

# Chronic pain in elderly nursing home residents: the need for nursing leadership

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## Chronic pain in elderly nursing home residents: the need for nursing leadership

The incidence of chronic pain amongst elderly people in nursing homes is very high, making pain in this population a serious problem for aged care facilities. Research studies reveal a pattern of poor pain management in this setting despite the high incidence of pain suggesting that the management of pain in nursing homes is limited in scope and only partially effective. What is not fully appreciated by health professionals is the impact pain has on the lives of elderly people who live in nursing homes. In the study reported here a phenomenological method was used involving several in depth interviews with elderly people over a period of 9 months. Field notes of observations were also recorded as the participants went about their everyday lives in the nursing home. The discussion focuses on some of the themes drawn from the study with an emphasis on a key theme 'being constantly pained'. The findings of the study highlight what it is like to experience pain and how this impacts on everyday lives of elderly people. The paper concludes with some suggestions for health professional for improving care in this area.

*Keywords:* aged care, chronic pain, elderly, pain management, phenomenology

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## Introduction

There are few human experiences that are as compelling as pain, yet it remains poorly managed by professionals in a range of health care settings. While there is a large body of research into the mechanisms of pain and pain management and improved techniques for pain control, elderly people (65 years and over) have been largely, and sometimes systematically, excluded from pain studies [Ferrell 1996, American Geriatrics Society (AGS) panel on chronic pain in older persons 1998,

Farrell 2000]. As a result, our knowledge about pain in elderly people is limited. It is the lack of knowledge and other factors that have contributed to the situation where elderly people live in nursing homes with chronic, unrelieved pain. Indeed, the incidence of pain in this setting is very high.

In nursing homes in Australia (Madjar & Higgins 1996), the United States of America (Roy & Thomas 1986, 1987, Ferrell *et al.* 1990, 1995, Parmelee *et al.* 1993, Sengstaken & King 1993, Shapiro 1994, Fox *et al.* 1999, Weiner *et al.* 1999, Fries *et al.* 2001) and

Singapore (Lau-Ting & Phoon 1988), the incidence of pain has been reported to be as high as 44–80%. Complications of chronic pain such as depression, decreased socialization, sleep disturbances and impaired mobility are also common among elderly residents along with conditions such as cognitive dysfunction and malnutrition that are potentially worsened by the presence of pain (Ferrell 1995).

The high prevalence of pain in elderly people, and its impact, make pain in this population an important public health issue (Fox *et al.* 1999). Indeed, it seems incongruous that while scientific research has uncovered many of the biochemical and neurobiological processes of pain, along with the development of sophisticated treatments for its control, many elderly people continue to live with unrelieved pain. In institutionalized elderly people however, there are several factors that contribute to this situation including the knowledge, attitudes, and beliefs of health carers, and the elderly person's beliefs about pain as a normal part of ageing (Wells *et al.* 1997). What is needed however, is nursing leadership in order to ensure that elderly people do not spend their dying days with relentless and unrelieved pain.

In the following discussion a review of the literature about pain management in elderly people provides background to the selected findings of a study that explored the lived experience of chronic pain in elderly people who lived in nursing homes in Australia. In this study, a phenomenological method was used involving several in depth interviews with 13 elderly people over a period of 9 months. Field notes of observations of the participants were also taken as they went about their everyday lives in the nursing homes. Approvals to proceed with the study were provided by the Area Health and Unversity's Research and Ethics committees and informed consent was obtained from all participants.

## Literature review

Whilst the list of studies into the management of pain in elderly people in nursing homes is growing (Fox *et al.* 1999), the findings of these studies reveal a consistent pattern of poor pain management despite the high prevalence of pain in this population (Ferrell & Ferrell 1990, Ferrell *et al.* 1990, 1995, Marzinski 1991, Fentiman *et al.* 1993, Sengstaken & King 1993, Yates *et al.* 1995, Madjar & Higgins 1996, Feldt *et al.* 1998, Horgas & Tsai 1998, Kaasalainen *et al.* 1998, Parish & Willis 1998, Won *et al.* 1999). The research generally suggests that the approaches used for pain management in nursing homes are limited in scope and, given what is known about the mechanisms of pain, can only be

partially effective. Analgesic drugs seem to be used sparingly and non-pharmacological approaches are often absent. The prescription of mild analgesics, often p.r.n. (Ferrell *et al.* 1990), suggests medical practitioners underestimate the requirements for ongoing chronic pain. In addition, a p.r.n. prescription leaves the administration of analgesics to the discretion of nursing home staff. More importantly it relies for detection of pain, and monitoring of effectiveness of pain management strategies, on unqualified staff who provide most of the direct care in this setting (Nay 1992, Ersek *et al.* 1999, Nay & Closs 1999, Kovner *et al.* 2000, Horgas & Dunn 2001) and in the absence of routine pain assessment it is likely that many people go without adequate pain relief.

Given that chronic pain has few objective clinical signs (Rapin 1991, Stein & Ferrell 1996), its assessment largely relies on self reports which may be misunderstood by health carers (Portenoy & Farkash 1988, Ferrell 1991, Otis & McGeeney 2000) because elderly people often under-report pain (Ferrell & Ferrell 1990, Ferrell *et al.* 1990, Helme *et al.* 1992, Herr & Mobily 1991, Won *et al.* 1999) and regard it as a normal part of growing old (Ferrell *et al.* 1990, Ferrell & Ferrell 1990, Helme *et al.* 1992, Herr & Mobily 1992, Fentiman *et al.* 1993, Yates *et al.* 1995, Brockopp *et al.* 1996, Stein & Ferrell 1996, Parmelee 1997, Weissman & Matson 1999). They often fear further tests and treatments motivated by concern that their disease is worsening and a fear of increasing dependence (Hofland 1992) or death (Stein & Ferrell 1996). They may also fear being labelled a 'complainer' (Hofland 1992, Walker 1994, Yates *et al.* 1995). Some elderly people have misgivings about the use of narcotics and reporting pain to their physician, and some fear taking regular doses of analgesics because of side effects (Walker *et al.* 1990). Also, many believe they are not taken seriously when they report pain (Wakefield 1995, Brockopp *et al.* 1996) or that health workers are too busy or not interested in their pain (Fentiman *et al.* 1993, Yates *et al.* 1995). There are those who do not understand the problems that might result from untreated pain or the benefits of taking regular analgesia (Brockopp *et al.* 1996) and some elderly people have no expectation for the relief of pain (Walker 1994, Yates *et al.* 1995). Such expectations are often based on previous experiences (Yates *et al.* 1995) and the elderly person's own beliefs about pain (Ferrell & Ferrell 1990, Ferrell *et al.* 1990, Helme *et al.* 1992, Herr & Mobily 1992, Yates *et al.* 1995).

There are many barriers to the effective management of pain in nursing homes (Stein & Ferrell 1996). For

example, the method of delivery of care may be a significant barrier, as most direct care is provided by unqualified staff (Nay 1992, Ersek *et al.* 1999, Nay & Closs 1999, Kovner *et al.* 2000, Horgas & Dunn 2001) who lack education in normal anatomy and physiology, ageing processes, illness, disease pathology and pharmacology, let alone education in pain assessment and management. In Australia, unqualified, untrained nursing assistants comprise around 50–60% of the staffing in nursing homes (Nay & Closs 1999) despite the high dependency needs of the residents and the high levels of complex care provided in this setting. In hostels, which provide care for elderly people with low dependency needs, there is no requirement to employ registered nurses. In the USA, staffing with unqualified, untrained nursing assistants may be as high as 70–90% (Ersek *et al.* 1999, Nay & Closs 1999, Kovner *et al.* 2000, Horgas & Dunn 2001). Coupled with a limited number of qualified professional nurses and infrequent visits by physicians, the detection and assessment of pain and its subsequent management in nursing homes is, at best, haphazard (Parish & Willis 1998, Weissman & Matson 1999).

Another major concern in nursing homes is the absence of formalized and regular assessment of pain (Ferrell *et al.* 1990, Sengstaken & King 1993, Madjar & Higgins 1996). Adding to this concern is that the efficacy and effectiveness of pain assessment tools have not been widely studied with elderly people (Gagliese & Melzack 1997). Some small studies, however, have used a range of tools (Herr & Mobily 1993, Herr *et al.* 1998, Weiner *et al.* 1998, Scherder & Bouma 2000, Fries *et al.* 2001) with some reported success.

The lived experience of chronic pain in elderly people who live in nursing homes demonstrates that the pain is not only very painful but that much could be done to relieve the elderly person's distress. What makes chronic pain in elderly people different from acute pain in younger people is its presence within an aged and frail body. With limited capacity and reserves for coping, elderly people constantly struggle with pain that is relentless, debilitating and rarely relieved. Having constant pain is tiring and exhausting.

### The painfulness of chronic pain

The pain of the elderly people in this study was often associated with chronic problems, such as arthritis and ageing pathology like osteoporosis and vascular disease. There were multiple sources of pain and each pain had its own unique quality. This meant that pain varied widely in its nature with differing intensities, locations, and temporalities. Unlike acute pain in younger people,

the participants' pain was pain they knew would never go and never be completely relieved. As one of the participants said,

'I'm full of it [pain]. There's nothing they can do... Nothing really. I take a couple of Panadols when it gets too bad. But I don't take them very often because they upset me. They make me sick in the stomach. I don't bother with them. I just put up with it... I'm having a bit of heart trouble today [chest pain]. There's nothing they can do with it. I've had it for years. I try to do without tablets. I take that many. It's not really severe but it's enough to know it's just there... There's nothing you can do... I just get sick of things... I don't know how to explain it all to you. Honestly... When it gets bad, it's no good love. I don't have the strength'. (Ellen)

Ellen suffered with widespread arthritis and cardiac disease. Every part of Ellen was touched with pain. She had no expectation for relief, instead, she tolerated the constant presence of pain. Her pain was so debilitating that it sapped all her energy, strength and will. Any small movement of her body caused pain and, like others with pain, there were times when words were inadequate. Only when the pain became too much to bear did Ellen call to staff for help and relief.

### Being forgotten

When pain became overwhelming, only then, did many of the participants request pain relief. Their requests for pain relief always came after periods of intense pain and anxious deliberations about whether to bother the nurse or the doctors. The participants' requests for analgesia, however, were to their consternation, forgotten sometimes.

'The other night I asked for a pain killer and I think he [the nurse] must have forgot about it. I was cranky about that'.

'Did you eventually get it?'

'No I didn't. I kept waiting for him [the nurse] to come in. You know how busy they would be. I could hear the buzzer going... you can't get anything [said in a loud voice]. It is kept over the other side. They are busy over there and they don't worry about this side. Yesterday I wanted something and it was two hours I had to wait. Last night I didn't get any... Anyhow, I suppose I can put up with it. But I asked for the pain killers and I didn't get it'. (Tony)

Mervin had also been forgotten,

'I was a bit off. You know how you get the tummy turning over and all that – a bit off colour, and they said, "well what do you want to do?", and I said, "I think I'd rather stay where I am" [in bed]. They went, "oh, good oh", so they put me into bed and forgot me'.

Both Tony and Mervin were totally disabled and dependent on the nursing staff. Tony had an above knee amputation of his right leg and a left-sided paralysis following a cerebro-vascular accident. He also had diabetes, peripheral vascular disease and cardiac disease. He had arthritis and reported pain in all joints including his neck. Mervin had widespread arthritis with severe deformity of his fingers and hands. A fall at home resulted in a fractured hip which led to hospitalization for a total hip replacement. Following several failed attempts at a replacement Mervin was left disabled when the prosthesis was removed permanently due to a wound infection which had now become chronic.

At night Tony was lifted onto his bed by a mechanical hoist. Once in place in bed on his side this was where he stayed until the nurses returned, if at all, to reposition him. Tony could not move to reposition himself at night and as his discomfort increased so too did his pain. While Mervin was much smaller in frame and lighter than Tony, he too was unable to move himself about in bed.

Participants were rarely, if ever, free of pain. All of them had their own methods for easing pain, some used heated wheat bags for painful joints, others preferred to be left in quiet solitude. All were prescribed analgesics, but most of the time overall pain relief was clearly inadequate. Pain relief measures were arbitrary and inconsistent. Any form of pain relief, including massage, the application of heat, for example, or the administration of analgesics that were prescribed as needed (*p.r.n.*), largely depended on the level of activity occurring in the nursing home, the availability of registered nursing staff, and the staffs' own perceptions about pain or the participants' level of pain. Analgesic medications prescribed routinely were always administered, however it is likely that these were inadequate or inappropriate given the level of pain expressed by the participants in this study.

All the participants in this study suffered with multiple sources of pain. Some of the words the participants used vividly describe the extent of their pain as the following shows.

'throbbing, like an electric shock, sharp, gnawing, burning, stinging, aching, dull, sore, awful, bad,

horrible, like living hell, murder, ugly, terrible, shocking, excruciating, discomforting, distressing, nagging, niggling, or severe'. (Participants 1–13)

One does not need great imagination or to have had pain in order to envisage pain that is both constantly painful and distressing.

## Overwhelming pain

Overwhelming pain was pain that was extremely intense and also unpredictable. It often took the participants by surprise as they attended to their everyday lives. Worse still was that it was pain that was always punctuated by pain that was present elsewhere; less distressing, but nevertheless present.

Unlike the pain Deslie had every day as a result of widespread arthritis and Paget's disease, episodes of overwhelming pain were so complete as a presence and overpowering that Deslie, not knowing what to do with herself, could not hide her pain. As she said,

'But when it is really cold, oh boy, oh boy! I have sat down in the big room [the common room] and I've tried to go down there, and I have been sitting down there and I haven't known where to put meself [sic]. I can't hide my heart... the way it has got me. Oh the pain it's so shocking'. (Deslie)

As the months of the study passed, Deslie's pain worsened. While some pain relief measures were being taken by staff, they were clearly inadequate. As Deslie said,

'I am crying out for help, I really am. It is day in and day out and it is wearing me down. I said, "I don't know what to do with meself [sic]". I get so uncomfortable and miserable... When I try to move all this ugly pain goes through me now. But I have to yell when it is real bad... well I have been sitting down in church on a Wednesday there, like in the Church and I would go to move, Oh! I would let out a yell because you have got no control over it you know it just hurts so much'.

In this excerpt, Deslie tells us that she 'had to yell' in response to the overpowering nature of her pain. The pain had become so relentless and so severe that Deslie could no longer control it. The misery she felt was the legacy of her pain and she had lost her battle with it. Ultimately, what the participants wanted was a release for overwhelming pain.

## Unvoicing pain

'Unvoicing pain' shows how participants hid their constant every day pain as they attempted to subvert their responses in order to get on with their lives. To dwell with the presence of unrelieved pain by giving it a voice was to risk being marginalized further from any social contacts and from the nursing staff on whom the participants were dependent. 'Unvoicing pain' meant the participants often withdrew into their own world.

Tony described himself as 'an independent sort of bloke'; he could 'take' a lot of pain, and he had 'taken a lot of pain in his youth'. Taking pain was an indication of his strength and resilience. Tony, however, learned first hand the failure of words,

'When I was at [hospital] – they were a worse lot of nurses. One, they wouldn't take any notice of you. You would ask them and they would just walk away as though they didn't hear you. If you wanted anything done, you had to say "please" for each one. Will you do that please, will you do that please, will you do this please. You can't say "will you please do so and so, will you please do so and so". It doesn't work... There was a chap next to me... and he used to be calling out and he used to be in pain. He was calling out to the sisters and they wouldn't come and I pressed the buzzer. And they used to book it down against me. I get bad circulation and when they touched the sheet, any part where they touched the sheet it used to burn like it had a candle underneath it, and I couldn't move my foot and I used to hold on to the buzzer for a long time sometimes until they come and moved me foot. Anyhow the sister asked me if I used the buzzer seven times last night. I said "I didn't use it". It was for the chap next to me. In the end she said, "it's not fair to go on", and I said "it is not fair to go on crook at me like this either". She said "right, into isolation you" and that's where I went. Put a curtain around and went away and left me. Left me there for the rest of the night'.  
(Tony)

The nurses who walked away 'as if' they did not hear Tony sadly reflect the poor quality of care provided in this situation. Tony knew the nurses had heard him but chose not to respond which shows how complaints of pain can alienate. 'Isolation' as a form of punishment for complaints reinforces the power and control that health carers have over those with pain and it is these actions alone that reinforce the imperative to 'unvoice' pain.

## Discussion

From their descriptions, the participants revealed that to have pain in old age while living in a nursing home is to be constantly pained. Pain and pain relief were rendered unimportant by caregivers; nurses and physicians alike. Responses to pain and the need for pain relief were often overlooked, subsumed to routines, other priorities and the expectation that pain was an integral part of growing old. The experience of pain for the elderly people in this study was understood as something necessarily experienced because of their age and that there was little if any hope for relief. Ultimately, pain was rarely spoken about. Its existence was smothered in silence or words that veiled its presence. Putting up with pain was a common response to questions about the experience of pain and the pursuit of relief from pain. Not wanting to worry or bother nurses was also a frequent comment. Participants simply 'put up with pain' as an attempt to dismiss its significance because past experience suggested that help would not be forthcoming.

## Conclusion

That the incidence of chronic unrelieved pain is high in nursing homes is unacceptable. Indeed, it calls for nursing leaders to lobby government bodies to fund research in this group in order to address studies designed to determine the most effective approaches to managing pain in this population. Research questions that need to be considered include, for example: What is the most effective method for assessing pain in elderly nursing home residents including those with cognitive impairment? What are the most effective pharmacological and non-pharmacological approaches to managing the most common pain types found amongst the nursing home population? What role do complementary therapies play in the relief of chronic pain? What combination of pharmacological and other strategies are effective for managing chronic pain in nursing home residents? What is the impact of the use of mechanical devices for lifting on pain? What are the knowledge needs of health care workers in nursing homes in order to ensure effective management of chronic pain? What are the knowledge needs of elderly people in nursing homes in order to ensure pain relief? What are the long-term effects of chronic pain on elderly people in nursing homes? How do the physical and social environments of the nursing home impact on levels of pain?

Nursing leaders need to be aware that effective care for elderly people with pain in nursing homes must

relate to their situation, the possibilities that are available to them that include the elderly person's understandings of the world, their meanings, practices and personal concerns. In order to engage in caring practices, nurses and other health professionals need to be able to understand the perspective of the person in their care in relation with other people and the world in which they live. Because elderly residents often live with pain made worse by some of the activities of nursing home staff and other residents, staff need to be attentive to the presence of pain and to the individual's preferences and needs in relation to pain. More attention needs to be given to acknowledging the presence of pain, to listening to the concerns of elderly residents in relation to their pain and allowing them to have more say in what happens to them. By being more mindful about the presence of pain in elderly residents and mindful of approaches to daily care and routines that might exacerbate a resident's pain, nursing home staff may make a profound difference to the resident's lives. Attentiveness to care exemplified by tenderness, gentleness, carefulness and unhurried approaches may reduce the impact of care activities on the experience of pain. The extensive use of mechanical devices for lifting, whilst sometimes the only option for moving a resident from one place to the next, should also be considered in the light of the possible distress, pain, and injury it might cause frail and debilitated bodies. A more human and safer approach for some residents might be for staff to take time to manually lift residents with pain using their knowledge of the mechanics of lifting and safe practices rather than the routine use of mechanical devices.

Registered nurses also need to monitor closely the activities of unqualified staff. As in adults in the general population, elderly people require knowledgeable nurses who are able to detect, assess and help manage chronic pain, and when necessary administer and titrate analgesic medications, take action to prevent side effects, and monitor for signs and symptoms of adverse effects. It is a concern that unqualified staff provide most of the direct care to elderly residents in nursing homes when they are not educationally prepared to undertake many of the complex tasks, including those involved in pain management. Registered nurses should ensure that unqualified staff is not responsible for residents requiring complex care and they should also ensure that the activities of unqualified staff does not exacerbate the pain of elderly residents. Unqualified staff also need to be made aware of the basic tenets of lifting and moving residents safely. For all nursing home staff, listening attentively, observing mindfully and seeking guidance, as the most appropriate approaches to care in order to

reduce pain may also help. Speaking kindly and with respect that acknowledges the elderly resident's place in the world as an intelligent, experienced adult and not as a child, may assist in elevating their sense of self-worth and value in the nursing home and in society.

Acknowledging long-held likes, dislikes, preferences and interests may also help to retain the elderly residents' sense of individuality and self. By recognizing the power of pain to take over, nursing home staff will be in a better position to provide the skilful care that is needed to reduce elderly residents' pain. Ultimately, understanding human beings in particular situations and contexts allows us to be more effective, skilful and compassionate carers (Benner & Wrubel 1989, Von Dietze & Orb 2000).

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