HEARING THE VOICE OF PEOPLE WITH DEMENTIA-REVISITED

Trinity College Dublin
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John

- Qualified mental health nurse (1986; Essex)
- Employed at the University of Manchester/GMW since October 2006
- Trust (Hospital) and University base
- PhD 1999: North Wales – 1986-2005
- Interest in early adjustment and transitions through dementia
- Greater Manchester West remit but predominantly Salford focus
- Salford; significant area of deprivation
- PhD is only degree
Hearing the Voice of People with Dementia
Opportunities and Obstacles
Malcolm Goldsmith

Preface by Mary Marshall:1996

Advisory Group
The Joseph Rowntree Foundation
York: 1993-1995
Dr Lesley Jones; Me; Sue Benson;
Harry Cayton; Martin Shreeve; Derek Brown

Literature review
6 interviews with people with dementia
12 fragmented interviews
Observation
‘Our knowledge about dementia is still rather basic, and understanding about the many aspects of the subject is not developing at the same speed or with the same degree of insight.’

page 20
Editors
John Keady, University of Manchester
Penny Harris, John Carroll University

Editorial Board [2002-2011]
Charlotte L Clarke, Edinburgh University
Jaber F Gubrium, University of Missouri
Ingalill Hallberg, Lund University
Bère Miesen, Psychogeriatric Center
Stephen Post, Case Western University
Margaret Shapiro, University of Queensland
Linda Teri, University of Washington
Peter Whitehouse, University of Cleveland

Associate Editors
Over 30 from 10 different countries, including people with dementia

First Edition: Feb 2002; now on Volume 11
HEARING THE VOICE OF PEOPLE WITH DEMENTIA-REVISITED

Presentation split into 4 areas:

- Summary of our Work in Manchester
- Hearing the Voice: Some Research and Practice Examples
- Future Directions
- Questions and Answers
Summary of Our Work in Manchester
MH Division research organisation

- Complex Interventions & Service Reconfiguration in Mental Health
  Prof Karina Lovell

- Mental Health Professional Workforce Issues
  Prof John Playle

- Dementia and Ageing
  Prof John Keady
Dementia and Ageing Research Theme

Clusters

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

Transcending themes

• Family-centred practice
• Transitions
• Neighbourhoods
DART Group

Started September 2007

- Current membership: John Keady; Andrew Hunter; Caroline Swarbrick; Christine Brown Wilson; Dawn Edge; Emma Ferguson-Coleman; Graham Stokes; Helen Barnes; Helen Pusey; Jacqueline Kindell; Jill Pendleton; Julie Gregory; Katie Paddock; Lesley Jones; Malcolm Carey; Marina Adra; May Yeok Koo; Moira Attree; Penny Bee; Richard Ward; Rosanne Cawley; Ruth Elvish; Sarah Campbell; Sean Page; Simon Burrow; Siobhan Reilly; Xia Li

- Admin Support: Rosie Perry
Recent accepted Publication (Journal of Clinical Nursing)

Development of the bio psycho social physical model of dementia

Involves: Lesley Jones, Ingrid Hellström; Richard Ward; Susan Koch; Caroline Swarbrick; Vivienne Davies-Quarrell, John Keady

PHYSICAL DOMAIN

- **Physical Wellbeing** – prevention issues and health promotion/education
- **Physical Health and Examination** – assessment, observing, maintaining health e.g. diabetes, mixed presentations.
- **Physical Care** – personal care, diet, fluids, toilet needs, skin care, nail care, hair care, bowel needs, own clothes,
- **Physical Treatment** – use of medications; multiple co-morbidities; ethical parameters
- **Physical Environment**; own home to acute care to care home; signage; personalised; recognisable
Coping with Assessment

In 1383 Emma de Beston formally of Cambridge was assessed for idiocy by asking her:

- In what town she was
- How many husbands she had had
- How many days there were in a week
- How many shillings there were in 40 pence
- If she would rather have 20 silver groats than 40 pence

Reference
Dementia: Different Perspectives

Medical Model

Social Model

Lay Understanding and Experience
Displaced Meanings

First Research Interview: 1992

‘Alzheimer’s disease you say? I’ve never heard of that. I just look after my husband you see’

and

‘wandering behaviour’ = ‘his get up and go’
Awareness and Time

People can cope with this disease. But you need time.

(Sterin, 2002 p.9)

Reference:
Early signs of (undiagnosed) Alzheimer’s

- Problem-solving difficulties
- Being unable to concentrate for prolonged periods
- Thought Block
- Inability to quickly recall names
- Losing track of conversations
- Feeling disassociated from reality
- Becoming sad and depressed
- Feeling unduly angry
- Tearfulness
- Feeling and becoming lost in familiar surroundings
Early signs of (undiagnosed) Alzheimer’s

- Not being able to fully co-ordinate and control speech and actions
- Writing block
- Heightened sense of taste and smell

NB: This list is not intended to represent fully all reported first signs. Some people reported an initial experience of a combination of such signs.

John: 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:
Main concerns of caller

<table>
<thead>
<tr>
<th>Main Concerns</th>
<th>Frequency (absolute)</th>
</tr>
</thead>
<tbody>
<tr>
<td>What help is currently available to me?</td>
<td>13</td>
</tr>
<tr>
<td>Problems being experienced with my memory</td>
<td>12</td>
</tr>
<tr>
<td>What will happen to me in the future?</td>
<td>11</td>
</tr>
<tr>
<td>Not being a burden to my family</td>
<td>9</td>
</tr>
<tr>
<td>That proper medical investigations have been undertaken</td>
<td>7</td>
</tr>
<tr>
<td>Being a younger person with dementia</td>
<td>7</td>
</tr>
<tr>
<td>The possible cause of the memory loss</td>
<td>6</td>
</tr>
<tr>
<td>Genetic link</td>
<td>6</td>
</tr>
<tr>
<td>Having difficulty holding conversations</td>
<td>5</td>
</tr>
<tr>
<td>GP not taken my concerns seriously enough</td>
<td>5</td>
</tr>
<tr>
<td>Who will take care of my family when I can no longer do so?</td>
<td>5</td>
</tr>
<tr>
<td>Diagnostic testing procedures</td>
<td>4</td>
</tr>
</tbody>
</table>

Reference:

“From the person with dementia’s point of view, it can be quite demoralising finding that one is unable to remember three simple words, spell a word forwards or backwards, or remember the day, month and year. It is important for those administrating the test to understand how the person with dementia may be feeling.”

Reference
WHAT IS THE MEANING OF EVIDENCE?
Experiencing Dementia: A Socially Constructed Model

Identifying and Changing the Narrative
Developing the Narrative: Working Alone

‘Caring Taboos’

One male carer’s experience:

“I hate doing that for her. I know it’s only once a month but I find it embarrassing just buying those things never mind having to find out how to use them. I deal with it by bathing her every day until it’s over. At least I know she is clean then and I can put them on (her) the best I can”

Male spouse carer aged 54 years

Reference

Developing the Narrative: Working Together

Example:

I feel fine the way I am now, we enjoy life, we go out and my grandchildren they come to see me. I don’t want to know what the future holds......we take it one day at a time.
Centre Stage Diagrams

Acknowledgements to Dr Sion Williams, Bangor University

And all our PhD students ...
Development of Research

- Objectivist vs. Subjectivist debates
- Biographical and narrative research methods

‘Constructivist grounded theory’ that addressed the:

‘mutual creation of knowledge by the viewer and viewed {that} aims towards interpretive understanding of subject’s meaning’

(Charmaz, 2000 p.510)

Reference
Sarah’s chapter headings

The development of Sarah’s Life Story Script resulted in:

- **Chapter 1** – An introduction to my life
- **Chapter 2** – Childhood
- **Chapter 3** – Teenage years
- **Chapter 4** – Working life
- **Chapter 5** – Married life
- **Chapter 6** – Life after the death of my husband
- **Chapter 7** – Megan and the fellowship
- **Chapter 8** – Current life with Laura
Working with Sarah

- Developing a Life Story Script and Personal Theory involved 19 researcher-practitioner visits;
- The first 7 visits were with Sarah and Laura; all subsequent visits were with Sarah alone;
- Of the 19 research contacts, two became clinical visits.
Sarah’s diagrams

- Visually, Sarah saw her experience as a ‘see-saw’

- Movement and momentum are constantly changing and stability goes ‘up and down’

- Three diagrams were eventually co-constructed as an agreed representation of her life.
My diagnosis

Making mistakes but living with them
Laughing at what I do or say
Knowing my limits
Telling people my diagnosis
Living each day as it comes
Fighting and getting through it
Having my home
Taking my dog out
Trips to Llandudno

Diagram 3 – Sarah: Keeping Balance

Losing balance
Making mistakes
I have changed as a person

Finding balance

Keeping balance
Making mistakes but living with them
Laughing at what I do or say
Knowing my limits
Telling people my diagnosis
Living each day as it comes
Fighting and getting through it
Having my home
Taking my dog out
Trips to Llandudno
Sarah: Practice implications

- Working from Sarah’s knowledge, words and understanding of her condition
- Substituting making mistakes for dementia in dialogue
- Keeping the life story script as a living document and rehearsing new lines when recall becomes uncertain/altered
- Providing supportive counselling for an abusive marriage
- Valuing person knowledge
- Changing practice through new working procedures
Practice Change: Reconstructing Memory Work

- Carry out assessments in the home to introduce the concept of ‘testing’ in a less formal way and reduce performance anxiety.
- Control over sharing of the diagnosis is given to the client/family, where appropriate, they can choose who shares the diagnosis with them i.e. doctor, nurse, occupational therapist. The person can also choose the location of this procedure i.e. their own home.
- Facilitate an understanding that memory clinic involves a full psychosocial service, as well as offering medication.
- Joint assessments
- Less reliance on the use of objective measures of ‘assessment testing’

Reference
**Reference:**

NEIGHBOURHOOD WORK
Neighbourhood Review Structure

- Included studies:
- 18
- [14 articles; 2 books; 2 reports]
Neighbourhood Review Findings

Findings from our review were themed under three headings

1. Outdoor Spaces [defined as ‘life outside the front door and the practicalities of getting out and about in the neighbourhood’];

2. Built Environment [defined as ‘dementia-friendly environments and how the environment can enable, or disable, people with dementia’]; and

3. Everyday Technologies: [defined as ‘how people with dementia interact/access technology outside the home and/or in preparing to leave the home to engage with the outside world’].
Neighbourhood Review

We did not identify any studies that took account of the socio-economic profile of different neighbourhoods and their implications for living with dementia, or that addressed the diversity of the population with dementia and consequently how culture and identity might further shape the meaning and experience of local places and spaces.
Salford development: Open Doors support network

VALUES AND VISION

- The OPEN DOORS Support Network “opens doors” for people with dementia and carers to radically and innovatively support the delivery and development of dementia services within Salford [Mike Howorth]

- OPEN DOORS has been developed by the initial collaboration from representatives from The Salford Memory Assessment and Treatment Service, Reach Beyond, Day Hospital and inpatient dementia services at Woodlands and the University of Manchester, with funding supported by Salford PCT and the University of Manchester
Optimal care

Optimal care depends upon the family and professional caregivers communicating well. If they are to communicate well they must operate with the same concepts and use a common vocabulary.

Reference

Some recent publications


Thank You