

CASE STUDY

A relationship-centred approach to managing pain in dementia

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Sharron Tolman

Admiral Nurse, St Cuthbert's Hospice, Durham, England

Karen Harrison Denning

Head of research and publications, Dementia UK, London, England

Correspondence

sharron.tolman@stcuthbertshospice.com

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Abstract

The presence of pain in a person with dementia can often be missed. The diagnosis of dementia can overshadow the pain-inducing symptoms of other co-morbid conditions with distress behaviours being attributed to the behavioural and psychological symptoms of dementia. Such distress behaviours of a person with dementia often have a profound and alarming effect on family carers. This Admiral Nurse case study explores the assessment and management of pain in a person with dementia in partnership with the family carer.

Keywords

Admiral Nurses, carers, dementia, end of life care, mental health, pain assessment, palliative care

THE POPULATION of the UK, as in other developed nations, is ageing. In 2011, 9.2 million people in England and Wales were aged 65 and over, an increase of almost one million from 2001 (Office for National Statistics 2013, Alzheimer's Society 2014). A UK study by Brayne et al (2006) found that people aged between 65 and 69 had a 6% chance of dying with dementia. Deaths in early life from infectious disease have decreased and the management of other conditions, such as cardiovascular disease, is becoming more successful. The treatment of, and survival rates for, some cancers are also improving, therefore a higher proportion of the world's population is living to older age. This has led to an increase in the number of people living long enough to develop the multiple co-morbidities associated with older age, in particular, neurodegenerative diseases such as dementia (Sampson and Harrison Denning 2013). Such multiple co-morbidities will often have pain as one of their most significant symptoms (Lichtner et al 2016).

Pain in dementia

People with dementia often experience several co-morbid conditions at the same time, but there is widespread evidence that untreated pain in this group is common (Scherder et al 2009) and that they often have inequitable access to effective pain assessment and management. Retrospective interviews with relatives and carers indicated that significantly more dementia patients were reported to experience pain in the last six months of life compared to those with cancer: 75% versus 60% (McCarthy et al 1997, Sampson et al 2015). Untreated pain is a major contributor to reduced quality of life for people with dementia and can lead to increased discomfort and distress. Lack of proper pain assessment can cause a

range of complications including delirium, sedation and increased confusion (Pryor and Clarke 2017). It may also lead to the inappropriate prescribing of antipsychotic medication. The assessment and treatment of pain are particularly challenging because some people with advanced dementia have a reduced ability to verbalise their pain and discomfort. Commonly used assessment tools may be unreliable and difficult to use, which leads to symptoms being missed and misunderstood (Corbett et al 2014).

Most people living with dementia are supported by a family carer, who is well placed to assess their pain. This article presents a case study (Case study one) to illustrate how an Admiral Nurse supported family carers in the assessment and recognition of pain in a person with dementia who was unable to communicate their pain in a conventional way (Box 1). It also discusses how this led to more effective treatment and management of the person's pain. The names and any identifiable factors have been changed to protect the anonymity of those involved.

Assessment of pain in dementia

Self-report is the gold standard for pain assessment given the subjective and unique way that pain is experienced by individuals. Despite the problems in communication, and the widely held belief that people with dementia cannot articulate their pain, many with moderate to severe dementia can report pain reliably (Zwakhalen et al 2006). However, Miriam had an expressive aphasia that resulted in marked communication difficulties and meant that she was unable to express or articulate symptoms or how she was feeling in a conventional way.

Pain and symptoms of other co-morbid illnesses may be missed in people with dementia due to the

attribution of behaviours and signs to BPSD (see Box 2), rather than an underlying physical pathology (Kostopoulou et al 2008).

On the face of it, Miriam's signs and symptoms were seen as being due to her dementia and, given the known signs of BPSD (Box 2), this response may not be unusual. George had coped as Miriam's main carer for two years, but now struggled with Miriam's behaviour. He too thought this was a progression of her dementia and expressed to the district nurse that he 'could cope no longer'.

However, pain in a person with dementia who has difficulties with communication often manifests as behavioural change such as agitation, distress,

social withdrawal, depression or resistive behaviour as included in BPSD (Scherder et al 2009, Sampson et al 2015). Important to note is the close similarity between the signs of BPSD and those that indicate that a person with dementia may be in pain (see Box 3), which may in part explain why the two may be difficult to differentiate.

Where a person with dementia has communication difficulties, as with Miriam, it may be necessary to use objective observation or a validated behavioural observational pain scale such as the Abbey pain scale (Abbey et al 2004) or Pain Assessment in Advanced Dementia (PAINAD) scale (Warden et al 2003). There is no consistent evidence to suggest that pain experience is more or less intense in people with dementia, but they may have difficulties in interpreting their pain signals as well as communicating this to others.

The assessment of pain in people with advanced dementia is, however, complex. It has been suggested that there is no evidence that pain produces any signs or behaviours that are unique to pain (Regnard et al 2003). Regnard et al (2007) suggested that such symptoms, for example, agitation, restlessness and repeated vocalisation may be the result of other forms of distress and thus tools such as the Disability Distress Assessment Tool (DisDAT) may be more appropriate. Sometimes, raising the issue of the possibility of pain is not straightforward. Family carers may feel confident the person they are caring for does not present with pain, as with George (Case

BOX 1. Admiral Nurse service approach

Admiral Nurses focus on the needs of the whole family affected by dementia, including psychological support to help the person with dementia and carers to understand and deal with their thoughts, feelings and behaviour, and to adapt to the changing situation. The caregiver and recipient must adjust to the transformation of their relationship into a caregiving one; this includes a change in the balance of roles, as the caregiver takes more responsibility for the welfare of the recipient. Admiral Nurses can offer expert input here.

Admiral Nurses use a range of specialist interventions that help people live well with the condition and develop skills to improve communication and maintain relationships. The government-led dementia strategy emphasises early diagnosis, early interventions and support, intersectoral support and integrated working and support for carers.

Admiral Nurses' work with families is an invaluable source of contact and support at points of difficulty in the dementia journey, including diagnosis, when the condition progresses or when tough decisions need to be made, such as moving a family member into residential care. Anticipated problems are misdiagnosis, delayed diagnosis and lack of information and services for people with dementia and their families, which give rise to the risk of inappropriate management, crises, poor psychological adjustment to the diagnosis, reduced coping capacity and ability to forward plan. Admiral Nurses help families cope with feelings of loss and bereavement as the condition progresses. Family care does not end once 'hands-on' caregiving ceases. Dementia guidelines support the principle that family carers should be supported during the illness and into bereavement. For family carers, the more social support that is received during the years of caregiving, the easier it is to adjust and adapt post-bereavement.

Admiral Nurses provide advice on referrals to other appropriate services and liaise with other health professionals on behalf of the family. Such knowledge may help them provide general information, as opposed to just that which is medical such as further diagnosis and management of medical problems. For example, a nurse specialist could potentially make timely referrals, if needed, to sources of specialist legal advice and use legislation to reduce disputes.

(Rahman and Denning 2016)

Case study one: Miriam

Miriam was 78 years old and had been referred to the Admiral Nurse by her district nurse. Miriam had received a diagnosis of dementia from her GP just over two years ago. Her GP wanted to refer Miriam for a full memory assessment at local mental health services but she declined. The stigma of being seen as having a 'mental health' problem was a concern for Miriam at that time. However, Miriam now had breast cancer with metastases in her bones. The district nurse was concerned as Miriam's husband, George, was struggling to cope with his wife's behaviour. The district nurse reported that Miriam's cancer was 'stable' and that the behavioural symptoms appeared to be due to her dementia.

During the initial assessment visit to her home, Miriam appeared restless, unable to sit for any length of time, often getting up from the chair and wringing her hands constantly. She seemed tense, unhappy and irritable when her husband spoke about how she had been. She had an expressive aphasia where she experienced great difficulty expressing herself verbally, with conversation being stilted. George stated that her sleep was disturbed and appetite greatly reduced.

Miriam's distress behaviour was perceived to be related to her diagnosis of dementia. However, evidence suggests that in people with a diagnosis of dementia, co-morbid conditions, especially pain, are often not identified until their signs and symptoms become severe (Sampson et al 2009) or that distress behaviours due to pain are misinterpreted as the behavioural and psychological symptoms of dementia (BPSD). This is explored in the next section.

BOX 2. Behavioural and psychological symptoms of dementia

- » Aggression
- » Agitation or restlessness
- » Screaming
- » Anxiety
- » Depression
- » Psychosis, delusions and hallucinations
- » Repetitive vocalisation, cursing and swearing
- » Sleep disturbance
- » Shadowing (following the carer closely)

(Cerejeira et al 2012)

BOX 3. The signs of possible pain in a person with dementia

- » Agitation or fidgeting
- » Repetitive movements
- » Tense muscles
- » Decreased function
- » Panic
- » Body bracing
- » Increased and repetitive calling out
- » Changes in sleep patterns
- » Tears or crying
- » Withdrawal

(Pace et al 2011)

study two), stating 'I would know if she was in pain'. Not necessarily accepting the 'no pain' response can be a significant emotional challenge for family carers. They may also feel the care they provide is being questioned or judged. The guilt and grief of caring for a person they love with dementia can be overwhelming, painful and distressing for family carers (Newbrunner et al 2013).

Managing pain in the person with advanced dementia requires careful assessment for possible underlying causes. This should include clinical examination, observation of behaviours at rest and during movement and discussion with family members or staff who know the person well. In some cases, response to a trial of analgesic may be a diagnostic tool (Herr et al 2006). The aetiology of pain may be acute and may, for example, be associated with urinary retention, constipation (Kovach et al 2006), myocardial infarction, deep vein thrombosis or acute infection. Common chronic causes of pain in people with advanced dementia include pressure ulcers, undetected fractures, poor dentition, awkward positioning in chair or bed and arthritis (Davis and Srivastava 2003). With Miriam, it was more likely that the pain was related to conditions in her recent past medical history, namely cancer.

My (ST) initial assessment of Miriam was in-depth and holistic, largely to rule out any other treatable condition, such as depression. An assessment of pain in people with dementia often involves working closely with family carers to gain a collaborative history and support them to understand how pain can present in dementia (see Box 3). Presentation of pain can often come as a surprise to family carers and may be different to what they might have expected. Taking a short life history can help, specifically looking at how the person may have coped with pain or distress in

the past and in helping them to understand what pain indicators they can look out for in the future. It can take time for the carer to feel confident and comfortable with your suggestions and ideas.

Monitoring Miriam's distress behaviours

Miriam was receiving no analgesia. I (ST) asked George to keep an account of Miriam's behaviour to enable us to observe for any patterns or triggers and to see if he had found any strategies helpful in reducing her distress. George was unable to identify anything that he felt was significant and increasingly struggled to cope. As we have noted, pain tools are available for use with people with dementia. Sometimes family carers welcome their introduction to help them demonstrate the evidence of pain or otherwise in the person they care for, but in George's case it added to his stress. I asked George some questions, using the Abbey pain scale (Abbey et al 2004), to determine if Miriam was experiencing pain and to support her GP in considering a trial of analgesia. For example, 'Have you noticed Miriam whimpering or groaning?' and 'Have you noticed Miriam protecting parts of her body when care is given (guarding)?' In this way, we started to get a picture of how Miriam's distress behaviours were an expression of her unrecognised pain. George became more confident with the scale and less stressed as he thought he was working towards making things better for his wife. Using this scale also helped George to recognise signs of contentment in Miriam as well as distress to build a picture of her overall well-being.

Most people living with dementia are supported, either in their own homes or other settings, by a spouse or other family member. This person usually has in-depth knowledge of the person and their methods of communication and nuances and may, therefore, be well placed to support the assessment of pain. They will often need guidance on those behaviours that can be characteristic of pain. We used the Abbey pain scale (Abbey et al 2004) to observe Miriam's behaviour. The more commonly used pain assessment approaches, for example, self-report or pain thermometer (this assesses pain by asking patients to indicate the intensity or severity of their pain on a diagram of a thermometer), may be unreliable and difficult to use in people with a reduced ability to communicate, which often leads to symptoms being missed and misunderstood (Bracegirdle 2012). Untreated pain is a major contributor to reduced quality of life and disability, and can lead to increased behavioural and psychological symptoms, which can then become a vicious circle. However, the opposite to agitated and distressed behaviours can manifest itself, such as stillness, apathy and withdrawn behaviour which can all indicate pain in a person with dementia. However, as in Miriam's case, it is more likely that agitated and aroused behaviour associated with pain is more commonly misinterpreted as being indicative of a

Case study two: George (Miriam's husband)

Through the initial discussions with George, he concurred that Miriam had experienced several health problems over many years and coped stoically, rarely 'complaining' or seeking help. She had continued to work even during long and difficult chemotherapy treatments for primary breast cancer. I enabled George to see how historic elements of Miriam's approach to managing illness and pain were still present even with dementia. This helped George to understand that Miriam may still be less likely to talk about any pain or discomfort she may be experiencing. I explained that in people with dementia, it may also be that we need to use different words to help them express how they feel; words or descriptions they may be more familiar with now to express their pain.

Miriam's recent behaviour had caused George much concern and he worried that her 'dementia was becoming more advanced' and that using an analgesic may make the situation even worse. He was also worried about possible side effects or the risk of Miriam becoming over-sedated. However, what made him most anxious was that Miriam clearly could not tell him whether she was in pain or not and that we may give her treatment she did not need and perhaps not act in her best interests.

People with dementia report higher levels of pain in the last six months of life than those with cancer, but pain control is often inadequate (Davis and Srivastava 2003, Kovach et al 2006). The assessment and treatment of pain are particularly challenging due to the reduced ability of some people with advanced dementia to verbalise their pain, discomfort and anguish (Chatterjee 2008). This often manifests as behavioural change such as agitation, distress, social withdrawal or depression (Sampson and Harrison Denning 2013). As with Miriam, in addition to the discomfort and distress caused by pain, her inability to verbalise pain was likely to be the underlying cause of behavioural symptoms. If such behaviours are misattributed to BPSD it can lead to inappropriate treatment with antipsychotic medications.

decline in dementia. Consistent use of an appropriate pain assessment tool is therefore vital to effective pain management (Bray et al 2015).

Management of pain in dementia

Treating pain in people with dementia, as in the wider population (World Health Organization (WHO) 2009), requires a stepped approach (American Geriatrics Society Panel on Chronic Pain in Older Persons 1998). Depending on the cause, non-pharmacological interventions may be helpful, particularly where there is a musculoskeletal aetiology. Such interventions may include repositioning, provision of optimal seating or specialist beds, physiotherapy, massage, heat or cold. Simple analgesia such as paracetamol or non-steroidal inflammatory drugs can be effective. There are anxieties about giving analgesia to older people. In a study involving patients with fractured neck of femur, participants with cognitive impairment were prescribed one third as much analgesia as cognitively intact controls (Morrison and Siu 2000). There is no consistent evidence to suggest that pain experience is less intense, but people with advanced dementia will have difficulties in communicating that they are in pain and interpreting pain signals. The key to achieving a good result is regular prescribing, as required medication is often not given because people with advanced dementia may not request it or report they are in pain. If a regular analgesic regimen is ineffective, opioids should be considered. Side effects such as delirium, constipation or sedation may occur but in practice these can be managed. An important study by Husebo et al (2011) demonstrated how this approach to the management of pain significantly reduced agitation in nursing home residents with moderate to severe dementia. Regular paracetamol was effective in 63% of participants and of the 25% who received opioids, only 2% had these discontinued because of side effects.

There are various risks of under-treating people with dementia at the end of life due to the lack of knowledge about the complexity and nuances of the condition (Mahon and Sorrell 2008). Inadequate and ineffective pain management is high among these risks (Torke et al 2010, WHO 2011), and can lead to a range of complications including delirium, sedation and increased confusion (Robinson et al 2008, Bracegirdle 2012).

Treating Miriam's pain

By using the Abbey pain scale (Abbey et al 2004) George and I (ST) agreed that Miriam was experiencing pain. With Miriam's GP, I discussed the results of the pain scale scores, taken over several days and at different times. Miriam's GP prescribed a buprenorphine patch. The pain-relieving medication helped to a certain extent, which highlighted that pain was a significant factor in Miriam's distress. However,

principles of good 'total' pain management (see Box 4) then needed to be considered, as well as having a robust, regular analgesic plan and treatment review in place.

Essential to my role was supporting George throughout as he too was distressed and finding the right treatment plan for Miriam took some time. Non-pharmacological options were considered to help George manage his distress. George needed time to reflect and talk about Miriam, their life together and what mattered to them most. Sometimes, when the physical or emotional health needs of the person with dementia take priority, the family member can feel that their past and present relationship is being lost or overshadowed by the condition. Once Miriam's pain was becoming better controlled, I took the opportunity to undertake some life story work (McKinney 2017) and to plan care for her in the future with George, by giving him the opportunity to talk about his past and present relationship and life with Miriam. Initially he chose to do this without her being present so that he could be honest and open about how he felt without fear of distressing her further. It became clear that it was important to George that I had the opportunity to 'know' Miriam before the diagnosis of dementia and to understand the changes in her over time.

Conclusion

Dementia is primarily a condition of older age and is, therefore, commonly associated with many other age-related conditions, including long-term health conditions. Multi-morbidity is common in people with dementia and, on average, they will experience an additional 4.6 chronic illnesses, many of which will induce pain (Guthrie et al 2012). Nevertheless, family carers often feel ill equipped to manage the complex health needs of the person they care for and frequently do not know what to expect. 'I'm not a nurse' is commonly cited by family carers, yet they are relied on to make clinical assessments and judgements about the person they care for. As with George, they have often supported the person with dementia through several episodes of ill health in the past, but the uncertain trajectory of decline (Samsi and Manthorpe 2014) and recovery can be distressing and confusing for families. This can lead to heightened anxiety and apprehension in family carers, compounding the uncertainty about what to do for the best. Pain

BOX 4. Total pain

Total pain is a clinical idea and approach developed by Cicely Saunders, the founder of the modern hospice movement. Total pain recognises pain as being physical, psychological, social and spiritual. Pain is not just a physical sensation, but can be a consequence of, for example, loneliness, spiritual distress or an inappropriate diet.

(Leleszi and Lewandowski 2005)

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can potentially be relatively simple to manage in dementia if attention is given to its possibility and assumptions about behavioural change being a natural consequence of dementia are avoided. A free resource to support family carers is published by the National Council for Palliative Care and is available to download.

Implications for practice

» Pain in dementia is often not complex but where there is little verbal communication and the emphasis is on nurses to determine the presence of pain, behavioural assessment tools can be useful.

- » Be aware that a change in behaviour to stillness, quietness and withdrawal can also indicate the presence of pain in a person with dementia.
- » Involve family members in your pain assessment to try to ascertain an individual's past pain indicators and management strategies. Family carers play a vital role in monitoring the health and well-being of a person with dementia.
- » Regularly assess for pain to ensure that it remains controlled, to avoid breakthrough pain and to assess whether the analgesia prescribed is having the desired effect.
- » Initiate regular analgesic plan and ladder for treatment reviews.

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