

Dementia Project News

Findings Summary 3

October 2012

Dementia Talking Project Update



UNIVERSITY OF
BIRMINGHAM

Welcome to the third Dementia Project newsletter. In this issue we focus on the Dementia Talking Project, funded by the British Academy, which asked the following questions:

- How is dementia represented in society?
- How are people with dementia communicated with and about?
- How can the communication strategies of people with dementia and their carers be understood, improved and facilitated?
- In what ways can communication through everyday conversation improve the care of people with dementia?

We have now finished collecting the data for this project and we have started to analyse it and write up the findings. We were thrilled to collect much more data than we originally planned. Dr Elizabeth Peel collected 45 hours of video recordings of communication between people living with dementia and those caring for them. Heartfelt thanks to the three families who participated, those living and working in the specialist dementia care home where recording took place over the summer, and the patients and staff at the memory clinic where appointments were recorded earlier this year. Without your involvement and support we wouldn't have been able to collect all this valuable information about how communication in dementia care happens in real life. Dr Peel also interviewed 12 carers asking them about their views about communication in dementia care, and many thanks too to those carers who agreed to be interviewed.

To date Dr Peel has given talks based on the dementia care home conversations at the Arts and Humanities Research Council (AHRC) funded *Resourcing Care Workshop* at Keele University in September and the Centre for Research in Sociology and Policy Studies at Aston University in October. Next month she is presenting '*Good to see me as well': person-centred dementia care in interaction*' at the Department of Sociology at the University of York.

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Hot Off the Press



Medical Law
Review article
just published

Dr Peel has
raised over
£2000 running
for dementia
charities

The Inter-
national
Institute
for the
Sociology
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Our first journal article from the dementia projects was published this month! The article is called **"He was like a zombie": Off-label prescription of antipsychotic drugs in dementia**, and was published in the *Medical Law Review*. You can read the abstract here: <http://medlaw.oxfordjournals.org/content/early/2012/10/08/medlaw.fws029.abstract>.

If you'd like a copy of the article please let us know (our contact information is on the back page of this newsletter) and we'd be delighted to send it to you. In brief, in this article we provide a legal argument for the closer regulation of the drugs that are given to people with dementia who experience behavioural and psychological symptoms. Most antipsychotic medications are not licensed to treat people with dementia and are prescribed 'off-label'. Drawing on our data from the dementia projects we argue that the practice of off-label prescribing needs to be regulated in order to protect vulnerable patients.

Other News



In the last newsletter we mentioned Dr Peel's forthcoming half marathon in May 2012 to raise £500 for Dementia UK. Liz smashed her target and raised £1,178 (including gift aid). The Hinckley Half Marathon course was very hilly, but the weather was good and she managed to shave a whole 14 minutes off her previous best time. This effort has taken her fundraising total for dementia charities to over £2000.

Since the last newsletter, Dr Harding has moved to take up a new post at the University of Birmingham.

Invitation to Workshop in Spain

Dr Rosie Harding has been invited to present findings from the Duties to Care dementia project at a prestigious workshop at the International Institute for the Sociology of Law, Oñati, Spain in April 2013. The workshop, entitled 'Wealth, Families and Death: Socio-Legal Perspectives on Wills and Inheritance' will bring together leading scholars from across the world to discuss socio-legal understandings of wills and inheritance. Dr Harding will be presenting findings from the Duties to Care project about carers experiences of managing the financial arrangements of people living with dementia who have lost capacity to make decisions about their own finances, and experiences of acting as attorneys and deputies under the Mental Capacity Act 2005.

Communicating our Findings

We currently have two journal articles being considered for publication in leading journals in the area. This first one is called: **"It's a huge maze, the system, it's a terrible maze": Dementia carers' constructions of navigating health and social care services.** As we know, a complicated range of health and social care services are needed to support people living with dementia. In this article we focus on carers' talk about health and social care services. We found that navigating 'the system' and accessing appropriate care and support for the person living with dementia was typically presented as a considerable challenge. Dementia services were described as a 'maze', and carers deployed battle and fighting talk in their accounts. This article highlights that carers find accessing and navigating dementia care services and support time-consuming, unpredictable and often more difficult than the caring work they undertake. Dr Peel presented this work at the *BPS Division of Health Psychology Conference*, which was held in Liverpool in September, and the *2nd Global Congress for Qualitative Health Research* which was held in Milan in June.

The second journal article is called: **'The Living Death of Alzheimer's' versus 'Take a Walk to Keep Dementia at Bay': Representation of dementia in print media and carer discourse.** Dr Peel takes the title from newspaper headlines published in *The Daily Mail* in April 2011 and *The Express* in October 2010. In this article she analyses 350 recent British national newspaper articles about dementia and what carers say about the public perception of dementia. The analysis shows that there has been a recent growth in the amount of media coverage that focuses on everyday health and lifestyle changes people can make to 'stave off' dementia. She argues that this emphasis on individual responsibility for getting (or not getting) dementia in later life is problematic for carers and for society as a whole. Dr Peel presented this work at the *British Society of Gerontology Conference* which was held in July at Keele University.

"there has been growth in media coverage about lifestyle changes to prevent dementia"

Next Steps

Dr Peel and Dr Harding are currently seeking to take forward their work on dementia through a range of different avenues. We have submitted an application for a large scale project involving researchers from the Universities of Aston, Birmingham, Loughborough and Keele to the ESRC/NIHR Dementia Initiative. The Government announced in July that it was going to allocate £13 million pounds to fund social science research about dementia and our five year project is being considered as part of that funding initiative. We have a number of public and private sector partners involved in this bid as well as charitable organisations. If you would like to know more about the project, or would like to get involved do get in touch with us. We will find out whether we have been successful in getting through to the next stage in December 2012.

Dr Harding is also taking forward work in this area through her AHRC funded 'ReValuing Care' Research Network. See www.revaluingcare.net for more information.



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About the Dementia Projects



**BRITISH
ACADEMY**
THE UK'S NATIONAL ACADEMY FOR
THE HUMANITIES AND SOCIAL SCIENCES

The Dementia Projects were supported by the British Academy

Dr Elizabeth Peel is Principal Investigator for the 'Dementia Talking' project. It was funded by the British Academy (Mid Career Fellowship MC110142), from September 2011 to August 2012.

Dr Rosie Harding is Principal Investigator for the 'Duties to Care' project. It was also funded by the British Academy (Small Grant SG1000017), and ran from October 2010 to February 2012.

The research has been carried out by Dr Elizabeth Peel (Psychology, Aston University), alongside Dr Rosie Harding (Law, University of Birmingham), with research assistance from Susan Westwood (Keele University) and Bradley Crook (Dudley & Walsall MHPT).

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