Responding to the pain experiences of people with a learning difficulty and dementia

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Abstract
People with a learning disability are living longer. This increased longevity brings with it the conditions of older age including dementia. Amongst people in the general population who have dementia there is inadequate pain recognition and treatment1-4. Limited research has been undertaken on the pain management needs of people with a learning disability who have dementia, yet they will experience high levels of physical health needs that will, as a consequence, result in pain5,6.

The research study ‘Responding to the Pain needs of People with a Learning Disability and Dementia’7 explored the detection, management and understanding of pain amongst a range of professional groups involved in supporting people with a learning disability who have dementia. The study also recorded the experiences and views of some people with a learning disability who had dementia.

The dilemmas and obstacles to effective pain management were explored. It was found that the pain experiences and management of people with a learning disability who have dementia mirrored findings in the general population. The research did, however, identify extra and compounding issues in relation to people with a learning disability. Drawing on this research this article outlines recommendations for practitioners and service providers and discusses the key lessons for responding more effectively to pain in people with Down’s syndrome and dementia.

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Introduction

People with Down’s syndrome now have a much higher life expectancy. A result of this is an increased incidence of the conditions associated with older age. Dementia is an example of one of these. People with Down’s syndrome are particularly vulnerable to the onset of Alzheimer’s type dementia. People with Down’s syndrome can experience more complex health needs when compared with the general population and critically, much of their health needs are unrecognised and unmet. They experience higher levels of unmet health needs than the general population and are more likely to have a greater prevalence of pain.

The research study reported in this paper was based on the premise that the existence of a high level of unrecognised and, therefore, untreated pain among people with dementia in the general population is likely to be replicated among people with a learning disability.

Method

The study took place over a 16-month period. The main phase of the work involved six research sites located throughout the United Kingdom, chosen for their varying size and geographical spread, and included residential and non-residential service provision. In each site there were interviews with three primary groups: older people with a learning disability and dementia; support staff; and members of the community learning disability team and General Practitioners (GPs).

Findings

Diagnosis overshadowing

There is evidence that the fact that someone has a learning disability can often ‘override and obscure physical illness’. There is also, within the general population of people with dementia, a tendency to attribute changes in the individual to the progression of their dementia, rather than other causes. Indeed, ‘challenging behaviour’ is often seen as an inevitable part of dementia. There was evidence in this study that people with both a learning disability and dementia experienced the impact of these responses leading to ‘diagnostic overshadowing’. In such cases the diagnosis of dementia was used as an explanation for the changes in the

PALABRAS CLAVE
Síndrome de Down; Demencia; Dolor

Resposta a las experiencias de dolor de las personas con dificultades de aprendizaje y demencia

Respuestas a las experiencias de dolor de las personas con dificultades de aprendizaje y demencia viven más tiempo. Esta longevidad conlleva la aparición de enfermedades asociadas con la edad, entre ellas la demencia. En personas de la población general con demencia no hay un buen reconocimiento y tratamiento del dolor. La investigación llevada a cabo sobre las necesidades de tratamiento del dolor en personas con dificultades de aprendizaje y demencia es limitada, aunque estos pacientes presentarán un alto nivel de necesidades de salud física que, como consecuencia, se traducirán en dolor.

En el estudio de investigación Resposta a las necesidades derivadas del dolor en personas con dificultades de aprendizaje y demencia, se exploró la detección, el tratamiento y la comprensión del dolor en una serie de grupos profesionales implicados en la asistencia a personas con dificultades de aprendizaje y demencia. En dicho estudio también se registraron las experiencias y las opiniones de algunas personas con dificultades de aprendizaje y demencia.

Se examinaron las disyuntivas y los obstáculos para el tratamiento eficaz del dolor, y descubrieron que las experiencias y el tratamiento del dolor en personas con dificultades de aprendizaje y demencia eran similares a los datos obtenidos en la población general. No obstante, en la investigación se identificaron cuestiones adicionales y agravantes relacionadas con las personas con dificultades de aprendizaje. A partir de esta investigación, en este artículo se resumen las recomendaciones para médicos y proveedores de servicios, y se tratan las lecciones principales para responder de la manera más eficaz al dolor de personas con síndrome de Down y demencia.
person’s behaviour rather than understanding the behaviour as being pain not dementia related.

An example of this in the study related to explanations given for night time disturbance amongst people with a learning disability and dementia. Often people with dementia wake at night and there is, as a result, a tendency amongst those supporting people with dementia to attribute all night time disturbances to the impact of the dementia. It is evident that there are many non dementia related reasons why someone may wake at night with the existence of painful conditions being an important one of these. One of the painful conditions that many people with Down’s syndrome and dementia will experience is arthritis. This is a condition that is particularly painful at night when joints stiffen. Staff were not picking up on the arthritis but were attributing night waking solely to the fact that the person had dementia, they were not offering pain relief.

Focusing on ‘behaviour that challenges’

People with a learning disability, for a variety of reasons, can more often present with behaviour that challenges their carers and services than their non-disabled age matched peers\(^5\). If someone already has a history of behaviour that others find challenging it is possible that a pain related behaviour when they have dementia might be seen as a repeat of previous behaviours.

Pain is positively associated with screaming, aggression and verbal agitation in dementia\(^6\). It is interesting to reflect on the types of behaviours that can result from pain experiences. Questionnaires to groups about their responses to pain elicit most of the following,

- increased irritation,
- moaning,
- withdrawal,
- crying,
- screaming,
- swearing,
- aggression,
- poor eating,
- anxiety
- hitting out if touched or threatened to be touched in the painful area,
- pacing.

Many of these behaviours are also labeled as challenging amongst people with Down’s syndrome who have dementia. The misinterpretation of the meaning of the behaviour is compounded by the fact that often the primary response to ‘challenging behaviour’ in people with dementia is treatment with anti-psychotic medication\(^7\) or sedation. These responses only serve to mask the symptoms and make the identification of pain less likely.

Case Study Jane

Jane is 51 years old. She has Down’s syndrome and has been diagnosed with dementia. Every morning Jane screamed, shouted abuse and hit out as staff helped her out of bed and along to the bathroom. There was some feeling that this behaviour was because she did not want to get out of bed and face the day. She was seen as ‘being stubborn’. This seemed to be confirmed by the fact that the screaming and hitting stopped after the bathing was done and as the day progressed. The morning procedure became increasingly distressing for everyone concerned.

Jane had arthritis. This is a painful condition that is worse in the mornings after the person stiffens up during the night. A decision was made to give Jane Paracetomol 20 minutes before she got out of bed. This resulted in a complete change in her behaviour.

This is an example of an alternative response to ‘challenging behaviour’ where pain relief can be tried to see if the behaviour changes. If it does then it may be an indication that the behaviour is caused by pain. The next stage is to identify where the pain is and what is causing it, but the initial use of pain relief can begin the process of an accurate diagnosis.

Communication difficulties associated with dementia

The person with pain is the only person who knows how bad and enduring the pain is. Others have to ascertain the nature of the pain through observation and communication. The need to pay attention to subtle and often almost imperceptible changes is critical and staff often talk about recognizing something as small as ‘worried eyes’ as the key to pain recognition. Staff will already be attending to these changes in people they support, what is important is that when the person has dementia the same attention is given. One useful way of understanding pain is that pain is what ever the person says it is. Clearly this presents problems for pain identification in relation to people with dementia where communication can be an increasing difficulty.

Many people with Down’s syndrome will have experienced communication problems prior to the onset of dementia. With the onset of dementia communication deteriorates from the previously achieved level. Damage to the parietal lobes results in a number of significant problems for pain communication. People will lose the ability to find words including those that describe the pain. They will also lose a sense of the geography of their body and therefore the ability to indicate their head, their foot; their left and their right and so will no longer be able to physically indicate where the pain is located. The person with a toothache may not only fail to find the word ‘toothache’ they may also be unable to locate the place where the pain is.

People will sometimes use a general phrase such as ‘My head hurts’ because they cannot find the word ‘toothache’. This can lead to problems for assessment. If a person persistently says their leg hurts and yet they are walking well there is a temptation to think that there is no pain. It may be that the pain is elsewhere. People will often use phrases they used in the past as a way of expressing pain. For example, people may constantly say they have a ‘tummy ache’ because this was a pain they would have had in their childhood and probably the one best remembered. This does not mean that this is the location of the pain it is simply the use of a well remembered pain related phrase.
The influence of the person’s previous history on current assessments

If someone has in the past presented with certain behaviours it is possible that the new behaviours will be seen as a regression. It is important to consider that the present behaviour, whilst similar to previous behaviours now has a different meaning. An example of this would be Bob, who was always considered as a bit cantankerous and uncooperative. The onset of Blepharitis after his diagnosis of dementia made him extremely bad tempered but this was initially interpreted by the staff as Bob ‘him up to his old ways.’ It is important to remember that if we do not understand what is motivating a behaviour then our assessment may well be inaccurate.

Beliefs about pain thresholds

The study found a persistent belief that people with a learning disability have high pain thresholds.

Case Study Keith

Keith is a man with Down’s syndrome and a diagnosis of dementia. He is in his early fifties.

Keith has a severe back problem. He is often seen shaking and unable to walk because he is in so much pain from spasms. However, when asked ‘Keith is your back hurting?’ He replies ‘no I’m alright’ even though he is unable to walk. He is also reported as sometimes having diarrhoea and sickness. He ‘would be vomiting into a bucket’ whilst also telling staff that he is fine. This man was described as ‘having a high pain threshold’.

Past experiences may lead people to deny the existence of pain. Some older people with Down’s syndrome may have lived in large institutions. Their experiences of past responses to their pain will not necessarily be positive. Throughout this study there were examples of people whose previous experience of others’ response to their pain made sure they never complained again. Less dramatically but still a determinant of people’s reaction to pain is the recognition that in large institutions people did not necessarily get the attention they needed. If someone has learned not to complain early in their life then this is the behaviour to which they are likely to return when they develop dementia. People with a learning disability, like their non disabled peers, will have individual and differing responses to pain. If some of these differences are exaggerated and generalized into a belief about high pain thresholds then there is a danger that there will be a reduced sensitivity amongst staff to the possibility that someone might be in pain.

Awareness of the impact of older age on people with Down’s syndrome

People with Down’s syndrome in previous generations did not live into their old age. This means that staff are often ill equipped with the necessary knowledge skills and experiences of older age and in particular of dementia.

Despite the fact that “general practitioners are the health professionals most commonly consulted by people with intellectual disability”13, most medical practices will only have a limited experience of people with Down’s syndrome as they only comprise a small proportion of any General Practitioners (GPs) list. Additionally, most GPs will have limited experience of people with dementia even within the general population. ‘A GP with 1,500 to 2000 patients can expect to include 12-20 people with dementia, depending on the age profile of the list’19. Consequently the amount of experience that any one GP will have of people with Down’s syndrome and dementia is going to be fairly limited.

This study found highly varied experience, knowledge, skills and attitude among the GPs in relation to supporting people with a learning disability and dementia. Clearly, this also led to significant variations in knowledge, skills and attitudes towards the pain management needs of this group. Examples of GPs who were recognized as providing a high level of good support, reinforced Lennox and Eastgate’s assertions on the importance of people with a learning disability having one doctor who consistently meets their health care needs.

This low experience rate of many GPs is compounded by the fact that direct care and support staff who are often well aware of the needs of younger people are not often aware of the possible painful conditions of older age. People will also experience painful conditions that are nothing to do with age but are particular to individuals as a result of their lifestyles, life events and individual health. It is significant then that even conditions that people have had for many years can be overlooked in old age. The diagnostic overshadowing in relation to dementia can also be seen in relation to older age. The acceptance of pain as an inevitable part of old age should be challenged.

The use of ‘as required’ (PRN) medication

Pain relief is often prescribed ‘as required’. This is problematic in relation to people with dementia where staff find it difficult to recognise when the person is in pain. ‘As required’ medication of analgesia is not recommended for people with dementia. The World Health Organisation (WHO) guidelines are clear (1996). ‘As required’ should not be the primary approach to pain management for people with dementia. There should be regular administration; the treatment should be adjusted from one step to the next according to increasing or decreasing pain severity, history of response and side effect profile20.

Once analgesia is given it must be monitored. Because of the nature of the support that people with a learning disability receive a number of people may be involved in their care. Often a member of staff, carer or support worker may give pain relief and then, by the time the effects have worn off, someone else may be with the person. It is critical that all involved know about the pain relief given and that this is regularly evaluated. This is not an option if the pain relief is going to be properly administered and monitored.
Non-pharmacological interventions to relieve pain

The use of non-pharmaceutical interventions to prevent, reduce and relieve pain is to be encouraged and the study observed several positive examples of where these were highly effective. For chronic musculoskeletal pain which is associated with increased age the ‘application of heat and massage or positioning can sometimes be all that is needed’[1]. Chronic degenerative joint disease causes pain in the back and limbs and osteoporotic spinal deformity causes back pain. The need to support people’s bodies with appropriate seating, the use of aromatherapy, massage and music to relax people and the slowing down of activities and interventions will all contribute to pain reduction. People in pain will tense up and stiffen their body. The significance of almost all the above interventions is that they are directly or indirectly relaxing. They do not necessarily take the pain away but they may reduce the secondary impact so making it more tolerable.

Conclusion

The findings from the research study exploring responses to the pain experiences of people with a learning disability and dementia raise concerns that older people with a learning disability and dementia may, like the general population with dementia be experiencing high levels of unrecognised and untreated pain. There are several reasons for this: ‘diagnostic overshadowing’, the focus within the service on ‘challenging behaviour’ and the problems with communication that develop with the onset of dementia. The effects of these are compounded by a low level but still persistent belief that people with a learning disability have high pain thresholds. The detection of pain is further inhibited by reduced awareness amongst staff of the painful conditions of older age. Crucially, the use of ‘as required’ analgesia is unsatisfactory as a response to pain relief for people with Down’s syndrome and dementia. The use of non-pharmacological interventions should be considered.

Key lessons to be drawn include the following, based on the recommendations from the research,

– All staff require training on the impact of dementia. This should include recognition of how communication difficulties may impact on the expression of and recognition of pain.
– There is a need for everyone involved in supporting older people with Down’s syndrome to be aware of the potentially painful conditions of older age.
– Training on ‘challenging behaviour’ must include recognition of the impact of dementia on pain behaviour and recognition.
– ‘As required’ analgesia should not be the primary approach to the management of pain in people with a learning disability and dementia. Treatment must follow World Health Organisation Guidelines
– The use of non-pharmaceutical interventions should be integrated into pain prevention and management.

A poster and guides for carers and doctors which highlight the need to look for pain can be obtained from Joseph Rowntree website at www.jrf.org.uk/dementia/

Conflict of interests

The author affirms that they have no conflicts of interests.

References