The Personal and Societal Impact of the Dementia Ambient Care (Dem@Care) Multi-sensor Remote Monitoring Dementia Care System

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The Dem@Care Project

3 Themes

- Diagnostics
- Enablement
- Safety

3 scenarios

- @Lab (France/Greece)
- @Home (Ireland/Greece)
- @Nursing Home (Sweden/France)

2 loops of care

Home-based loop
- Between people with dementia and their caregivers
- Sensor-based, context-sensitive, evolving, personalised
- Offer encouragement, warnings, alerts

Clinician loop
- Faithful log of health-related information
- Summaries, trends, pattern analysis
- Monitor improvement, stasis or warn clinician of deterioration
- Supports care decisions
Data Collection in Five Domains

Person with Dementia

SLEEP
- Night time sleep, awakenings, bed exits, Difficulty falling asleep, insomnia onset, day-time sleep and napping

MOOD
- Observed behaviour, physical stress levels, speech analysis, subjective mood reporting

PHYSICAL ACTIVITY
- Amount of physical activity in the home, outside the home, dedicated exercise, movement speed, distance travelled, activity intensity

SOCIAL INTERACTION
- Face-to-face social contact, initiated and received phone contact, speech analysis

ADL/IADL
- Meal/Drink preparation and consumption, daily tasks (e.g. watch tv, listen to music, read, hobbies, chores)
Dem@Home Sensor Toolbox

- Sleep
- Social
- (I)ADL
- Activity
- Mood
The Dem@Care System

- Clinician is able to monitor
  - Sensors recordings
  - Analysis results (e.g. completed activities) from the current or previous dates/periods

- Person with dementia and the carer are able to read messages-prompts-advice that come from
  - The System
  - Clinician
Dem@Care: Aims and Methodology

- **Research Questions**
  - @Lab: Can Dem@Care contribute to the assessment of dementia above and beyond traditional assessment methods?
  - @NH: Can Dem@Care effectively support nursing home staff to care for people with severe dementia (including BPSD)
  - @Home: Can Dem@Care optimise the functional status of the PwD and support their independence and autonomy

- **Methodology**
  - @Lab: Quantitative between group (Healthy, MCI, AD); $n=380$
  - @NH and @Home: Multiple case study design; $n=13$
  - @H: Multiple case study design; $n=16$
Personal and Societal Impact

- Four beneficiary groups
  - the PwD, informal caregivers, the clinician, and formal care staff
- Stakeholders
  - end-users, academics and professionals, and policy-makers

- **Personal Impact:** Quality of life (PwD/Carer)
  - Independence, Sense of Improvement, Security & Safety
- **Social and Economic Impact:** Builds from personal impact
  - Social inclusion, increased understanding of BPSD
  - Early diagnosis increases, staff costs reduce, at home for longer
- Advance technical, clinical, and ethical state-of-the-art
Personal Impact - People with Dementia

- Increased autonomy and independence in daily life
  - “I feel kind of in control, do you know what I mean? In control of my day.” [@H PwD]

- Sense of improvement across the five domains addressed
  - “Well I couldn’t imagine that I can wake up after 8 o’clock in the morning. I used to wake up before 5 o’clock” [@H PwD]
  - “I see my father is getting better! He is more active and walking a lot” [@H Carer]
  - “We are talking a lot more now ... we are finding it easier to talk” [@H Carer]

- Improved diagnosis and management of care

- Overall sense of improvement in subjective quality of life
Personal Impact – Informal Caregivers

- **Key carer concerns:** taking medication and eating properly, sleep, adequate physical exercise and stimulation

- Improvements for the person with dementia translated into improvements for their informal caregivers
  - “It is a feeling of safety and relief that every caregiver of an elder person must have” [@H Carer]

- Increased independence for some caregivers
  - “I’m going away for the week in September .... He’s independent at the moment as we are trying to keep him as independent as long as we can... I used to give him his tablets, now he takes them himself” [@H Carer]
  - But, carer independence was most related to the severity of dementia

- Overall sense of improvement in quality of life
  - “My experience has been brilliant ... I found it fantastic” [@H Carer]
Personal Impact – Clinicians/Formal Carers

- Facilitate timely and accurate diagnosis while delivering efficiencies in terms of time and cost
  - Improved assessment/diagnostic procedures (incl differential diagnosis)
  - Improvements in clinical reasoning (@NH)
  - Reduction in observer bias

- More timely identification and better understanding of functional, behavioural, and emotion pattern changes
  - “I was able to identify problems and issues [e.g. REM sleep] that otherwise would have been impossible” [Clinician]

- Improved capacity and quality of care. Formal carers can:
  - develop and evaluate personalised interventions
  - better manage the care of the person with dementia
  - better manage the emotional and social disturbances of the Behavioural and Psychological Symptoms of Dementia (BPSD)
Societal Impact

- **Economic: Cost efficiencies**
  - Time savings (diagnosis/assessment)
  - Improved workflow, clinical reasoning, and intervention selection
  - Potential to reduce costs for national healthcare systems
  - Potential savings in the home environment – harder to quantify

- **Social: Inclusion and awareness**
  - Improved understanding of BPSD and reduction in social disturbance and therefore isolation @NH
  - Manage appointments and remain connected with life outside the home
  - Engagement with new social groups
  - Project dissemination activities

Difficult to evaluate the longer-term economic and societal outcomes but successful attainment of personal impacts for each stakeholder group will, over time, lead to these outcomes.
Scientific Impact: Advancing Technical SoA

- Novel visual-sensing algorithms
  - New approaches for perceptual analysis of egocentric video content
- Advanced physiological sensing and audio sensing
- Highly accurate real-time event detection and people tracking
- Creation of new knowledge structures, reasoning methods, rules, associations, and algorithms
  - Intelligent machine learning and dynamic model adaptation
- Novel context-aware multi-sensor, intelligent, event-driven feedback mechanisms
  - Adaptive visualisations of daily activities
  - Personalised alerts enabling scheduled problem checks and other automated interventions
- Integration and orchestration of sensing analysis and clinical applications
Scientific Impact: Advancing Clinical SoA

- Novel and holistic solution supporting all aspects of the clinical management of dementia

- Assessment and diagnosis
  - Improved early detection of dementia over and above traditional assessment methods alone – ability to detect subtle behaviour changes
  - Successfully differentiate between healthy, MCI and AD patients
  - Improved assessment of circumstances surrounding BPSD and their contribution to the expression of BPSD for an individual

- Treatment and care
  - Preventative care decision-making
  - Timely updating of care plans for the person with dementia

- Potential to support clinical trials
  - Selection and enrolment of participants
  - Support assessment in more ecologically valid environments
Scientific Impact: Advancing Ethical Debate

- Informed consent
  - High-tech nature of AAL may make it difficult for the PwD to fully understand what they are consenting to => Rolling consent
  - Ambient monitoring requires additional third party consent – no agreement in the literature as to how this should be handled

- Privacy and surveillance
  - Impaired cognitive status does lead to situations where data is captured that the PwD would not want to be captured
  - Risk of surveillance when monitoring ADLs or monitoring off-site
  - Carers do not always understand the ethical implications

- Best interests of the person with dementia

- Risk of replacing or reducing human interaction
  - Discussion time with clinicians needs to be preserved
  - Importance of therapeutic face-to-face contact highlighted @H
Conclusions

- **Value of objective ongoing assessment**
  - Analysis of sensor level data shows promising results although the real value of the Dem@Care system is the ability to:
    - **Triangulate data from various sensors measuring varied domains**
    - **Identify improvement, stasis, and/or deterioration over time**

- **Supports that enable Dem@Home use**
  - Easy to use sensors, data transfer, and automated feedback
    - **Caregiver is still required as primary source of support**
    - **Clinician needs to make the effort to ensure that people understand how ICT can and may not help, and that informed consent is given**
  - Importance of well-supported training periods
  - Importance of personal interaction with the clinician (or researcher)
  - Perceived benefits must be stronger than the perceived effort to use the technology
Conclusions

- Personal impacts found for all beneficiaries and stakeholders
  - Value of objective ongoing assessment/triangulation of data
    - Improved clinical assessment of a person’s cognitive, functional, and emotional status in a familiar environment
    - Supports ongoing monitoring of improvement, stasis, or decline
  - Individualisation of interventions and treatment plans
    - Improvements for person with MCI/dementia based on feedback and monitoring
  - Potential for increased carer independence

- Advancement of technical, clinical and ethical state of the art

- But, difficult to evaluate economic and social impacts as:
  - Not all projects include a health economics element
  - Projects typically don’t run for long enough (esp. development projects)
  - Need to develop short-term metrics that we know deliver benefits in the longer-term
Thank you for your attention

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