



PhD Studentship

Exploring stigma and prejudice towards people living with dementia in Extra Care Housing

Closing date: 31st Oct 2022

Interview date: 15th/16th Nov 2022

Supervisory team

Director of Studies:

[Dr Julie Barrett, Association for Dementia Studies, School of Allied Health and Community, University of Worcester](#)

Supervisors:

New Prof/Director of Association for dementia studies or Senior / Principal Research Fellow

[Dr Vanessa Pritchard-Wilkes, Head of Strategic Influence and Strategic Lead on Dementia and Wellbeing, Housing 21.](#)

[Research Group: Association for Dementia Studies](#)

Collaborating organisations: Housing 21

<https://www.housing21.org.uk/>

<https://www.housing21.org.uk/about-us/our-work-with-dementia/>

The Project

Applications are invited for a fully-funded, full-time PhD studentship for the project: Exploring stigma and prejudice towards people living with dementia in Extra Care Housing.

This PhD Studentship will explore experiences of stigma in relation to Extra Care Housing residents who are living with dementia and identifies the challenges and successes experienced by housing providers in addressing these issues.

Context

Dementia related stigma

The term stigma was first used in social sciences (Goffman 2005), defining it as the relationship between a particular trait and social stereotypes. For the individual stigma has been linked with low self-esteem, feelings of shame, a sense of dehumanisation and experiences of social isolation (Urbanska et al. 2015). The current lack of a cure, poor effectiveness of treatments that aim to reduce symptoms and growing public awareness of the disease and its effects, has resulted in considerable fears of getting dementia, which, in turn has led to a high-level stigma being associated with dementia (Corner and Bond 2004). There is now a widespread recognition of an urgent need to reduce the stigma and negative attitudes associated with dementia (Batsch and Mittelman 2013; Jolley and Benbow 2000).

A meta-analysis literature review conducted by Werner (2014) found strong evidence of stigma in relation to people living with dementia, the most common negative emotions being shame, humiliation and disgust. Stigma is perceived as ubiquitous and results in negative consequences for the individual (leading to low self-esteem, shame, humiliation, and social isolation), families (leading to depression, increased burden, concealment, feelings of moral failure and decreased use of services), professionals (leading to differential or delayed diagnosis or treatment) and society (differential access and use of services and increased institutionalisation) (Evans, 2018). In the UK, dementia related stigma and discrimination is often perpetuated by the media (Evans, 2018). The language used in association with dementia in the media often portrays it as disastrous (Peel, 2014). Peel (2014) examined 350 national newspapers and found numerous examples of negative headlines about dementia, containing words such as 'epidemic', 'Tsunami', 'a bomb ready to explode', 'terrible affliction' 'brain wasting' and 'worse than death'. Television news channels continue to use the outdated phrase "suffering from dementia". In recent years, in recognition of the rapid growth in the number of people living with dementia and the associated personal, social and economic costs, many governments across the world have developed national strategies to improve diagnosis, treatment and support. Most of these strategies include dementia awareness campaigns, in recognition of the fact that dementia related stigma that can prevent people from seeking a diagnosis and therefore the opportunity to access appropriate care and support (Evans, 2018).

Dementia related stigma in Extra Care Housing

Although there is a growing body of research evidence that demonstrates the potential of Extra Care Housing (ECH) to promote quality of life and wellbeing for older people (Atkinson et al. 2014), there is some evidence to suggest that, despite a common aspiration to provide a 'home for life', ECH often struggles to support residents with dementia and the reality is that many move to residential care when they experience significant problems (Brooker et al, 2009; Twyford, 2016). It is well established that social isolation can have a negative impact on quality of life for all people, and in particular those living with dementia (Cohen-Mansfield & Wirtz, 2007). Studies have identified stigma and prejudice as possible barriers to social interaction for residents living with dementia, which would further impact their quality of life (Evans et al., 2007). The Housing and Dementia Research Consortium (HDRC) undertook a series of case studies in 2012 to assess the provision of care for residents living with dementia in ECH schemes (Barrett, 2012). It was found that residents in the integrated model schemes displayed a negative attitude and prejudice against those residents with dementia and this was the main challenge for management and staff.

In 2015 the HDRC conducted a workshop with HDRC members, including housing providers and commissioners, academics, architects and consultants, to explore the advantages and disadvantages of different models of ECH for people living with dementia (Barrett, 2015). There were three findings from the workshop with relevance to stigmatisation: integrated schemes may perpetuate friction between residents with and without dementia and resentment towards residents with dementia; the 'dementia wing' in separated schemes may create a focal point for

dementia stigmatisation, a “dementia ghetto” as it were; stigmatisation of the whole scheme may occur for dementia specialist schemes within the local outside community.

In an HDRC study exploring the views of people living with dementia in ECH and their family carers (Barrett et al., 2016), the focus group participants felt that an integrated model facilitates social interaction and reduces resentment and stigmatisation towards residents living with dementia. It is clear that more rigorous research is needed to understand the causes and aggravators of this stigmatisation of and prejudice towards ECH residents living with dementia.

In recent years some providers of housing for older people have developed strategies for becoming dementia friendly organisations and have put in place initiatives to challenge stigma and increase awareness (e.g. The Guinness Partnership, 2015; Housing 21, 2020). A recent survey of ECH settings conducted by the HDRC to explore the provisions, policies and procedures relating to people living with dementia in Extra Care Housing within the UK found that other residents do occasionally display negative reactions towards the residents living with dementia. By far the most common response to this negative attitude was to provide education / awareness training, usually in the form of ‘Dementia Friends’ sessions (Barrett, 2021). The majority of respondents felt that they had been successful in reducing negative attitudes although there is no independent empirical evidence concerning the effectiveness of such measures. According to the recent APPG inquiry report on housing for people with dementia, “Living well with dementia in extra care housing relies on good design and effective management of the environment, including tackling stigma and addressing prejudice among residents who don’t have dementia” (Twyford and Porteus, 2021). However, although the report recommends that providers of housing for older people “Ensure that those providing care and support for people living with dementia sign up to be dementia ‘friends’”, it does not make any recommendations for residents not living with dementia. The proposed study will address the evidence gaps and determine successful approaches to tackling the stigma issue in ECH.

Aims and research questions

The aims of this project are to explore and understand stigma in relation to people living with dementia in ECH and determine the causes and aggravators. Also, to identify the challenges and successes experienced by housing providers in addressing the negative attitudes and prejudices of other residents towards residents living with dementia.

Research questions:

- What types of stigma are associated with dementia within ECH and what are the causal factors?
- What are the negative connotations, attitudes and emotions associated with dementia among other ECH residents?
- What are the impacts and consequences of stigma, prejudice and discrimination on residents living with dementia and their families?
- What challenges do housing providers experience in relation to these negative attitudes and what are the most successful approaches in addressing them?

Indicative Methodology

The successful PhD candidate will be responsible for formulating the detail of this proposal. However, it is anticipated that the study will adopt a mixed methods approach. A survey of ECH schemes could be used to determine if a problem with prejudice and discrimination towards people living with dementia exists and the strategies used to address the problem. Case studies involving interviews with residents, both with and without dementia, and staff could provide a more in depth understanding of the issue, the impacts, challenges and successes. Study outputs could include a guide to best practice in addressing stigma among ECH care housing residents towards residents living with dementia

Potential academic significance and impact of research

The Association for Dementia Studies is one of the leading centres for research into extra care housing in the UK. Stigma and prejudice has been highlighted in our work as a significant barrier to quality of life for people living with dementia. This research will therefore build on our substantial portfolio of work in this setting and will contribute towards our ongoing expertise and academic reputation.

The findings of this research have the potential to have a significant impact for people living with dementia and those who care for them. Key themes will be disseminated through our collaborator, Housing 21, one of the largest providers of extra care housing and retirement housing in the UK. We will also communicate key messages to a range of providers, policy makers and commissioners through our existing networks including the Housing and Dementia Research Consortium, the Dementia and Housing Working Group, and the Housing Learning and Improvement Network.

References

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Details of the studentship

The studentship is offered for a 4-year period on a full-time basis. The studentship is campus based. During the period of your studentship you will receive the following:

- a tax-free bursary of £15,609 for 3 years
- a fee-waiver for 4 years (expectation that full time students complete in 3 years. If student enters year 4, bursary stops but fees waived)
- a budget to support your direct project costs including dissemination costs
- a laptop and other IT equipment and software as appropriate to the project
- use of the Research School facilities
- collaborating organisation will provide support and guidance for the PHD student within the Extra Care Housing setting, including access to training and understanding of ECH and access to participants across multiple locations.

You will be expected to play an active role in the life of both the Research School and of your academic School. You will be given opportunities to gain experience in learning and teaching within the School under the guidance of your Director of Studies.

Application Process

To begin the application process for this studentship please go to <http://www.worcester.ac.uk/researchstudentships> and click 'apply now' next to the project you wish to apply for.

It is expected that applicants will have the following qualifications:

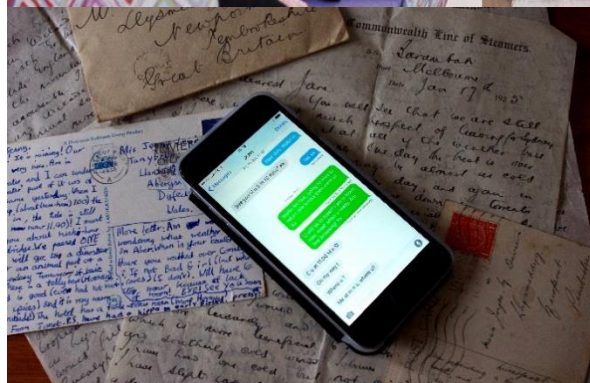
- Education to Masters Degree level in a relevant area.
- A First or Upper Second Honours Degree

It is also expected that applicants will be able to demonstrate the following:

- A sound understanding of, and interest in Person-Centred Dementia Care Research
- Experience of relevant social research methods and skills
- Ability to contribute to the research design of the project
- Proficiency in oral and written English
- Proficiency in IT relevant to the project, e.g. Microsoft Word, Excel, etc.
- Self-motivation, ability to organise and meet deadlines
- Good interpersonal skills
- Ability to work independently
- Ability to work as part of a team
- Commitment and an enthusiastic approach to completing a higher research degree.

The Interview

The interview will provisionally be held on 15th/16th Nov 2022 via Microsoft Teams. Shortlisted candidates will be given at least 7 day's-notice of interview. As part of the interview and selection process, shortlisted candidates will be asked to write a short



reflective review of a relevant journal article or book chapter. Alongside the interview, shortlisted candidates will also be asked to give a 10 minute presentation on a related topic.



Research at the University of Worcester

Research at the University of Worcester has grown significantly over the last 10 years. The outcomes of the Research Excellence Framework 2014 (REF 2014) showed that Worcester was the most improved University in the UK based on Research Fortnight's "Research Power" measure. The University's continued progress was shown in the outcomes of REF 2021 which demonstrated that both the scale and quality of our research has further increased, with over 40% of our research recognised as world-leading or internationally excellent.

The University has been successful in winning funding from a wide range of major funders: Research Councils such as AHRC, BBSRC, ESRC and NERC; major charities such as the Leverhulme Trust, the Alzheimer's Society and the British Academy; health-research funders such as the NIHR, the Department of Health and local NHS Trusts; European funding through Horizon 2020 and Erasmus+; and funding from local, national and global businesses.

The University is focused on research which addresses real world challenges and provides solutions to these challenges:

- [Human Health and Wellbeing](#)
- [Sustainable Futures](#)
- [Digital Innovation](#)
- [Culture, Identity and Social Exclusion](#)
- [Professional Education](#)

The University continues to provide a robust infrastructure for research. It has a well-established Research School which houses its growing research student body and which provides a comprehensive programme of researcher development for staff and students. It has a well-established Research Office, responsible for research funding, governance and strategy. The University is committed to further developing its research profile, through a strategic approach to its support for and investment in research. Its fully-funded studentships are part of this investment.

Research School

The Research School is a focal point for all our research students. It provides:

- day-to-day support for our students, both administrative and practical, through our dedicated team
- a Research Student Study Space with both PCs and laptop docking station

- a comprehensive Researcher Development Programme for students and their supervisors
- a programme of student-led conferences and seminars

School of Allied Health and Community

Allied Health and Community at Worcester encompasses subject areas including Physiotherapy, Occupational Therapy, Paramedic Science, Advancing Clinical Practice, Health and Social Care, Mental Health, Nutritional Therapy, Public Health, Palliative Care, Physician Associate training, Social Work and Youth and Community Studies.

We pride ourselves on our teaching excellence, applied research and practice development. We work closely with our local community and with partners across a wide range of sectors to enhance the student experience and to provide students with an invaluable insight into professional practice.

Furthering understanding of all areas of health and society is a key objective of the School and we conduct research of international importance that helps to shape our lives. The School hosts the internationally renowned research centre, the [Association for Dementia Studies](#).

The School's transformational research projects seek to address some of the major issues both within our professions, local services, our community and beyond it. By pulling together academics working across disciplines to tackle important, social, scientific and environmental challenges, these projects are making an impact on people's lives and helping to expand our base of world-leading research.

Widening Participation

As part of its mission statement the University is committed to widening participation for its higher degrees. Although most candidates will have an undergraduate and/or a Masters degree, the University is happy to accept applications from candidates with relevant professional qualifications and work related experience.



For further information or an informal discussion on this project, please contact Dr Julie Barrett (Director of Studies) via email at j.barrett@worc.ac.uk

Applications can be made at:

<http://www.worcester.ac.uk/researchstudentships>