

Title: Research and education to understand fire risks associated with dementia: a collaborative case study (Innovative Practice)

Abstract

This paper reports on outcomes from the evaluation of a collaborative project between a University and a Fire and Rescue Service where research and education were developed to inform understanding of fire risks associated with dementia. Project outcomes were determined using a mixed methods approach (survey, reports, statistics, case studies, course evaluation forms). Main outputs were a research report that identified dementia specific fire risks and safety strategies, and an education package for Fire and Rescue Service staff and volunteers. The evaluation demonstrates the value of collaborative partnerships to develop understanding of risks pertinent to particular vulnerable groups and research informed education.

Keywords: dementia; fire; partnership working; research informed education; risks.

Introduction

Policy in the United Kingdom advocates ageing in place. The home environment can provide support, stimulation and independence for people with dementia, as well as support for family carers (Soilemezi, Kallitsis, Drahota, Crossland, Stores & Costall, 2017a). There are also wider economic benefits to society realised through reducing the cost of state provided care (Holley-Moore & Scrutton, 2015). Maintaining independence whilst avoiding unnecessary risk is a difficult balance requiring continuous assessment (Heward & Kelly, 2015; Soilemezi et al, 2017a; Soilemezi, Drahota, Crossland & Stores, 2017b). The majority (two thirds) of the 820,000 people with dementia currently living in the UK reside in their own homes in the community, rather than in residential or long term care (Alzheimer's Society, 2015).

However, concern over home safety is the main reason for family carers deciding to place somebody with dementia into residential or long term care (Bowers, Clark, Crosby, Easterbrook, Macadam, MacDonald, Macfarlane, Maclean, Patel, Runnicles, Oshinaike & Smith, 2009). This means that early intervention to address safety risks is central to enabling people to remain living in their own homes, for as long as possible (HM Government, 2012). Fire and Rescue Services across the United Kingdom now have a statutory duty to prevent injuries and deaths from fires as defined in the Fire and Rescue Services Act 2004. National statistics reveal that since this duty has been introduced, the number of fire fatalities in the home for all age groups has declined; with the exception of those aged 60 and over (remained constant) and those aged 80 and over (slightly increased). Other research highlights risk factors of injury or death from fire in the home are: being aged 60 and over; living alone; and impairment, disability or dementia (US Fire Administration, 2006). However, the extent to which dementia increases the risk of injury or death from fire is currently unknown. There is a lack of statistics reporting the number of people with dementia who are injured or die in fires in the home in the UK; one reason being that Fire and Rescue Services do not collect this information as standard (Heward & Kelly, 2015). However, combining these risk factors with predictions of an increase in the number of people aged 60 and over and of people living with dementia, leads to an assumption that the risk of injury or death from fire in the home will continue to increase. Alongside these demographics, examples of fire risks being heightened by dementia are prevalent; including frequent stories of people with dementia putting an electric kettle onto a gas hob. However, there is a paucity of research and education that identifies potential dementia specific fire risks. Therefore, this project between a University and a Fire and Rescue Service sought to develop knowledge of fire risks and safety strategies in the homes of people with dementia, exploring these topics with professionals as well as people with dementia and carers themselves. This knowledge was then used to educate Fire and Rescue Service staff and volunteers to support people with dementia and their family carers' wellbeing and safety at home.

Project overview

The project had eight stages which were undertaken by either the University or the Fire and Rescue Service, both based in the South of England. The University carried out exploratory research (Heward & Kelly, 2015) and developed an education programme to inform understanding of fire risks associated with dementia, followed by an evaluation of outputs and impact of the project (Heward & Kelly, 2017). The Fire and Rescue Service identified assistive technology designed to reduce fire risk and developed partnerships with key local service providers in the area. In this paper, we summarise key findings from the project evaluation (Heward & Kelly, 2017), focused on the outputs and outcomes of the project to date.

Evaluation design, methods and analysis

This was a realist evaluation (Pawson & Tilley, 1997) which asks ‘what works for whom in what circumstances and in what respects, and how?’ Data were collected over an 18 month period between April 2015 and September 2016, using a mixed methods approach. Using a variety of methods allowed different types of information to be gathered about the project, allowing for a deeper understanding of the outcomes. Primary data were collected through an online survey emailed to all UK Fire and Rescue Services through Survey Monkey. The survey had a mixture of closed and open ended questions seeking to explore current provision of dementia specific fire safety advice and guidance across the UK. The response rate was 24% (n=13/54 Fire and Rescue Services). The Fire and Rescue Service also supplied the University with the following data for secondary analysis: Project Update Reports (n=5) that included information about key activities or outputs both directly and indirectly linked to this project; anonymised case studies that demonstrated how the learning from the project was implemented by the Fire and Rescue Service; statistics on accidental dwelling fires, including the numbers of injuries and fatalities; Dementia Awareness Course Evaluation Forms which were completed by staff that attended the course (n=74); follow up Dementia Awareness Course Evaluation Form completed by staff six months after taking part in the training (n=5).

Responses to surveys and course evaluation forms were added to Excel and a descriptive analysis of the frequency of responses to each question was undertaken.

Comments made in responses to open ended questions were used where appropriate to illustrate thoughts and experiences. The remaining data from the other sources was analysed thematically (Joffe & Yardley, 2004). The analysis was inductive, in that themes were allowed to emerge from the text as the analysis progressed, rather than imposing a theoretical framework to the data (Boyatzis, 1998). Data were analysed by one researcher (MH) and then discussed with the other researcher (FK) to determine final themes. Ethical approval was obtained from the University Research Ethics Committee prior to the start of data collection. Principles of informed consent, voluntary participation, the right to withdraw, confidentiality and anonymity were adhered to.

Findings

Educating Fire Service staff and volunteers about dementia

A dementia education programme was developed by the University for the Fire and Rescue Service frontline staff. The content was informed by the research undertaken by the University (Heward & Kelly, 2015), including information about types, symptoms, behaviours, and communication in dementia. The education programme was rolled out using a train the trainer model in which the University delivered a one day workshop to seven Fire and Rescue Service staff who were nominated as the Fire and Rescue Service Dementia Champions. These Fire and Rescue Service staff then rolled out the training to all frontline Fire and Rescue Service staff and volunteers (76 members of staff had completed the training when the evaluation data were analysed in 2016, with the remaining staff and volunteers expected to complete the training in future months). Feedback from Fire and Rescue Service staff that attended the course suggested that they found it informative to gain '*an awareness of how people with dementia feel*'. It was also described as relevant to their role: proving an overview of the signs '*to look for during incidents/inspections*' and when conducting '*Safe and Well Visits*'; and an awareness '*of the support mechanisms in place when encountering [people with] dementia*'.

There was an increase in staff knowledge and awareness of dementia as a result of attending this course. Learning from this course appears to be embedded amongst staff who completed evaluation forms six months after attending (despite the low response rate 6.76% or n=5/74). Staff were asked to rate a series of questions on how they felt after attending the course (using a five point scale: strongly agree, agree, neither agree or disagree, disagree or strongly disagree). All respondents stated that they felt more aware of the signs and symptoms of dementia following the course (80% (n=4) stated strongly agree and 20% (n=1) stated agree): *'...highlighted various aspects of the condition [dementia] that I wasn't aware of'* (Firefighter, follow up course evaluation). All respondents stated that they felt more confident about approaching someone with dementia following the course: *'I do feel more confident but also know my limitations'* (Firefighter, follow up course evaluation). The majority stated that they felt that they communicate differently with people with dementia as a result of attending the course; although one person stated: *'I hope I would show the same degree of understanding and respect both pre and post course'* (Firefighter, follow up course evaluation). All respondents stated that they felt that the course provided them with relevant information about dementia: *'I now know more [about dementia] due to the course'* (Firefighter, follow up course evaluation).

Supporting people with dementia to reduce risk of fire at home

The evaluation demonstrated an increase in the support offered to people with dementia by the Fire and Rescue Service, as well as the significance of creating a partnership with a local service provider. As part of this project the Fire and Rescue Service reviewed their own policies and processes to ensure they fit the needs of people with dementia. This led to the creation of a dedicated email address for staff to use if they were concerned about vulnerable members of the community who might be living with memory loss or dementia, where a safeguarding referral is inappropriate. The emails sent to the this email address would be monitored by the Fire and Rescue Service Safe and Well Team who have more time and specialist knowledge and training to be able to provide support such as fire retardant bedding

and blankets, assistive technology and signposting to other agencies. A Firefighter described the benefit of this process in reducing the risk for a lady involved in a fire incident, as well as reducing his concerns about her by knowing that she is being further supported by colleagues with specialist knowledge and time to discuss matters in detail and with family and carers if necessary:

'The incident I attended... was a high risk individual that caused me concern during the incident due to the nature of her condition and the likelihood of further incidents at this address.... I was happy to refer this individual through the recently set up Dementia email address. On return to watch after my rota days I was really pleased to have been fed back to reference what action had been taken. You had obviously received my email and asked [name of Safe and Well Advisor] to carry out a follow up visit. He emailed me on his return highlighting the fact that this individual was extremely high risk and that he had implemented control measures to aid her safety, informed the relevant personnel of his actions, booked another follow up visit and included critical information on the turn out instructions. These actions have made me feel much better about that individual, it proves that this system works very well and ultimately made a high risk member of our community safer in her own home'.
Firefighter.

At the time of the evaluation the Fire and Rescue Service were in the process of developing a range of fire prevention resources specifically for people with dementia and their carers such as leaflets, and bedtime checklists. The Fire and Rescue Service had also established a pilot partnership project with a local telecare provider. In the past the Fire and Rescue Service had noticed that referrals for assistive technology had been lengthy as the assessment was undertaken by a small team at the local council. The Fire and Rescue Service offered all of their Safe and Well Advisors (whose job it is to visit people in their homes to undertake safety checks and fit smoke detectors) to be trained to be able to refer people immediately with equipment being fitted later that day or the following day. During this pilot, there was also no cost to the individual for the equipment or ongoing maintenance as this was being funded by the telecare provider. Reassessments to check health status and discuss new needs (for example, bathroom adaptations or stair lifts etc.) would be undertaken during regular maintenance checks. There are clear economic and social

benefits of this type of joint working and potential lifesaving outcomes of fitting telecare linked smoke detectors into the home of the most vulnerable members of the community; particularly people with cognitive impairments, dementia or mobility difficulties who may not respond to the smoke detector or be able to get out of their home if there was a fire.

Impact and further work

The evaluation highlights the strength and potential reach and impact that local level studies can have. The project has gained interest nationally across the United Kingdom from other Fire and Rescue Services. Indeed, Fire and Rescue Services have specified that they have/will use the findings from the research (Heward & Kelly, 2015) to: *'...plan future ways of working and the direction of safe and well visits for people with dementia'*; *'...train our staff to become more Dementia aware...offering staff and public Dementia friend's sessions'*; and *'...put together a plan for [name of Fire and Rescue Service]... to become more dementia friendly and this will continue to be influenced by the findings'*. The Fire and Rescue Service involved in this project are considering developing the dementia education programme into an e-learning package which could be used nationally by all Fire and Rescue Services. As a small scale study it was not possible to determine the longer term impact of this project at the time of this evaluation. Further research could explore the longer term impact of this project and the relevance of these findings and the training material for other service providers who visit and care for people in their own homes (such as the Police, Ambulance staff, Social Workers, Occupational Therapists, Domiciliary Carers, Housing Associations etc.).

Conclusions

Firefighters and other frontline staff and volunteers at the Fire and Rescue Service are now better informed about dementia and have received training to enhance their communication skills with people with dementia. This project has raised awareness of dementia amongst Fire and Rescue Service staff, as well as enabling the voices of people affected by dementia to be incorporated within fire safety advice and

guidance. This means that Fire and Rescue Service staff and volunteers are better equipped to support people with dementia in the local community, as well as colleagues who may be experiencing memory loss or other symptoms of dementia themselves, or within their families. Increasing awareness of dementia alongside developing the provision offered to people living with the condition and their carers and families also supports wider policy initiatives to develop dementia-friendly communities. This project demonstrates the value of collaborative projects between service providers and Universities for pushing forward gaps in knowledge. In this case, to provide new opportunities to reduce the risk of injury and fatalities in fires at home; whilst maintaining independence, inclusion and wellbeing for people with dementia and their family carers.

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Declaration of conflicting interests

The Authors declare that there is no conflict of interest.

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