

## When Hollywood touches on our research

*by Klara Lorenz*

The Personal Social Services Research Unit at LSE (**PSSRU**) recently contributed to the LSE Literary Festival with a discussion on '**Perception of Madness: understanding mental illness through art, literature and drama**'. Dr Sarah Carr, Paul Farmer, Nathan Filer and Dr John McGowan provided interesting perspectives on the different, but changing nature of illustrating mental illness in movies and stories. They discussed opportunities to improve the general understanding of complex mental health conditions as well as the contribution to counter stigma.

A few weeks ago a movie touching on another important area of PSSRU's research entered British cinemas. With '**Still Alice**' an important societal issue has reached Hollywood. The story of the successful linguistic professor who has to learn to live with early onset Alzheimer's has received international attention, great critiques and earned Julianne Moore an Academy Award.

The story of Alice and her family having to face cognitive deterioration, the change in personality of the person with dementia and the increasing need for care and supervision is a story that an estimated **850,000** people with dementia and their families across the United Kingdom could also tell.

While the movie makes an important and careful contribution to a better understanding of dementia and the need for care and support for people with dementia – all aspects PSSRU has worked extensively on – I would like to highlight another aspect.

Throughout the movie Alice has been supported by her husband and children. However, only in a couple of scenes the role of relatives, the unpaid carers, really came across. There were few moments when Alice's partner has to get up at night to stop her from wandering, when he worries about her safe return and when the question arises of who will provide care to her when she becomes more and more dependent. It is estimated that in the UK **670,000** people provide this kind of care and support. For many carers these are everyday situations.

While unpaid carers are not the focus of this movie, they are an important part of our work and the main focus of my PhD. A **recent study** has shown that unpaid carers contribute 44.1% to the societal cost of dementia. The provision of unpaid care to people with dementia by their partners, children, grandchildren and friends amounts to an estimated **£11.6 billion of the total costs of dementia** (£26.3 billion). If family members were not prepared and in the position to look after their relatives, societal costs of dementia would increase significantly.

When the costs of unpaid care are estimated, the hours people spend providing care to their relatives are summed up and receive a monetary value. But research has found that people providing unpaid care also incur other costs. Many people providing care to (for example) a frail elderly relative carry large responsibilities, which can have an impact on the physical and mental health of carers. Research has found that carers have higher levels of psychological stress and experience anxiety, depression and psychiatric illness more frequently than non-carers (see **Arksey and Hirst, 2005, Bristow et al. 2008**).

In the movie Alice's husband and youngest daughter take on the responsibility of providing care. Alice represents a person with early onset dementia. While this is an important group of dementia patients, the majority of people experience the onset of dementia at an older age. This also means that the carers, both the partner and children, in most cases are older.



Across society the main care contributors at working age are women – wives, daughters, and daughter-in-laws. This can have important implications on their ability to remain in formal employment and therefore can affect the financial situation of the family and future pensions. It is also **known** that on many occasions the provision of care is taken on by a member of the family who has the lowest income or has been out of the formal labour market even before care was required. Policies have been put in place to support these people and with the **Care Act** every carer is entitled to assessment for support; however, more needs to be done.

The other important carer group are people who have reached retirement age, mostly providing care and support to their partners. In this carer group men become increasingly important. Due to increasing male longevity more couples are in the position to grow old together and to provide care for each other. As the chances of experiencing health problems increase with age many older carers may themselves be in need for support.

With the **MODEM project** and my PhD, within PSSRU, we aim to make a contribution to better understand what it means to live with dementia, whether there are specific characteristics of people developing dementia and what the needs of these people and their families are. We are also investigating whether there are possibilities to prevent or delay the onset of dementia, how the person with dementia and their carers can be best and most effectively supported and what the costs of illness are. Finally we aim to provide projections of how these issues are likely to develop for England over the next 25 years. With my PhD over the next couple of years, I aim to contribute to the knowledge on the needs and costs of unpaid carers aged 65 and above providing unpaid care to people with dementia.

### About the author

Klara Lorenz is a PhD student within the Personal Social Services Research Unit at the LSE working on the supply of informal care and the needs of carers over the next 25 years attached to the MODEM project.

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