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findings

INFORMING CHANGE

Pain management for older people with learning difficulties and dementia

In general, the pain relief needs of older people with dementia are not adequately met. The aim of this research was to determine whether the same unsatisfactory treatment also applies to people with learning difficulties who have dementia and, if so, to make recommendations for improving practice. The research team was based at the Centre for Research on Families and Relationships, University of Edinburgh, and the Dementia Services Development Centre, University of Stirling. The researchers sought to develop an understanding of how older people with learning difficulties and dementia experience pain and to explore how these are managed. The team interviewed and observed people with learning difficulties and dementia, support staff and other professionals involved in their care and treatment. They found that:

- There was a concerning level of unrecognised and, therefore, untreated pain amongst people with learning difficulties who also had dementia.
- Staff attitudes towards and experience of 'behaviour that challenges', problems around communication, beliefs about pain thresholds, the impact of past treatment of some people with learning difficulties on their willingness to complain of pain and the use of agency/bank staff contributed to a low level of pain recognition.
- Of particular concern were the references made by people with dementia about the extent to which their pain caused them to wake at night. In a number of sites, staff identified such waking solely as a consequence of dementia and so failed to give pain relief.
- Sometimes staff were not sufficiently aware that people with learning difficulties who are getting older will experience the painful conditions, such as arthritis, that can accompany older age. Nor were they fully aware of how these might affect someone with learning difficulties.
- Where GPs had chosen to specialise in care and treatment of people with learning difficulties, staff felt there was a greater recognition of pain management needs
- There was inadequate training of staff at all levels in all professions about dementia and learning difficulties and, in particular, about the pain management needs of people in this group.
- There was little use of pain assessment tools.

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Background

A number of studies have identified that the detection and management of pain in older people and people with dementia is a problem. The majority of these studies identified a range of issues that result in physical pain being inadequately treated in these groups.

Limited research has been undertaken on the pain management needs of people with learning difficulties who have dementia, yet they will experience high levels of physical health needs that will, as a consequence, result in pain.

All the literature reviewed on pain and the needs of people with learning difficulties focused on children and young people; there appears to be little recognition of the pain care needs of older people with learning difficulties in general, as well as those with both learning difficulties and dementia.

This study aimed to examine the specific issues that facilitate or impede the appropriate identification and management of pain for an older person with learning difficulties and dementia. The researchers looked at determining what positive systems are in operation to identify and treat pain in older people with learning difficulties, as well as what barriers exist to effective pain management.

Factors that contribute to problems with pain recognition

The researchers identified a number of factors contributing to poor pain recognition.

Prominence of people with 'behaviour that challenges'
For a variety of reasons, people with learning difficulties more often present with behaviour that challenges their carers and services than their non-disabled peers. If someone already has a history of behaviour that others find challenging, it is often difficult to determine if the behaviour exhibited is a repeat of previous behaviour, new behaviour unrelated to pain or behaviour which may be caused by pain. Staff who are primed to interpret behaviour as challenging may not readily consider other potential meanings, such as it being a response to an experience of pain.

> "I think it is seen as 'behaviour' before 'pain'."
> (Manager)

> "She's very challenging, physically aggressive, verbally aggressive. I've been told that if she's in so much pain she wouldn't be able to lash out… . I've been told that by a physiotherapist … it is just seen as challenging behaviour."
> (Staff member)

Communication difficulties
People with dementia have difficulties with communication. The people with learning difficulties in this study had lost many skills of communication. As a consequence of the dementia, they had also lost the sense of 'the geography of their body'. This meant they could not accurately indicate where their pain was.

> "She will point to other areas. She will point to her stomach or her head and it is really in her mouth."
> (Staff member)

Belief about pain thresholds

Interviewees often expressed the belief that people with learning difficulties have a high pain threshold. This belief means that staff are not necessarily disposed to interpret behaviour as resulting from pain, if they believe that the person is not as likely to experience pain to the same extent or intensity as non-disabled people.

> "Their pain threshold is so high that sometimes you can have behavioural problems before you realise that it's actually pain that they're suffering from." (Staff member)

> "A great percentage of people with learning disabilities also have extremely high pain thresholds." (Staff member)

Past experiences

Many older people with learning difficulties will have had experiences of pain treatment that were distressing or have had their pain ignored. This particularly applied to people in the study who had previously lived in institutions.

> "In the old days it was a matter of suffering in silence." (Staff member who had previously worked in long-stay hospital)

The use of bank /agency staff

A critical factor in the recognition of pain was the extent to which staff had an understanding and knowledge of the person with dementia. Interviewees identified agency or bank staff as not having this knowledge.

The experiences of the person with dementia

People with learning difficulties interviewed for this study were generally able to articulate their distress and pain, and so more able than many to elicit pain relief. They were, however, still not getting adequate pain relief, either in the form of analgesia or from non-drug interventions. One area where untreated pain that caused particular concern was pain experienced at night. Such pain exacerbates the night-time waking that can be a characteristic behaviour of people with dementia.

> "My hip hurts … I can't lie on that, I feel it in bed." (Woman with dementia)

The knowledge, experience and role of staff

There was evidence throughout the study that although pain was sometimes considered in relation to people with dementia, staff were not sufficiently conscious of pain as a possible explanation for types of behaviour. Staff did, however, play a vital role in providing GPs with critical information that assisted in the assessment and diagnosis of pain.

> "I would take more notice of the views of experienced staff … than I would probably from my own observations." (GP)

The role of the GP

The need for GPs to develop specialist skills was evident. GPs who took part in this study had chosen to specialise. They were seen to have improved skills in relation to people with learning difficulties. Care staff identified a range of unsatisfactory practices amongst many GPs who had no specialist interest.

> "We have had locums … you can tell the difference, there is not the relationship there." (Staff member)

The role of the Community Learning Disability Team (CLDT)

There was a contradictory theme that ran through the interviews with members of the CLDT. Despite evidence that these staff were acutely aware that pain was an issue for people with learning difficulties, this did not seem to translate to the context of older people with learning difficulties and therefore people with dementia.

> "Since receiving the leaflet about the pain study, two of the people with a learning disability and dementia, who had challenging behaviour we treated for pain and their behaviour has significantly changed for the better. We did not think that it might have been pain. I feel really bad that we didn't think about pain first." (Community nurse)

Implications for practice

From this evidence, the researchers draw out the following recommendations for improving practice.

Increase pain awareness amongst all staff

All staff involved with the care, support and treatment of people with learning difficulties and dementia need training in pain awareness, covering:

- pain and pain management in older age;
- the subjectivity of pain experiences;
- communication problems caused by the onset of dementia and how these might hinder pain recognition;
- awareness that 'behaviour that challenges' may indicate the existence of pain;
- awareness of how dementia affects people and the consequent changes in behaviour that may affect people with learning difficulties as they grow older;
- use of life-story work to enable staff to understand the person's past, helping them in turn to understand present behaviour. This could be developed for everyone, preferably before they develop dementia.

Agency and bank staff need the same training on pain recognition as other staff; the researchers recommend cautious use of agency/bank staff.

Prevention and better management of pain

The following measures would help better day-to-day pain management:

- a simple, agreed system of recording important information about the individual's pain and its management;
- on-going relationships between support staff and identified GPs who demonstrate an understanding of the needs of people with learning difficulties and dementia;
- clear and simple instructions for staff to follow when contacting GPs and other doctors;
- use of analgesia in line with established guidelines (NICE guidelines, 2004): these recommend regular administration and treatment adjusted from one step to the next, according to increasing or decreasing pain severity, history of analgesic response, and any side-effects. This approach calls in to question the current prevalence of 'as required' (PRN) prescription;
- greater awareness of non-pharmacological interventions for pain management.

GP training and practice

Interventions by GPs could be improved by:

- including issues relating to learning difficulties in undergraduate and post-qualifying education for GPs;
- encouragement for some GPs to specialise in both learning difficulties and dementia.

Community Learning Disability Teams

Members of the CLDT need to have:

- a more heightened awareness of the impact of age and dementia on people with learning difficulties;
- training on the impact of older age and dementia on people with learning difficulties;
- higher priority given to pain in the assessment process for older people with learning difficulties and dementia;
- regular reviews of older people with learning difficulties and dementia who are experiencing possible painful conditions.

About the project

The research team consisted of Diana Kerr, Colm Cunningham and Heather Wilkinson. The researchers worked in sites throughout the UK. Interviews were conducted with people with a learning difficulty and dementia (6), direct care staff (49), managers (12) GPs (6) and members of Community Learning Disability Teams (13).

For further information

The full report, **Responding to the pain experiences of older people with a learning difficulty and dementia** by Diana Kerr, Colm Cunningham and Heather Wilkinson, is published by the Joseph Rowntree Foundation.

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