



The fragmented story of pain: A saga of economic discourse, confusion and lack of holistic assessment in the residential care of older people

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Summary The long-standing problem of overlooked and/or undertreated pain experienced by so many older people living in Australian residential care facilities condemns these people to a life robbed of quality. Such a degree of suffering experienced by older people calls into question the pain assessment skills of staff who work in residential care. However, the problem of undetected and unresolved pain experienced by older people is not simply a skill or knowledge issue. It is much broader than that.

In this paper we portray pain as likened to a story; a narrative that only the older person, as the author, can impart and one in which only they can communicate their experience of pain. Nevertheless, as opposed to seeking the older person's pain narrative, nurses attempt to measure the immeasurable. In part, their actions relate to the confusing terminology which envelops pain assessment. However, political policy and economic discourse also influences nurses' pain assessment practises to the detriment of older people and the profession of gerontological nursing.

Discussion in this paper includes the experience of pain for the older person, an overview of the specific role of pain-screening tools compared with the requirements of a person-centred pain assessment, and person-centred pathways to help nurses and others interpret and heed the older person's pain story. Analysis also incorporates the argument that current and previous Federal Government funding tools for residential care subtly impact on holistic pain assessment causing confusion for caregivers and fragmentation of the older person's pain story.

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Introduction

For older people and people living with dementia, their experience of pain is comparable to a story, which only the older person themselves can “write”. As the author of the story, the older person has a unique “pain signature” revealing the way in which they express their feelings about pain (Herr, 2002, p. 66). Interpreting the signature, though not always easy, is possible. However, human beings are curious creatures as they often read stories, which they choose by the cover of the book, as opposed to the value of the narrative under-the-cover. Pain does not make for gripping reading, and busy staff frequently believe that they do not have the time to read what to them is an inevitable saga, or in all probability, simply fiction.

Unfortunately, for those who consider the story worthwhile reading, the influence of several factors beyond their control leads to a struggle to comprehend the “story”. Consequently, our purpose in this paper is to clarify significant factors which cause many direct caregivers and Registered Nurses (RNs) to forsake the older person’s story and instead embrace concepts such as behavioural management and objectivism. By clarifying these issues, perhaps the older person’s pain story finally will be valued, heard, and heeded.

We begin this paper with discussion about pain prevalence and the impact of pain for older adults in residential care. Further discussion involves those requirements essential to completing a person-centred pain assessment followed by clarification of confusing terminology inferring that pain-screening tools are the same as a comprehensive and person-centred pain assessment. Finally, we provide an overview about the way in which Government funding tools have influenced and continue to influence the way in which caregivers and RNs assess and understand pain in older people living in residential care. An inclusion of the gamut of issues related to pain and older people is beyond the scope of this paper hence references are included to other articles for more detailed discussions about several important issues raised.

The epidemiology of pain

Nationally and internationally 70–80% of people living in residential care regularly experience pain (Department of Health & Ageing (DoHA), 2008a; Horgas, Nichols, Schapson, & Vietes, 2007), and for many of these people, it is an untreated and unrelenting experience (Bjoro & Herr, 2008). This is particularly the phenomenon for people living with dementia (Shega et al., 2007). It would be reasonable to argue that pain is endemic in residential care in Australia and in similar institutions in most other countries (e.g., Karp, Shega, Morone, & Weiner, 2008; van Herk et al., 2009; Vargish & Levine, 2007).

Understandably, the lived experience of pain faced by older people and in particular, people living with dementia, is described as one of the most neglected areas of residential care and subsequently, of the nursing profession (Cairncross et al., 2007; Scherder et al., 2009). It would appear that

stories are many, but readers require motivation, education and support.

The elusive nature of pain

Pain is a uniquely personal experience (Bjoro & Herr, 2008), which means only the person experiencing the pain can express or describe its intensity and related salient issues. For this reason, self-report of pain is considered the gold standard in keeping with the universally accepted definition by McCaffery and Pasero (1999) that pain is “what the experiencing person says it is, existing whenever he says it does” (as cited in Pasero, 2009, p. 50). Ferrell explains that McCaffery’s definition provided “a foundation for respect of people in pain” (2005, p. 88). Her definition presents a significant person-centred pathway for pain assessment of older people and people living with dementia – that is, all human beings are of absolute value and worthy of respect, and are entitled to be consulted about their pain, no matter their disease, disability or frailty (Kitwood, 1997).

However from McCaffery’s definition there also is an inference that challenges will emerge to effective pain assessment and treatment when older people cannot accurately self-report their pain. Without doubt communication difficulties do present many challenges, particularly when untrained caregivers comprise the body of staff in a residential care facility and RNs are not easily accessible (Holloway & McConigley, 2009). However a significant number of older people, particularly people living with dementia, can self-report their pain under the *right* circumstances (Herr, 2002; Pasero, 2009; Pautex et al., 2006). Staff members prepared to learn about the older person’s pain story are responsible for providing the best possible circumstances to facilitate this process. For a more thorough explanation of what such circumstances entail refer to Ferrell (2005), Hicks (2000), and Parke (1998).

Untreated pain may relate to staff members’ (or older people’s) convictions that ageing is the cause (Gagliese, 2009). McClean laconically portrays this issue as: “Fred went to the doctor complaining of a painful left foot . . . the doctor said: “*Fred, it’s just old age*” “*Well*” said Fred, “*how is it that my right foot is not painful when it is the same age as the painful left one?*” (2000, p. 8). Ageing does not cause pain, nevertheless, associated with growing older are increased risks of developing painful conditions (Gagliese, 2009).

In addition, there are numerous common examples of how pain presents in an atypical manner, particularly pain associated with masked cancers and fractures (Lawson & Richmond, 2005). The atypical nature of pain presentation in older people often also goes hand-in-hand with normal vital signs. Caregivers and RNs need to be cautious that during assessment, if vital signs are normal, they do not presume the absence of pain (Herr, Coyne et al., 2006).

There are many other important barriers to hearing and heeding the story of another person’s pain, and staff members at all levels need to be aware of these barriers. Those interested in learning more can find detailed discussion elsewhere (e.g., Bruckenthal, 2008; Cohen-Mansfield & Creedon, 2002; Gibson & Weiner, 2005; Horgas, 2003; McAuliffe, Nay, O’Donnell, & Fetherstonhaugh, 2009).

The lived experience of pain for older people

The narratives of pain experienced by older people are those of an emotionally frustrating experience, involving unpleasant bodily sensations (Morley, 2008). Such an experience is worse when no apparent objective biologic markers confirm pain presence (Pitorak & Montana, 2004). For older people, their untold stories of persistent pain may include terrifying and isolating experiences, frequently intensified by the onset of depressive symptoms and anxiety (Bruckenthal, 2008; Cairncross et al., 2007). Moreover, for many people, pain leads to feelings of vulnerability (Öhman, Söderberg, & Lundman, 2003) and loss of a sense of identity – that feeling of being a unique person (Morley, 2008).

Often the story of pain is one of the intense emotional angst and of envisioning a life robbed of quality. As one older woman explained, “*Living with pain is a contradiction in terms. Why? If you are constantly in pain, you don't have a life*” (Kumar & Allcock, 2008, p. 4). Thus, it is not surprising that pain holds the potential to wreak havoc on a person's physical, emotional, and social well-being, ability, and leisure opportunities (Herr, Bjoro, & Decker, 2006; Cowan, Fitzpatrick, Roberts, While, & Baldwin, 2003). Living with pain places older people at higher risk of loss of appetite leading to weight loss, sleep disturbance, loss of continence and mobility, increased risk of falls resulting in catastrophic outcomes, and even mortality (Cowan et al., 2003).

Unfortunately, if an older person's behavioural response markedly changes because of their pain it is common for staff members to believe that the person has a “behavioural problem”, as opposed to pain (Cohen-Mansfield & Creedon, 2002). Psychotropic medication rather than pain relief then becomes the panacea for the “problem” (Cohen-Mansfield & Creedon, 2002; Shega et al., 2007), the pain persists (Vargish & Levine, 2007) and the story remains untold or ignored.

It does not need to be this way if staff members attempt to interpret the person's pain narrative.

Person-centred pain assessment

The first step in the process of pain assessment involves attempting to elicit the older person's story of pain using the “right” question (Cowan et al., 2003; Pautex et al., 2006; Scherder et al., 2009). Even though the older person may not use words nurses might commonly employ to describe pain, the person is expressing their experience – their story. For example, Pitorak and Montana (2004) state that for many older people, being asked questions such as “are you in pain?” or “do you have pain?” may result in a “no” response, because the person may not realise that the “burning”, “tingling”, or “electric current” they are experiencing is actually pain. However, they may affirm pain if asked about “hurt”, “ache”, “discomfort”, or “sore”. According to these authors, one of the most common terms used by older adults to describe their pain is “hurt” (Pitorak & Montana, 2004, p. 418). The question that elicits a positive response is intrinsic to the narrative of pain for the person and requires recording in their care plan. The plan requires a section designed specifically for self-report questions and

answers in order that other members of the health care team may use the same or similar terms when reassessing the person (Pitorak & Montana, 2004).

If initially a person self-reports their pain, caregivers do not need to undertake pain screening but instead contact the RN or the General Practitioner (GP) for comprehensive pain assessment including physical, social, emotional, environmental and functional domains (Bruckenthal, 2008). More information, assessment and investigations may be required before the person-centred care plan is completed. In the process of assessment, if appropriate, RNs or the person's GP should request the implementation of an analgesic trial, using recommended nonopioid commencement doses for mild-moderate pain, or opioid commencement doses for more severe pain (Pasero & McCaffery, 2005), and/or adjunct therapies including complementary and alternative medicines (Horgas, 2003).

Furthermore, important information to be gathered includes the person's biography, personality, sensory disabilities, spiritual issues, emotional state, and the social and physical environment as these factors have a possible impact on the pain experience (Bruckenthal, 2008). Merely concentrating on physical causes of pain will not always result in effective pain relief, and increased life quality for the older person (Morley, 2008).

The overall aim of pain assessment is to guide all staff in the preparation of a care plan and strategies to ensure pain relief (Bruckenthal, 2008) so that the narrative ending reads that the author is free from pain. The final care plan should incorporate assessment information and other data gathered that is unique to the person experiencing the pain (Hadjistavropoulos et al., 2007).

During this process, all direct caregivers and RNs need to actively involve the older person and/or their representatives in steps of decision-making (Ferrell, 2005). This is especially important for developing interdependent relationships and for understanding historical and biographical narratives about the person's previous health and their manner of expressing and/or coping with pain (Kitwood, 1997).

Moreover, some time ago, Parke (1992) wisely counselled that staff needed to take for granted that older people and people living with dementia experienced pain until proven otherwise. Her ideas have not changed, as evidenced by the American Pain Society (2003) whose representatives also counselled that when making such an assumption an analgesic trial may be worthwhile as this can be a diagnostic and therapeutic approach.

Nursing knowledge regarding the type of pain a person experiences also is essential. For example, neuropathic pain is difficult to treat, not relieved by common analgesics and may cause the person to be hypersensitive to touch, heat or cold (Callin & Bennett, 2008). Therefore, commonly used aids to pain relief such as massage, heat or ice packs can prove extremely painful for these people (Batavia, 2004). Consequently, the assessment needs to include identification of the type of pain the person is experiencing (whether nociceptive, neuropathic and/or mixed category pain) (Horgas, 2003), and possible causes or contributing factors to ensure treatment prescribed is appropriate and does not in fact exacerbate the pain experience (Callin & Bennett, 2008). Regardless of the frequent suggestion that caregivers require further education in pain assessment and

management (Holloway & McConigley, 2009), these complex issues are nursing issues and not within the realm of knowledge that should be required of unlicensed caregivers.

Often it is wise to assess a person's pain over an extended period of time (Hadjistavropoulos et al., 2007). An effective way to do this is to compare the person's usual behavioural communication of feelings to changes that take place during a pain episode (their pain "signature") and/or movement including the provision of personal care or activities, and particularly after analgesia administration (Herr, Coyne et al., 2006).

The final and perhaps most important issues requiring attention are firstly, "knowing" the older person; being-in-relation-with and including the person in every decision, and secondly, and most importantly, "patience" by the nurse (Miller et al., 2005, p. 162). Pasero advises that an assessment framework of this nature "serves as the foundation for developing a sound plan for the treatment of ongoing pain" (2009, p. 53). For further information about pain assessment, readers can refer to articles by Bruckenthal (2008), Hadjistavropoulos et al. (2007), and Miller et al. (2005).

Terminology: screening versus physical and other assessment processes

It can be confusing when terms are used interchangeably, for example, "pain scale/screening/" and "a pain assessment". The use of reliable pain scales as screening tools enables many older people and people living with dementia who have difficulty with communication to identify the location and intensity of their pain through pointing to or marking a specific word, number, picture, or point, for example, on a pain map.

Behavioural observation tools assess behaviours suggestive of pain, for example, facial expressions like grimacing, verbal expressions such as shouting, withdrawal, anxiety, and temperament (Stolee et al., 2005). Observational screening tools enable identification of possible pain when a person's behavioural communication noticeably changes (Miller et al., 2005).

Essentially, screening during the assessment process provides a variety of *clues* unique to each tool used, but does not provide all the information to complete the 'story' of pain (Herr, Bjoro et al., 2006; Joint Commission Resources, 2008). Therefore it is imperative that nurses are careful not to confuse a pain-screening tool with a pain assessment. The purpose of a screening tool is to identify that a person *may* be experiencing pain. For detailed reviews of different pain screening tools refer to Hadjistavropoulos et al. (2007) and Herr, Bjoro et al. (2006).

Pain tools provide little information regarding the possible cause of the pain, barriers to effective pain relief, and the impact of pain on the person's physical, social, emotional and spiritual health and wellbeing. What many caregivers fail to understand is that pain tools "are not designed as diagnostic tools but they can be useful in highlighting the need for a more detailed clinical assessment" (Callin & Bennett, 2008, p. 213). Whereas, a person-centred pain assessment provides the possible cause and avenues for treatment and resolution of the person's pain and

distress – the most complete story possible under the circumstances.

Melding wisely suggests that, while pain screening can be beneficial, "there is no substitute for ... direct enquiry, clinical intuition, and commitment to alleviate pain ..." (2002, p. 6). Intuition is a blessed gift while rationality is a dependable servant (Radin, 2007). Regrettably, health care professionals and others honour the servant (the score) and overlook the gift (the intuitive ability to understand the story). Undertaking person-centred pain assessment requires honouring both the servant and the gift.

Consider the following common scenario and the way in which the caregiver applied the pain tool/s nominated by the facility and the sequence of events following on from her findings. Imagine a person living with dementia ('Mary') who the caregiver found sitting on the edge of her bed during the night, groaning and crying. Mary lived with dementia and added to this, she was distressed and as a result at that moment in time, she could not communicate to the assistant about her pain. The caregiver asked Mary if she "hurt" anywhere. Mary rubbed her spine. The caregiver showed her a large photograph of a vertical thermometer with words down the side and asked Mary if she could point to the place on the thermometer which best described her "hurt". Mary pointed to the top of the Iowa Pain Thermometer indicating the "most intense pain imaginable" (Herr, Spratt, Garand, & Li, 2007, p. 588). The caregiver knew Mary well, having helped her to bed most nights during the months since Mary's entry to the facility. She was aware that Mary was very different in her behaviour that night, particularly in her posture and facial expression. The pain-screening tool, her intuition, and her observations alerted the assistant to the need for a comprehensive pain assessment for Mary. To help Mary find a degree of relief from her pain until morning staff arrived, she contacted the Medication Endorsed Enrolled Nurse (EEN) on duty as the supervisor of the low care facility. The EEN provided Mary with the "as needed" mild pain relief recorded on her medication chart.

In the morning, the caregivers contacted the on-call RN from the co-located facility nearby and asked if she would join them in a staff meeting. The meeting included Mary and her daughter, who when contacted was eager to participate in any strategy to make her mother comfortable. After talking with her daughter, staff members discovered that Mary was about to undergo bone mineral density testing prior to entering the facility, however in the rush of admission, this was overlooked. The RN contacted the GP (the caregivers did not feel comfortable doing this) who visited and undertook a physical examination, which correlated with the findings of the RN's assessment undertaken earlier that morning. These examinations combined with the suggestion of osteoporosis indicated the need for an X-ray, which confirmed the presence of osteoporotic spinal fractures.

The GP undertook a medication review and suggested Calcitonin for pain relief according to Mary's diagnosis and pain severity, and a brief period of non-steroidal anti-inflammatory drugs (Papaioannou et al., 2002). The RN and caregivers consulted with Mary and her daughter and together they decided to implement care strategies including a warm shower prior to retiring; seeking advice from the

visiting physiotherapist about suitable exercises, and selecting an appropriate walking aid (Papaioannou et al., 2002). As staff members also observed exacerbation of Mary's spinal pain when she was lying flat, they obtained a specially designed pillow to support Mary in a semi-recumbent position when she was in bed. Soon, staff members observed noticeable amelioration of Mary's pain – she was sleeping peacefully throughout the night. The RN and the caregivers documented all information from the pain screening and assessment, and the strategies implemented, in Mary's care plan. They also documented the need for the implementation of a fall prevention program and review date for the plan.

Most importantly in this scenario, comprehensive assessment and the X-ray helped to uncover the neurobiology of the pain which in turn guided the GP in prescribing adequate and appropriate pain relief and assisted staff in planning nursing care specific to Mary's disease and trauma (Polomano, Dunwoody, Krenzischek, & Rathmell, 2008). The pain thermometer and caregiver's observations provided valuable *clues* (Joint Commission Resources, 2008) but not the wealth of information and guidance for pain relief as did the person-centred assessment.

Without doubt, person-centred assessment is not as easy or convenient for busy staff as using a brief pain tool, but the assessment process proves to be comprehensive and informative and in the long-term saves considerable time, energy and resources. More to the point, when a person in pain is relieved of their suffering, they may again experience well-being and increased function (Cowan et al., 2003).

From a person-centred approach, it is the person's 'story' that matters (Feldt, 2007) – their experience of the world, past, present and future; their perception of pain and how they wish to be involved and consulted in pain assessment and relief. Only through intuitive, experiential, and interdependent relationships and holistic assessment can we understand the person's pain story. This in-depth understanding of older people's pain stories can be difficult though in the current Australian residential care environment as explained below.

The influence of economic discourse on how pain is recognised and assessed

Australia is in the unique position wherein the Federal Government links the funding of a facility directly with nursing assessment and relevant care documentation provided by the facility (DoHA, 2008c). However, if facilities use only those assessment tools listed in the funding instrument, it has the potential to affect care quality to the detriment of people living and working in the facility, and this includes the quality of pain assessment (Nay, 2008).

Regrettably, after many years of political policy which has focussed on nursing assessment and care-planning, a subtle transformation has taken place from the language of nursing and of healing older people to a language of 'economic discourse' (Angus & Nay, 2003, p. 130). The language of economic discourse holds the potential to increase the likelihood of unintentional harm for the older person

(Heggen & Wellard, 2004). An example is the lack of recognition in the funding tool that all behaviours are an act of communication, usually of an unmet need (Nay, 2008; Smith & Buckwalter, 2005). Frequently, the unmet need communicated by the older person is that of untreated pain (Nay, 2008; Smith & Buckwalter, 2005). Terms introduced in funding tools include 'kicking, pushing, refusal (to cooperate), and demanding' (DoHA, 2008c, p. 44). Many of these and other terms used in funding tools to-date to describe 'behaviours' were and remain indicators of pain (Smith & Buckwalter, 2005). However, often pain is not the first consideration for providers and others; the issue is that the more recalcitrant descriptions of the older person documented in their assessments (whether fact or fable) – the more funding the facility receives. Such a focus on funding disregards the older person (Nay, 2008; Venturato, Kellett, & Windsor, 2007) and in doing so, disregards the stories of their pain.

Another obstacle inhibiting holistic pain assessment is that the current funding tool emphasises the importance of 'medical, mental and behavioural diagnosis' (DoHA, 2008c, p. 6). Yet contemporary research has established that an overwhelming need exists to shift the focus of caring for older people and people living with dementia from the 'diagnosis' to the 'person' (Anderson & Hosier, 2009; Edvardsson, Winblad, & Sandman, 2008; Nygaard & Jarland, 2005; Smith & Buckwalter, 2005). One reason for this shift in focus is that diseased cells, including diseased brain cells, cannot suffer or become upset or distressed. As Barnett (2000) points out, only people can suffer, and these emotions happen for a reason. More often than not, the reason is physical and/or emotional pain. In support, Cohen-Mansfield and Creedon (2002), when discussing pain, point out that RNs frequently concentrate on an older person's medical or mental diagnosis as the explanation for their behaviour while rejecting other possible reasons, such as pain. These authors query: '[d]o the labels *behavior problems* and *attention-seeking* detract from the attention devoted to certain?' [people living with dementia] (Cohen-Mansfield & Creedon, 2002, p. 72).

Diagnostic information is essential demographic data for future planning therefore this category is important. However, the tool would be more accurate, ethical and person-centred if, while the diagnostic category remains, re-wording of the category related to behavioural disorders were to reflect behaviour as communication (Nay, 2008). Thus, communication requires nurses 'investigate', interpret and respond to the person's unmet needs (Nay, 2008) as opposed to seeking 'interventions' to manage the person's behaviour, including behaviour modification strategies (DoHA, 2008c, p. 145) to elicit the person's 'co-operation' (DoHA, 2008c, p. 147). Another issue of concern is that no mention is made of pain categories. 'Interventions' listed in the current tool, as claimable for funding for pain relief, are limited to technical equipment, massage and heat packs (DoHA, 2008c, p. 37) which as explained previously, may cause further distress for a person experiencing neuropathic or mixed-category pain. Noticeably absent is funding for certain complementary therapies which have been established through research as effective and safe and which many older people find valuable in pain relief (Cartwright, 2007).

It is distressing to read in one sub-category of the tool that financial claims are acceptable for “screaming that is not an unmet need” (DoHA, 2008b, p. 44). As all communication has meaning, surely an older person “screaming” should alert staff that something is terribly wrong. In support, a recent study confirmed the findings of a number of previous studies about screaming and people living with dementia: that is, screaming represents meaningful communication and is most definitely representative of an unmet need (Bourbonnais & Ducharme, 2010), often that of pain (Barton, Findlay, & Blake, 2005). Bourbonnais and Ducharme identified screaming “as a language that is unique to an older person but that can be learned” essentially when caregivers have increased contact with older people which enables them to decipher the language of screaming – the pain signature (2010, p. 11). The pain signature the researchers uncovered was that screaming was a unique self-soothing reaction to the constant lived-experience of suffering and distress (Bourbonnais & Ducharme, 2010). This begs several questions, firstly, how do caregivers determine if screaming does not represent an unmet need? Secondly, will those older people living with dementia who scream continue to suffer because of the influence of economic discourse which leads staff to believe that older peoples’ pain narratives are simply “behaviours that disturb others”?

Conclusion

The language of pain assessment should embody the person and their lived-experience of being-in-the-world at that moment in time, and in previous times. Hence, when undertaking comprehensive pain assessment, as evidenced in this discussion, it is the person’s ‘story’ that matters. While it is imperative that nurses comply with Australian Government regulations regarding funding, it is also crucial that they do not allow the focus or language of a funding instrument to influence their assessment skills or nursing discourse.

Holistic assessment requires that caregivers know and care for the older person within a relationship marked by trust and mutuality, and caregivers require support from a skilled RN during the assessment phase. Pain screening-tools and numerical scores represent important paragraphs in a chapter of the story but they provide only part of the narrative. Pain assessment needs to reflect the whole of the story, or at least the most complete pain account that caregivers and skilled nurses can ascertain.

Before reading the first chapter of the person’s story, caregivers and RNs must establish if pain screening is required or if the story begins with details of the person’s self-report and/or a diagnosed painful condition. The RNs’ knowledge of the assessment process will ensure that remaining chapters of the person’s story are holistic and comprehensive. This holistic and person-centred approach to pain assessment is essential to ensure that the final chapter of the pain story of the older person and the person living with dementia ends with pain relief and comfort. Nevertheless, the story will remain fragmented unless skilled RNs or community-based Nurse Practitioners are available to assist caregivers in every residential care facility, regard-

less of whether the classification of the facility is high or low care.

Conflict of interest

There is no conflict of interest in relation to the preparation of this article.

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