UNIVERSITY OF LEEDS

OLDER PEOPLE AND THEIR CARING NETWORKS:
TELECARE & TECHNOLOGICAL SUPPORT IN EVERYDAY LIFE

Sue Yeandle and Emma-Reetta Koivunen, CIRCLE
Centre for International Research on Care, Labour & Equalities
University of Leeds, UK

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Overview of presentation

- **The AKTIVE and SENSE projects**
- **Everyday Life Analysis**
- **Caring networks and use of technology**
- **Strengthening weak ties – discussion points**

FOR INFORMATION - (slides not presented in the session)

- *About the AKTIVE project*
- *About the SENSE project*
- *AKTIVE publications*
- *Contacting us – further information*

Two linked research projects, England

Both used 'Everyday Life Analysis'

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AKTIVE - Advancing Knowledge of Telecare for Independence & Vitality in Later Life

- **60 older people (with falls /dementia) / their carers using telecare**
- **Recruited via 2 telecare services**
- **Men and women aged 65+**

Funding 2011-2014:

- UK Technology Strategy Board
- Partners: Inventya Ltd, Tunstall Healthcare (UK) Ltd, Universities Leeds and Oxford
- www.aktive.org.uk

SENSE - Using technology to support older adults with DSI: an everyday life analysis

- **38 older people with DSI / their carers using telecare / IT**
- **Recruited with support of SENSE user groups**
- **Men and women 65+, many in 80s and 90s**

Funding 2014-2015:

SENSE - UK charity for deaf-blind people

Researchers: CIRCLE, OIPA, SENSE

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Everyday Life Analysis of Technology Use

- Longitudinal qualitative research method
- Repeat visits, over 4-6 months
- Interviews and observations with older adults with falls, dementia (AKTIVE), DSI (SENSE) and the people involved in their care
- Diaries and photographs about technology use
- Method built trust with participants

Caring Networks Type 1: Family-Based - AKTIVE

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- Traditionally ‘what families do’; seen as ‘natural’ by some
- Coordinated by families who identified needs / arranged support
- Could involve other help, but family controlled choices
- Relied on ‘strong ties’ and local, supportive family
- Often worked well with telecare, which carers often valued
- Supported some people with dementia well
- But some older people have no local family, so not for all
- Conflict, tensions, being ‘organised’ upset some older people
- Family-based networks may not suit older people who want to be ‘fully in control’ in later life

Caring Networks Type 1: Family-Based - AKTIVE:

Mrs Barnard, 89, widow, dementia, lived with daughter

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- **Two daughters shared her care, arranging support, telecare (pendant alarm; smoke/carbon monoxide detectors; medication dispenser)**
- **Both daughters wished to maintain their careers**
- **Co-res. daughter worked 3 days pw, cared for mother other weekdays**
- **Home care support arranged on days she worked**
- **At weekends, Mrs B. enjoyed staying at the 2nd daughter's flat and co-resident daughter got a break and time to herself**

Well, [telecare] *has allowed me to go to work, it's made sure that once the care worker's been, mum's basically left on her own, which is no bad thing* [...] *Now she gets up and she might .. put the washing out if she can, that sort of thing* [...] *I have confidence in the way [a crisis] will be handled* [by the telecare service]. *I just have to be confident Mum will use it.*

Caring Networks Type 2: Complex - AKTIVE

- Involve many different people:
  - Family, neighbours, friends, contacts in local community
  - Care and health workers, cleaners, gardeners, others
- Built by / around the older person
- Rely on / maintain contacts established earlier in life
- Support independence, boost resilience, enhance dignity and control
- Telecare can strengthen these ‘weak ties’, which are vital for social cohesion

Caring Networks Type 2: Complex - AKTIVE

Mrs Tyne 94, widow, living alone

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- **Friends, neighbours, family, temp. home care support, pendant alarm**
  - **'Main carer' her neighbour (whose husband also gave support)**
  - **Daughter and granddaughter visited 2-3 times per week**
  - **Friends helped regularly with shopping**
  - **Neighbour explained that, after surgery, Mrs Tyne:**

'… couldn't go to her daughter's, because she's got stairs. She wanted to come home. So the hospital said they would put **[telecare]** ***in place. She'd had 2 major operations in 3 months. So we needed back-up, because if anything is wrong and she presses her button, I'm two minutes down the road to get here'***

Mrs Tyne (cont.)

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- **Mrs Tyne discontinued her home care once she could cope, despite mobility problems and risk of falls. Neighbour / carer saw the pendant alarm as 'a godsend' :**

  'It gives you peace of mind ..you know she can contact you … Before, yes, she could ring me up, but if she'd fallen and she wasn't near the phone, she couldn't'.

- **A 'bogus caller' alarm, added later, was also valued:**

  'If she goes to the door and ..doesn't know who it is, she can press that* [...] *That is a good thing, because there have been quite a lot of undesirables living* [nearby...] *it seems to have quietened down a bit, but she was very frightened then'.

Caring Networks Type 3:
Privatised Care Support - AKTIVE

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- Accessed through the market, involving payment or exchange, sometimes through very informal arrangements
- Can be set up without family help
- Attractive to those who do not want an official care assessment
- Some chose to purchase technology, equipment or services to meet needs they had identified themselves
- Beyond reach of many for financial reasons
- Only possible if telecare / other goods /services are available
- Current telecare market is not oriented to meet these needs

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Caring Networks Type 3: Privatised Care Support - AKTIVE

Mr Weston Widower, 87, lived 'alone', falls, recent surgery

- Care arrangements 'inherited' from late wife (with Alzheimer's)
- Retained support in place; private cleaner, help with cooking - later hired 'live-in' care worker
- Valued familiar surroundings, wished to remain in own home
- Acquired telecare (pendant alarm), handrails, stairlift privately
- Researched available products, selected ones to try out

"(I) have two good daughters – (but) they don't live nearby. They can't look after me, they have their own jobs to do. But they can advise me, for instance, arranging this [pendant alarm]. *They drew up the contract ... I haven't got the family to rely on, so you have to form a set-up. Fortunately, I have a good enough pension that I can afford to do that, and I live in a place that has everything."*

Mr Weston (cont)

"We decided to look for someone, and started to look through agencies. … [My live-in care worker] has been here for two months. We've got a very nice flat .. upstairs there, you see."

- Mr Weston valued being able to summon support; he had once used his pendant alarm
- Responder did not come quickly, and his privately employed care worker found him where he had fallen outside
- This concerned him, so he bought a small mobile phone which he wore around his neck (with his pendant alarm), calling this his 'back up' arrangement

How telecare fits in

- Enhanced all 3 network types – though none solely reliant upon it
- Not a replacement for human care
- Some, esp. early adopters, gained immensely:
  - Quality of life; peace of mind; reduced anxiety and fears; continued doing things they enjoyed or preferred to do themselves
- Telecare 'got in the way' or caused 'frustrations' for some, usually because of 'fixable' issues:
  - Installed too late or equipment inappropriate
  - Necessary support or information missing
  - Human or technical aspects in some way deficient
  - Equipment design let the user down or did not appeal to them

DSI case: Mr Churchill, 99, married, live-in carer, profoundly deaf with sight problems

- Cannot hear and barely lip-reads, so uses written notes
- Wife has dementia, poor vision, can no longer write
- Has live-in carer (6 weeks in 8) through agency, which provides good ‘relief carers’ for other 2 weeks
- Supplied with textphone, pendant alarm, hearing aids, walking frame, communication board (for wife)
- Feels audiology team has ‘given up on him’
- Son and friends visit, he can only go out with their help
- Formerly very active in local community, but relies on priest and friends to visit them at home
- Struggling to communicate with wife as her dementia worsens

DISCUSSION: Strengthening ‘weak ties’

- Weak ties support social cohesion*
- Unique aspect of telecare is use of local social contacts
- Arrangements require negotiation, forethought and planning
- Choice for telecare users, commitment by named responders
- When neighbours, friends, people in local groups/associations involved, telecare can build strength into ‘weak ties’
- Over-reliance on families can impose strain and tensions
- Important to enable older people to sustain / develop their networks of ‘weak ties’, but critical to recognise:
  - Older people have and want different kinds of caring network
  - Ambiguities in their identities and self-images matter (Hamblin, Paper 5)
  - Changes in bodily competence / frailty affect how systems work (Fry, Paper 4)
  - Social relations change; older people have little control of this (Koivunen, Paper 3)

*(Granovetter, M.S. (1978) ‘The Strength of Weak Ties’ *Amer. J of Sociology,* 78(6), 1360-1380)

AKTIVE: aims

Focus: **older people living at home** with **two types of frailty**:
susceptibility to **falls** and dementia / **memory problems**

Addressed

- ***challenges*** arising from population ageing
- ***opportunities*** arising from technological progress

Aimed to:

- add to knowledge of the **lives, needs and aspirations** of **older people, their families and carers**
- enhance understanding of **how they and home care / other service providers** who attend them might **access, engage with and make best use of 'telecare' equipment**

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SENSE - aims

- Aims of the research project:
  - Examine the role of telecare and associated mainstream and DSI-specific technologies to support older people with DSI to live independently.
  - Focus on the use, applicability, potential and value of these technologies for people with DSI as a specific client group.
  - How can technology help people with DSI overcome constraints in their everyday lives and achieve their aspirations?
  - What barriers to the use of these technologies by older people with DSI, exist and how could these be addressed?

AKTIVE PUBLICATIONS RELEASED IN 2014

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Research Report Volume 1: Literature Review

The Role of Telecare in Meeting the Needs of Older People: themes, debates & perspectives in the literature on ageing and technology

Research Report Volume 2: Seven AKTIVE Working Papers

1. ***Researching Telecare Use using Everyday Life Analysis*** S. Yeandle
2. ***Frail Older People and their Networks of Support: how does telecare fit in*?** S. Yeandle
3. ***Telecare and Older People's Social Relations*** E.-R. Koivunen
4. ***Coping with Change: frail bodies and daily activities in later life*** G. Fry
5. ***Lifestyles in Later Life: identity, choice and stigma*** K. Hamblin
6. ***Risk, Freedom & Control in Older People's Lives: the relevance of telecare*** K. Hamblin
7. ***Human factors that influence the performance of the telecare system*** P. Buckle

Research Report Volume 3: AKTIVE project Research Methods

The AKTIVE project's social, design & prospective hazard research: research methods S. Yeandle, P. Buckle, G. Fry, K. Hamblin, E.-R. Koivunen and C. McGinley.

Contact details

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AKTIVE Researchers

- Dr G Fry - CIRCLE
- Dr K Hamblin - OIPA
- Dr E-R Koivunen - CIRCLE
- Dr E Biianchera - OIPA
- Prof Sue Yeandle - CIRCLE

SENSE Research Team

- Dr K Hamblin - OIPA
- Kara Jarrold - SENSE
- Dr E-R Koivunen - CIRCLE
- Prof Sue Yeandle - CIRCLE

CIRCLE

Centre for International
Research on Care, Labour & Equalities
University of Leeds, UK
From 1st October 2015
Sue Yeandle & CIRCLE will be based at the University of Sheffield
s.m.yeandle@leeds.ac.uk
s.yeandle@sheffield.ac.uk from 1.10.15

OIPA

Oxford Institute for Population Ageing
University of Oxford, UK

Kate.hamblin@ageing.ox.uk