integrated sensor systems must require little end-user interaction and automatically detect situations where privacy should be respected.
- Consent processes must be developed that balance the rights of the person with dementia and those of third parties.
- Results are preliminary (*n* = 2) and require further validation withadditional Dem@Care @Home participants.

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ACKNOWLEDGEMENTS

This research has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under grant agreement 288199 – Dem@Care