

Drawn from Life: Biographical and social research in dementia studies

**MICRA and Alzheimer's
Research UK**

John Keady

on behalf of

February 19th 2015

Dementia and Ageing Research Team
School of Nursing, Midwifery and Social Work
The University of Manchester/
Greater Manchester West (GMW) Mental Health NHS
Foundation Trust



Dementia and Ageing Research Team

Clusters

1. Biographical and narrative work
2. Psychosocial interventions
3. Lifestyle and creative arts
4. Education

Transcending themes

- Family-centred practice
- Transitions
- Neighbourhoods
- Involvement

dementia

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Editors

John Keady, University of
Manchester

Penny Harris, John Carroll
University

Editorial Board

**Includes over 30 persons from 10
different countries, including
people with dementia**

**First Edition: Feb 2002;
now on Volume 14**



Methods

DART prizes creativity and personal knowledge

We use a range of methods, for example:

- Visual recording: photographs, video camera
- Interviews: face to face; 'walking' [outdoor spaces]; biographical; appearance
- Focus groups
- Social network mapping

Not always about large numbers of participants

Recent Study Examples

- **Deaf with Dementia** [SORD and Prof Alys Young lead]: Interface of culture, language and disability. First study: Subjective experience: Collective community knowledge transfer: Assessment tools. New diagnostic service developed.
- **The Hair and Care study**: Importance of appearance and the collation of appearance biographies. Translational component.
- **“Getting to Know Me”**: 6-hour training programme on dementia - delivered to over 750 NHS hospital staff across the North West. Free download of all materials.
- **Pain and Dementia in Acute Care**: Development of a decision-making tool for hospital staff.
- **Humphrey Booth Resource Centre** [Swinton]; Long standing commitment to applied research [lead: Dr Caroline Swarbrick]

DART Group

Eight current PhD students attached to DART.

- **Complexity in dementia** [NIHR CAT PhD studentship: Lesley Jones]
 - **Neighbourhoods and dementia** [Xia Li]
 - **Masculinity and dementia** [Sarah Campbell]
 - **Intergenerational family care in dementia** [May Yeok Koo]
 - **Semantic dementia** [Dunhill Medical Fellowship: Jackie Kindell]
 - **Theatre studies and 'performing dementia'** [University of Manchester Presidential Doctoral Award: Sarah Hunter]
 - **Deaf with dementia** [Alzheimer's Society: Emma Ferguson-Coleman]
 - **End of life and dementia** [University of Manchester Presidential Doctoral Award: Rachel Plant]
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- Write up year: Jackie and Emma
 - 6 new DART related PhD students starting October 2015 [3xNIHR CLAHRC; 2xESRC Neighbourhoods; 1xESRC CASE with the Manchester Camerata]

My Father's Life

- 'Living in a hole'
- Wrong Shoes
- Lists and memory aids
- Strength of our relationship
- Familiarity and routine
- A changed life

Reference:

Keady, J. and Keady, J. (2006). The wrong shoes; Living with memory loss. *Nursing Older People*, 17(9): 36-37

Prime Minister's Challenge on Dementia: Key Points

1. **Driving improvement in health and social care**
2. **Creating dementia friendly communities**
3. **Better research**

Emphasis: The importance of keeping people at home and in local communities: citizenship

Neighbourhoods and Dementia: A Mixed Methods Study 5-Year programme grant

Commenced 1st May 2014
Part of the PMs ESRC/NIHR
Dementia Initiative

John Keady - Chief Investigator



Neighbourhoods Study

- People living with dementia central to the programme: EDUCATE Group; Open Doors; ACE Insight CiC; Scottish Dementia Working Group
- 8 work programmes
- Independent Member-Led Projects
- UK Partners and Sweden: Center for Dementia Research
- 3 ESRC Studentships: 1 Scotland; 2 North West England, plus 2 additional PhD studentships based in Sweden

Final thoughts



- Importance (for us) of case study work
- Development of new social research methods
- Involvement of people with dementia to research their own experience
- Meaning of authentic knowledge
- The growing influence of public health and creative arts in dementia studies [social interventions]



Thank You