The role for telecare in supporting people with dementia and their carers

Professor Sue Yeandle
Centre for International Research on Care, Labour and Equalities
University of Leeds

2nd Yorkshire & Humber Assistive Technology Conference
Making a Difference with Telecare, Pavilions of Harrogate, November 22, 2010
Overview

- The challenge
  - key statistics on older people and dementia
- Supporting care at home
  - role of carers and home care services
- Telecare
  - benefits, evidence … into the mainstream?
## Dementia and age in the UK

<table>
<thead>
<tr>
<th>Age group</th>
<th>Estimated prevalence of dementia</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Women</td>
<td>Men</td>
</tr>
<tr>
<td>65-69</td>
<td>1.0</td>
<td>1.5</td>
</tr>
<tr>
<td>70-74</td>
<td>2.4</td>
<td>3.1</td>
</tr>
<tr>
<td>75-79</td>
<td>6.5</td>
<td>5.1</td>
</tr>
<tr>
<td>80-84</td>
<td>13.3</td>
<td>10.2</td>
</tr>
<tr>
<td>85-89</td>
<td>22.2</td>
<td>16.7</td>
</tr>
<tr>
<td>90-94</td>
<td>29.6</td>
<td>27.5</td>
</tr>
<tr>
<td>95+</td>
<td>34.4</td>
<td>30.0</td>
</tr>
</tbody>
</table>


The Alzheimer’s Society estimates that unpaid carers’ support for people with dementia represents 36% (over £6bn) of the financial cost of the disease, which totals £17-18bn (£25,472 per person with late-onset dementia)
Current Estimates About Dementia

Types of dementia (UK)

- Alzheimer's: 62
- Vascular: 17
- Mixed (AD&VaD): 10
- D with Lewy bodies: 2
- Fronto-temporal: 3
- Parkinson's: 2
- Other: 2

Alzheimer's Society and PSSRU at the LSE
People aged 85 and older with a limiting long-term illness (LLTI), England, 2008-2025

Source: 2001 SARs provided through the Cathie Marsh Centre for Census & Survey Research (Univ. of Manchester), with the support of the ESRC and JISC.
Men & women aged 85+, by living arrangement & limiting long-term illness, England [Census 2001]

**KEY:** CE = communal establishment; LLTI = limiting long-term illness

Carers providing unpaid care to a sick, disabled or older person, by age and sex: England

- Over 3.6m of working age (1 in 10 men, 1 in 7 women)

2/3rd of carers combine care with paid employment
Telecare enables some carers to sustain their paid work

Carers – latest survey estimates

- 48% of carers care for someone they live with
- 22% care for 50+ hours per week
- 60% are women
- 24% are aged 65+
- 35% care for a parent
- 27% care for a spouse

(Survey of Carers in Households England 2009-10: provisional results*)

Care of people 65+ with ‘dependency problems’, living at home**:  
- Half were supported by unpaid carers only (53%)
- A third were supported by ‘formal and informal’ care (34%)
- 1 in 10 received formal care only (9%)
- 3 per cent were ‘unsupported’

*Health and Social Care information Centre – full results of this survey due to be published December 2010  
** Pickard, L (2001) analysis of General Household Survey data  (Knapp and Price 2007,p44)
Telecare: evidence of impact and effectiveness

Expert Reviews:

- **Barlow’s report** for the **Department of Health in 2006** noted:
  - There is mounting evidence to suggest that telecare can make a difference to individuals and their carers, and to the health and social care system as a whole. \[1\]
  - Telecare is an emerging type of care delivery and there is now sufficient evidence to assist in setting up new trials and schemes. (p9)

- By January 2006 almost 9,000 articles about telecare had been published in scientific journals

- **Williams** \[2\] noted in **2008** that
  - “importantly, no study (of telecare) has yet demonstrated any negative or adverse effects”

---


Telecare: evidence of impact and effectiveness

- Bayer et al\(^1\), in a review article published spring 2007, cite worldwide evidence to support the following points:

  - Telecare *reduces the rates of entry to institutional care homes*, where residents will remain on average for several years (p70)

  - Telecare can be expected to have an effect on hospital admissions (p71)

  - Telecare helps individuals *to avoid the admission to institutional care* in some cases ‘postponing’ rather than ‘avoiding’ the need for this type of care

---

Northamptonshire: ‘Safe at Home’
Dementia Project

- Explored the use of telecare in the homes of 223 people with dementia in Northamptonshire
- Published study compared results from the project in Northamptonshire with a large control group of older people with dementia in Essex
- The technology was found to be very reliable
- 123 carers/relatives were surveyed (70% response rate)
  - In all but one of the scored items the carer stress scale score was lower (i.e. the relative or carer was less stressed)
- People in the control group were 4 times more likely to leave community and enter residential/nursing care
- Savings per person assisted were estimated at £3,690
- Net equivalent saving over a period of 21 months was £1,504,773

The Croydon Assistive Technology Dementia Project

- From 2004, to “pilot the installation of assistive and electronic technology to support people with dementia and their carers within their own home”

Evaluation findings in this project

- In every case, alarm events were detected by the equipment and appropriate responses made to avoid an escalation

- None of the service users needed hospital treatment as a result of these alerts, confirming the robust nature of the protocols

- Carers were overwhelmingly positive about the equipment and the relief it gave them

- Estimated annual savings of approximately £12,000 per service user

Carers Scotland project at CIRCLE, University of Leeds

Benefits of telecare for carers:

Feeling more relaxed, less stressed:

“When you have a vulnerable person to care for in your house, it feels like you’re on duty 24/7. So, it was wonderful, it allowed me to relax, gave me chill out time. I wasn’t on alert throughout the night.”

“I was on the verge of a breakdown before we got this help.”

“Before, the neighbours would call me in the middle of the night if they saw my mother wandering … there was a certain amount of pressure and concern when it was like this.”

Carers Scotland project at CIRCLE, University of Leeds

Benefits of telecare for carers:

More confident about the safety and wellbeing of the person cared for

“I’m less worried about him falling.”

“One of our family would usually have to be on ‘granny watch’ at all times in the evenings and weekends, but now we can go about our normal lives, knowing that we will get called if there is a problem.”

“Relatives and other family members can now come and care – and they feel more comfortable doing so with the telecare equipment in place.”

Carers Scotland project at CIRCLE, University of Leeds

Benefits of telecare for carers:

Feeling better supported in their role

“I can sleep easier and work easier knowing that a call out will happen if something is wrong.”

“We were at the point where we needed more home care. I was totally stressed out. But once we got telecare, it made a massive difference, it relieved a lot of pressure.”

“My caring role is the same, but it is just easier and more manageable now. It is not a replacement for a carer, but it does replace the running up and down I had to do, to constantly check he was all right.”

Benefits of telecare for carers:

Able to remain in paid employment

“Telecare has enabled me to maintain the hours that I work. It is difficult to get care workers who can cope with the level of care that my husband requires.”

“At the time it helped, when I worked, because it stopped me worrying so much when I was there.”

Almost half of the carers in the study were in paid employment; of these, over half worked full-time hours alongside their caring responsibilities

How does telecare help support working carers and their families?

- **Offers cost-effective support**
  - Low running costs, modest installation costs

- **Potential to enhance 3-way caring relationships**
  - Between health and social care providers; persons needing care / support and their carers

- **Provides preventative support**
  - Designed to reduce caring crises
  - Crisis responses are key disruptions for working carers/families

- **Telecare can ‘spread the load’ between family members**
  - Alarms/alerts are linked to several people, reducing reliance on a single family member
How does telecare support flexible working?

- **Carers can focus on their job when at work**
  - Carers are reassured that the person they are away from is OK – accidents prevented/promptly responded to; everyday risks reduced; the autonomy and independence of the person cared for is enhanced

- **Telecare can make part-time work possible**
  - Even for those with ‘heavy end’ caring roles

- **New innovations enable continuous real-time contact**
  - Remote communication is possible as & when needed around the clock

- **Makes flexible working possible for people who cannot work from home**
  - Flexible working is not limited to those who can work from home – telecare opens up options for those who must normally be at their worksite (office, factory, shop, meeting)
Key Findings about telecare and carers in CIRCLE’s Carers Scotland project

**ALL carers reported positive experiences**

- Fears about ‘intrusiveness’ allayed
- Improved ‘peace of mind’, less stress and worry
- A better night’s sleep
- Able to retain paid work
- More opportunity for a break from caring
- Better supported in their caring role
- Potential to reduce some caring tasks
- More confidence in safety of the person cared for
- Improved relationship with the person cared for
- Positive outcomes/autonomy for person cared for
Telecare has helped people with dementia in a range of different projects by

- Reminding the person to take their tablets at the right time
- Helping the person locate a lost item
- Making the person aware that it is day time or night time
- Assisting the person to phone a relative or friend (using pre-programmed numbers or pictures)
- Switching lights on automatically if they get up at night time
- Switching the gas off automatically if it is left unlit
- Alert a carer or monitoring centre that the person needs assistance
Concluding comments

Home-based **telecare is highly relevant to the needs of people with dementia** (and others with care needs)…..

- It will be important as part of a sustainable health and social care system that supports growing numbers of people with dementia
- Accelerating the pace on telecare makes good economic sense
- Telecare, *alongside other support*, is important to avoid compromising care quality as demand grows
- Telecare has the potential to support more effective delivery of better home care services
- Telecare could be used to improve job quality for care workers
- Has proven positive impacts on quality of life for unpaid carers
CIRCLE
Centre for International Research on Care, Labour and Equalities

Professor Sue Yeandle
Director, CIRCLE

Address: Department of Sociology and Social Policy, University of Leeds, LEEDS, LS2 9JT

www.leeds.ac.uk/sociology/research/circle

Tel +44 (0) 113 3434 4442 / +44 (0) 113 343 5003
Email s.m.yeandle@leeds.ac.uk