Assistive technology in dementia

Dr. Franka Meiland

Research line care and support in dementia
(head: Prof.dr. Rose-Marie Dröes)

Quality of Care

EMGO Institute for Health and Care Research

Dept. of General Practice and Elderly Care Medicine/
Dept. of Psychiatry
Information: fj.meiland@vumc.nl

Malta 12 October
Content

• Introduction Assistive Technology in dementia care

• State of affairs of AT

• Research on AT development

• Research on AT evaluation

• Conclusion & recommendations
Introduction on Assistive Technology in dementia care
Assistive Technologies
The term ‘Assistive Technology’ can be defined as “any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed.”  
(Royal Commission on Long Term Care 1999)

This includes a wide range of devices from simple ‘low tech’ items such as calendar clocks to more ‘high tech’ items such as automatic lighting and telecare sensors.

(www.atdementia.org.uk)
“Home-based care is much more cost-effective than care in a hospital or care home. As demand for these services increases, effective use of ICT technologies and services offers an attractive alternative to the costs and disruptions of early and unnecessary institutionalised care.” (European Commission, 2007)

Although for dependent older persons to help themselves in coping research on technology and ageing has increased in the last decade, there still is a great R&D need [...] the challenge is to produce technologies for dependent older persons to help themselves with coping in daily life in a way accustomed to their life styles. (Vision paper Joint Programming Initiative: More years, better life, 2011)
Expected benefits of AT

- facilitate memory and recall
- help manage potential risks in and around the home
- promote independence and autonomy, both for the person with dementia and those around them
- promote social inclusion
- improve the quality of life of persons with dementia
- reduce early admission to care homes and hospitals
- reduce the stress on carers and improving their quality of life

(Alz.org.uk, 2012)
The state of affairs

• Many assistive technologies are developed without or with limited involvement of people with dementia
  \cite{Barucha2009, Span2013}

• Positive effects of assistive technologies are reported

  - for persons with dementia: more confidence, enhanced positive affect, increased communication and activities, enhanced feelings of safety and security, less fear and anxiety \cite{Lauriks2007, Bemelmans2012}
The state of affairs

• Positive effects are reported of assistive technologies for caregivers: reduction in caregiver burden, anxiety and depression, improved competence, enhanced feelings of safety (Lauriks et al., 2007; Godwin et al., 2012).

• However, the methodological quality of studies is low (Lauriks et al., 2007; Topo, 2009; Nijhof et al., 2009; Peterson et al., 2012; Godwin et al., 2012).
Development of Assistive Technology in dementia care
Development of Assistive Technology

• Adapted to needs and wishes of the target group
  ➢ user – participatory design process
• Taking into account dementia related problems
• User-friendly and useful
• Proven effective
• Accessible
User-participatory design

- Workshops and focus groups with people with dementia and (in)formal carers
- Expert meeting sessions
- Small scale tests
- Field tests (e.g. interviews, observations, logging)
Research on AT: Development

Needs → Wishes → Functional requirements → Technological specifications

Design and development of assistive technology

(Hettinga et al., 2010; Meiland et al., 2012)
Top 5 unmet needs persons with dementia

Interviews: 231 community dwelling persons with dementia and 321 carers
a.o. Camberwell Assessment of Need in the Elderly (CANE)

<table>
<thead>
<tr>
<th>Persons with dementia</th>
<th>Carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Memory (10%)</td>
<td>1. Memory (33%)</td>
</tr>
<tr>
<td>2. Information (10%)</td>
<td>2. Daytime activities (16%)</td>
</tr>
<tr>
<td>3. Company (5%)</td>
<td>3. Company (13%)</td>
</tr>
<tr>
<td>4. Psychological distress (5%)</td>
<td>4. Eyesight/Hearing (9%)</td>
</tr>
<tr>
<td>5. Daytime activities (4%)</td>
<td>5. Information (9%)</td>
</tr>
<tr>
<td></td>
<td>Incontinence (9%)</td>
</tr>
<tr>
<td></td>
<td>Psychological distress (9%)</td>
</tr>
</tbody>
</table>

(Van der Roest et al, 2009)
Learning to work with new devices is hindered by

- memory and orientation problems
- poor understanding of verbal instructions
- problems with execution of purposeful activities (apraxia)
- difficulties recognizing/ understanding the meaning of pictures
- other physical impairments (e.g. vision, hearing, trembling)

(Meiland et al., 2012)
Assistive technology requires:

- simple to use interfaces, intuitively usable
- easy to configure by informal caregivers
- personalisable: attuned to personal needs, wishes, preferences (amount of information/ multimodal presentation/ use of buttons or not/ functionalities)
- not too childish

(Meiland et al., 2012)
**Need for Information**

- **Dem-Disc**
  Web based demand-oriented social chart

- **Into D’mentia**
  Experiencing dementia
  For more understanding, empathy and improved competence

- **Star course**
  E-learning for carers, volunteers, professionals
Other Unmet Needs areas (top 5)

• Memory support
• Social support
• Daily activities
• Safety (reduce anxiety/distress)
COGKNOW Day Navigator (FP6) 2006-2009

**Integrated system – multifunctional**

**Reminding function**
- Day, time, reminders
- Find mobile

**Social contact**
- Picture dialling

**Activity support**
- Media control function
- Activity assistance

**Safety warnings**
- Door/fridge open warning
- Help button
- navigation ‘Take me home’
ROSETTA integrated system

2009-2012: activity support; behaviour monitoring; surveillance

At home:
- Computer with touch screen
- Mobile device
- Sensors
- Cameras

At care organisation:
- Web portal with overview clients’ behaviours
- Mobile device for receiving alarm notifications and access camera images
Evaluation of Assistive Technology in dementia care
Research on AT: evaluation

- User friendliness
- Usefulness
- Impact in daily life (autonomy, quality of life, delay of nursing home admission, etc.)
- Technological issues (innovation, integration, stability, etc.)
- Implementation issues & business models
Research on AT: evaluation

Ethical issues

- informed consent
- privacy issues, restriction of freedom
- improved autonomy, reduced care?
- change in relationship carer - care receiver
- stigmatisation / dignity
- justice / equity
- safety and risks
- responsibility

(Gove et al., 2010; Niemeyer et al., 2012)
## Results of our ICT projects

<table>
<thead>
<tr>
<th></th>
<th>Dem-Disc</th>
<th>STAR course</th>
<th>Into Dementia</th>
<th>Cogknow</th>
<th>Rosetta</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>User participation development</strong></td>
<td>+ (carers)</td>
<td>+/- (prof)</td>
<td>+ (PwD, carers)</td>
<td>+ (PwD, carers)</td>
<td>+ (PwD, carers)</td>
</tr>
<tr>
<td><strong>User friendliness</strong></td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+/-</td>
<td>+/-</td>
</tr>
<tr>
<td><strong>Usefulness</strong></td>
<td>+/-</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td><strong>Ethics</strong></td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>+</td>
</tr>
<tr>
<td><strong>Technological evaluation</strong></td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+/-</td>
<td>+/-</td>
</tr>
<tr>
<td><strong>Exploring impact/outcome</strong></td>
<td>+ Needs, competence</td>
<td>NAY</td>
<td>+ knowledge</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Business models</strong></td>
<td>NAY</td>
<td>NAY</td>
<td>+</td>
<td>+/-</td>
<td>+</td>
</tr>
<tr>
<td>Conclusion and recommendations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


Recommendations research AT

• To improve usability and acceptability of Assistive Technologies it is important to include persons with dementia and caregivers in different phases of research (development, evaluation, implementation)

• Arrange enough time for the effect evaluation with a tool that works sufficiently

• Use preferably a (randomized) controlled design with appropriate sample sizes

• Pay attention to individual needs and wishes: what works for whom?
Recommendations research AT

- Critically review the outcome measures
  - Some are too general to allow for assessment of impact of assistive technology
  - Much variation in instruments used, which hinder comparisons between different interventions

- Important to combine efforts in Europe: e.g. Interdem group (with taskforces on methodology and assistive technology)
More information on our projects:

- www.cogknow.eu
- www.aal-rosetta.eu
- www.startraining.eu
- www.intodementia.nl

Correspondence
fj.meiland@vumc.nl

Thank you for your attention!