

People with dementia in hospital struggling with undiagnosed pain, study finds

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The frequency of pain experienced by people with dementia in hospital may be dramatically underreported, according to new research from University College London published in the journal PAIN today (25 March 2015). An observational study of 230 people with dementia found that, while nearly two thirds (57 per cent) of people with the condition were observed to experience pain, fewer than 40 per cent were able to report it due to the nature of their condition.

The research, funded by Alzheimer's Society and led by UCL's Dr Liz Sampson, saw academics assess people with dementia in two UK hospitals. Participants were assessed every four days for self-reported pain and also observed by the study team over the course of their stay in acute care. The team asked participants to answer to 'yes/no' questions as well as measurements on the FACES scale, a self-reporting pain scale based on asking people to point to drawings of faces of people in pain. Up to 39 per cent of participants self-reported that they were in pain. However, upon observation by academics, 57 per cent of the cohort were judged to be in some form of pain.

The researchers also found a strong association between pain, aggression and anxiety. Ninety per cent of people with dementia experience behavioural and psychological symptoms of dementia (BPSD) which can include these symptoms as well as agitation. According to the researchers, some BPSD could be to do with under detected or under managed pain, often triggering a cycle of poor care in a stressful environment.

George McNamara, Head of Policy and Public Affairs at Alzheimer's Society, said:

'It is not right that people with dementia are experiencing pain which is going unreported in a place where they go to get well. No one goes into care to do a bad job, and yet we hear regularly that front line staff don't have the training they need to manage the complex reality of dementia. We need to empower and train staff to deliver quality care to manage pain.'

'One in four hospital beds are occupied by someone with dementia. We want to see all NHS staff empowered to deliver the best quality care including recognising and managing pain where it occurs. A national standard for training of NHS staff would be a step forward in ensuring quality care is the norm across the NHS.'

Dr Liz Sampson, Senior Clinical Lecturer at University College London whose work is currently supported by the Marie Curie Palliative Care Research Unit, said:

'Hospitals are challenging places for people with dementia to be – they are unfamiliar surroundings which can be noisy, frightening and confusing. This can cause them great distress. It is very difficult to detect and treat pain in people with dementia, who often have difficulty expressing themselves or remembering that they have experienced pain. Sometimes people with dementia can try and communicate pain through challenging behaviours such as aggression or shouting out.'

The researchers found that pain was common in people with dementia who were admitted to hospital – nearly 40 per cent were in pain on at least one occasion during the time and nearly 60 per cent had pain on movement during their hospital stay. Being in pain was strongly associated with aggressive behaviours and anxiety.

Dr Sampson continued:

'We believe that improving pain management for people with dementia may reduce distressing behaviours and improve the quality of hospital care they receive. If staff understand that a change in behaviour in someone with dementia might indicate they are in pain, they can take simple measures to help with this. Staff are stretched in terms of time and resources, so we need to raise awareness, improve their training and increase specialist psychiatric support services within hospitals.'

Professor Bill Noble, Medical Director at Marie Curie said:

'The more we learn about dementia, the more we see how distressing the condition is, especially when it comes to the pain people with dementia feel but can't express.'

'This important study – the first of its kind in a general hospital setting - tells us that pain felt by people with dementia when in hospital can manifest as difficult or aggressive behaviour. By identifying this link, medical staff can better understand what people with dementia might be experiencing when they can't communicate it. We hope this knowledge will help improve the care people with dementia receive, help reduce their pain and improve their experience in hospitals, as well as minimising the stress of their families and carers.'

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Research reference: Sampson et al, (2015) 'Pain, agitation and behavioural problems in people with dementia admitted to general hospital wards: Longitudinal cohort study'. Published in PAIN on Wednesday 25 March 2015.

Notes to editors:

225,000 will develop dementia this year, that's one every three minutes

Alzheimer's Society research shows that 850,000 people in the UK have a form of dementia. In less than ten years a million people will be living with dementia. This will soar to two million people by 2051

Dementia costs the UK economy over £26 Billion per year. This is the equivalent of more than £30,000 per person with dementia.

Alzheimer's Society champions the rights of people living with dementia and the millions of people who care for them

Alzheimer's Society works in England, Wales and Northern Ireland

Alzheimer's Society supports people to live well with dementia today and funds research to find a cure for tomorrow. We rely on voluntary donations to continue our vital work. You can donate now by calling 0845 306 0898 or visiting alzheimers.org.uk

Alzheimer's Society provides a National Dementia Helpline, the number is 0300 222 11 22 or visit alzheimers.org.uk

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