Ethical Challenges Associated with Technology use with People with Dementia

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Use of Technology with Dementia

- 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 Technology Projects

- 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
## AAL - Ethical Challenges

*(Novitzky et al., 2014)*

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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
Informed Consent

- 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
Third Party Consent

- 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
Surveillance

• 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
A Threat to Self-Identity

• 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
Conclusion

• 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
Thank you for your attention

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