

Ethical Challenges Associated with Technology use with People with Dementia

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- Rising dementia prevalence increases the need to find acceptable, efficient, and cost-effective solutions that enable a heterogeneous population of people with dementia to live well at home and remain integrated with their communities for longer
- Technology-based solutions have been suggested as potential solutions to these needs but some ethical issues associated with their use remain unresolved
- Two recent DCU projects will be used to illustrate some of the issues and to review some of the potential solutions

- Dementia Ambient Care (Dem@Care)
 - Ambient Assisted Living (AAL) system
 - Personalised real-time support enabling the person with dementia to remain independent for longer
 - Maintain capabilities, social integration, safety, monitor current needs, detect changing needs, and reduce workload for carers
- Sensecam Reminiscence Therapy
 - Lifelogging and Reminiscence
 - External stimuli trigger memory and recall
 - Focused on the effects of using lifelogging technology

Person with Dementia	Informal Carer	Researcher/Clinician
User Involvement in R&D	✓	✓
Acceptance of ICT	✓	Automated machine diagnosis
Informed Consent	✓	Motives for participating
Prevention of Harm	Benefit	Human-centred approach
Monitoring, Surveillance	The value of human care	Safety and security
Embarrassment, Stigma	Data collection, safety and protection	Meaningfulness of and need for data
Social Exclusion	Overprotection	Allocation of resources

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- Importance of including people with dementia, informal carers in the co-design process, but
 - New systems require testing, sensors may malfunction,
 - New learning is required
 - Each can increase stress and anxiety for system users
 - Training periods were found to decrease anxiety and they were key to technology acceptance
 - Ongoing researcher (therapist) contact essential

- High-tech nature of AAL may make it difficult for the person with dementia to fully understand what they are consenting to
 - Rolling informed consent recommended
 - Easily achieved when a researcher/therapist is involved, but how would this be managed for an 'off-the-shelf' product?
- Ambient functioning means that additional informed consent is needed from co-habitants
 - Experience suggests that this is generally achievable
 - Consent from other third parties (e.g. visitor to the home) is more difficult
 - No clear recommendation exists

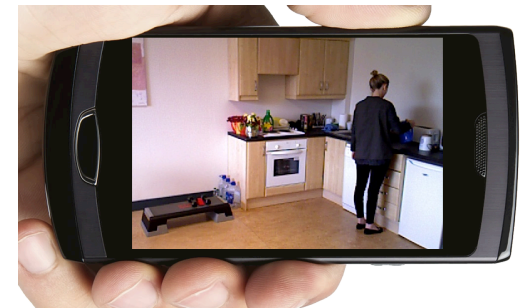
- Hofman (2013) - although written informed consent is not needed from all third parties, participants should seek their verbal permission
 - Novitzky (personnel communication, 2014) argues that researchers cannot rely on this happening given the possible impairments of people with dementia
 - Third parties need to be informed in another way (e.g. an information notice on entry to the monitored area)
 - But, this fails to respect the person with dementia's rights not to disclose their condition
- So, further debate is needed

- The impaired cognitive status of the person with dementia does lead to situations where data is collected in situations that they would not want to see captured
 - Sensor ‘privacy’ options can be forgotten
 - Research protocols can be forgotten
- Researchers need to be aware of these issues
 - Develop additional safety nets in home environment
 - Provide a means to delete unwanted data



- Risk of Surveillance when monitoring ADLs
 - Determine which activities to monitor
 - What constitutes ‘normal/abnormal’ function?
 - Hofman (2013) asks if normality be defined in a heterogeneous population?

- Continuous ‘monitoring’
 - Has been requested by carers
 - Unethical for Dem@Care but these technologies exist



- Reviewing lifelog images may increase an individual's awareness of their memory problems and severity of their forgetfulness
- Can reveal some uncensored details that may never have been freely articulated as identity components (e.g. pipe smoking, wine glass)
- When the person with dementia can no longer access the memories of recent events, the images can be confusing and stressful
 - Using Sensecam becomes voyeuristic and unethical and comparable to surveillance

- Understand the motivation for technology use in order to appreciate the different ethical challenges it will raise, especially if the system benefits the carer more than the person with dementia
- The possibly harmful effects in the home environment need to be weighed against the any potential benefits
 - Most common concerns: stress, consent, privacy, surveillance
 - Aim for stress-free goal-oriented solutions
 - The provision of independent living must be the main priority with clear physical and emotional benefits
- Need to question if the technologies are meaningless without the researcher/therapist relationship

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