

Rethinking Dementia – ABSTRACTS

1. Deaf people with dementia and their carers: communicating experiences, attitudes and service provision.

Deaf people who use BSL (British Sign Language) are a distinct linguistic and cultural minority. Their experiences of dementia and their information and support needs have not been studied from within a shared cultural experience. This groundbreaking study has involved Deaf people with dementia in exploring their experiences of living with dementia both in their own (Deaf) community and the wider 'hearing' world. A Deaf researcher, with a shared cultural linguistic identity, has worked alongside Deaf people with dementia and Deaf and hearing carers, travelling through their stories, observing how their caring and cared-for relationships are constructed and learning what it means to be Deaf and to have dementia. BSL is an entirely visual language. The community is a small but tightly knit one on a national not a local scale. What differences do these features of everyday life make to the early recognition of dementia? This study is already impacting on the implementation of policy and service improvement through contributions to the guidelines for the implementation of the National Dementia Strategy in England, a dementia pledge case study, and a specialist contribution to the SCIE dementia gateway.

2. Early Dementia User's Co-operative Aiming To Educate (EDUCATE)

The EDUCATE project aims to enable volunteers in the early phase of dementia to bring their skills and experience to raise awareness for dementia in Stockport and to educate others about their experience. EDUCATErs are powerful in changing attitudes, raising awareness, changing perceptions and reducing the prejudice and stigma associated with dementia, thereby improving dementia care services.

With the help of people with dementia and their carers, EDUCATE:

- Develops and participates in information, education, awareness and training in the field of dementia care.
- Is a voice of and for people with dementia locally
- Positively influences policies and promotes improved services in Stockport

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3. What happens to people with dementia identified in general hospital?

Two thirds of general hospital beds are used by older people, many of them people with dementia, and half of all people admitted to nursing and residential homes come from

general hospitals. Yet little is known about the transition from hospital to a care home and decisions, often permanent, may be made quickly, under pressure, and without the involvement of the person with dementia. 'What happens to people with dementia identified in general hospital?' was a research project funded by the Alzheimer's Society during 2008-2011: a collaboration between Warwick University, Surrey University and The Open University. Researchers identified people with dementia on general wards in two hospitals and conducted face-to-face interviews as well as assessments of quality of life, mood, carer stress and costs of care, which were repeated at 6 months and 12 months after discharge. Where people were expected to be moving to a care home, prospective and retrospective interviews about the transition were conducted. This presentation, drawing on 15 cases, concentrates on this aspect of the project, looking at attitudes to and expectations of life in a care home before and after the move, and at the process of decision-making about timing and choice.

4. *"Getting to know me"*: Enhancing skills in the care of people with dementia in general hospitals

Recent guidelines suggest that the care of people with dementia in general hospital settings should be improved. The aims of the current project are: i) to design and develop a dementia care training programme to be used within general hospitals; ii) to evaluate the impact of the training programme; and iii) to design scales with good psychometric properties to measure knowledge in dementia and confidence in working with people with dementia.

The development of the training programme has involved the design of a range of materials for staff and patients, including a short DVD to be used for teaching purposes. The development and filming of the DVD has been undertaken with people with dementia and a carer. Today's lunchtime session will provide an opportunity to watch the DVD, and members of the project team will be available to discuss any questions or queries about the ongoing work.

5. *'And the men opened the boot of a very very ancient car...'*: Second stories, memory and identity in conversations involving dementia.

Drawing on a single case of a story-telling taken from a conversation recorded in a nursing home setting, this paper will consider how identity and memory are co-constructed through social interaction. The data illustrate how, despite the challenges of dementia, everyday conversational routines and story-telling repertoires can enable a person's life to recover meaning, for themselves and for others. This small-scale research study employs an interdisciplinary approach to understanding dementia in a person's everyday life, drawing on ethnography and conversation analysis. The data and analyses provide observations on the place and function of narrative in everyday

lives, the impact of dementia on conversational routines, and the influence of home versus institutional environments on opportunities for conversation. Combined analysis of the conversation recordings and ethnographic observations poses questions for research such as: What is the role of narrative in understanding dementia? What can conversations involving dementia tell us about how narrative operates in everyday conversation in general? What part is played by imagery, rhyme and rhythm in evoking memory? And is this a study of dementia, or a study of a person's life into which dementia began to creep?

6. *"It just looks like a field to anybody else"*: Interdisciplinary perspectives on the role of the neighbourhood for people affected by dementia

Declarations about the assumed importance of community encapsulated by the ongoing persistence of slogans encouraging us to 'think and act locally' raise important questions about the role of localised networks, relationships and places in the lives of those affected by dementia. In this paper we present findings from an interdisciplinary research project exploring the meaning of neighbourhood for carers of people with dementia. Drawing on insight from sociology, social work, geography and architecture, we consider the ways in which neighbourhoods can be considered physical, social, and memorialised manifestations of past, present and anticipated support. Analysis of data gathered through a creative blend of participative research methods, including network mapping, mobility diaries, and walking interviews, demonstrates some of the ways in which the intersection of personal, social and built forms of the neighbourhood afford a collective capacity to support in ways that we may only just be beginning to understand.

7. Sharing memories: Couplehood and joint identity

Besides briefly presenting CEDER we would like to talk our work on couples and dementia. When faced with dementia couples together attempt to sustain their relationship, something that often entail re-defining and re-negotiating the meaning and substance of the relationship. It is also evident that in facing the dementia and its consequences, the spouses use their relationship in order to cope with the problems that follows from the disease and that affects both of them. One example is the way a married couple organized their interaction in order to be able to tell a joint story about their shared life. Not being able to tell stories and cherish the common history is a potential threat both to the experience of belonging together (the couplehood and we-ness) and to the participants' individual identities and their past. Most spouses and family members try to remediate the communicative problems caused by the progressing AD by taking over some of the functions lost by the person with AD.