

Résumé

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## **Étude qualitative sur le point de vue des personnes âgées et des aidants naturels quant à l'évaluation et au traitement de la douleur**

**Ronald Martin, Jaime Williams, Thomas Hadjistavropoulos, Heather D. Hadjistavropoulos et Michael MacLean**

La documentation disponible donne à penser que la douleur chez les personnes âgées, en particulier celles atteintes de démence, est sous-évaluée et sous-traitée. Dans le cadre de cette étude qualitative, des personnes âgées, du personnel infirmier de première ligne, des administrateurs de résidences pour personnes âgées et des aidants naturels de personnes âgées souffrant de démence donnent leur point de vue sur la manière dont on évalue et on traite actuellement la douleur. L'opinion des participants complète les résultats de recherche cités dans la documentation. Même si certaines explications et solutions possibles concernant le sous-traitement de la douleur chez les personnes âgées font écho aux points de vue exprimés dans la documentation, les participants ont également mentionné des facteurs et des solutions qui ont été pris en compte de manière moins formelle, comme les obstacles systémiques à une évaluation et un traitement efficaces de la douleur. Ils ont également souligné la nécessité d'avoir d'autres stratégies en plus de la médication pour contrôler la douleur. Cette étude examine l'impact de ces résultats.

Mots clés : douleur, personnes âgées, démence, évaluation de la douleur, traitement de la douleur

# **A Qualitative Investigation of Seniors' and Caregivers' Views on Pain Assessment and Management**

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The literature suggests that pain in the elderly, especially among seniors with dementia, is under-assessed and under-treated. This qualitative study solicited the perspectives of seniors, front-line nursing staff, nursing-home administrators, and informal caregivers of seniors with dementia on the current status of pain assessment and management. The views of these participants complement the research findings reported in the literature. While some of their explanations and potential solutions concerning under-treatment of pain in seniors echo views that have been presented in the literature, the participants also pointed to factors and avenues that have been given less formal consideration (e.g., systemic barriers to effective assessment and treatment of pain). They also highlighted the need for pain-control strategies beyond medication. The implications of these findings are discussed.

**Keywords:** pain, elderly, seniors, dementia, pain assessment, pain management

Most chronic health problems that are associated with aging, such as arthritis and osteoporosis, carry a substantial burden of pain. As a result, pain is a common preoccupation among older adults (Parmelee, Smith, & Katz, 1993; Roy & Thomas, 1986). In their survey, Cook and Thomas (1994) found that 50% of older Canadians reported experiencing daily pain and another 28% reported experiencing pain at least once during the previous week. In a study with elders living in the community, 86% reported experiencing significant pain during the previous year, with close to 60% reporting multiple pain complaints (Mobily, Herr, Clark, & Wallace, 1994). Pain is also a pressing concern for seniors who live in institutions (Chiou & Buschmann, 1999). Proctor and Hirdes (2001) conducted a large-scale study with seniors living in nursing homes and found that overall pain prevalence was 49.7%, with 23.7% of the residents experiencing daily pain. Marzinski (1991) examined patients' charts in an Alzheimer unit and, consistent with the idea that dementia does not spare a person from the many sources of pain that might afflict others, found that 43% of the patients had painful conditions. Proctor and Hirdes (2001) conclude that the association of pain with conditions that typically cause pain is comparable for seniors with and without dementia.

This finding complements those from several other studies, involving a wide variety of methodologies, and suggests that seniors with and without dementia react similarly to painful stimulation (e.g., Gibson, Voukelatos, Ames, Flicker, & Helme, 2001; Hadjistavropoulos, LaChapelle, MacLeod, Snider, & Craig, 2000; Porter et al., 1996).

Despite its high prevalence, pain is largely under-treated among seniors. This was recognized in a recent large-scale survey of the membership of the American Pain Society and the American Academy of Pain Medicine. Specifically, Ferrell et al. (2001) found that the under-treatment of pain among seniors represents one of the most pressing ethical concerns for pain clinicians. For example, although findings suggest that psychosocial interventions for pain in seniors are effective (e.g., Ferrell, Rhiner, & Ferrell, 1994), only rarely do seniors receive psychosocial treatment. The under-treatment of pain is especially pervasive among seniors with cognitive impairments. For example, Marzinski (1991) found that, although 26 of 60 patients with Alzheimer disease had painful conditions, only three patients were routinely given analgesics. Further, Kaasalainen et al. (1998) found that almost half of cognitively intact patients were receiving scheduled pain medications, compared to only 25% of those with cognitive impairments. Other investigators have reached similar conclusions (e.g., Horgas & Tsai, 1998).

Numerous reasons have been offered for the under-management of pain among older adults. Sengstaken and King (1993) found that physicians often fail to detect pain problems among seniors with neurological problems. Kapp (2003) argues that the under-treatment of older patients is a function of the fear of litigation and concern about the high cost of medication, particularly in the case of for-profit Health Management Organizations, in the United States. Other reasons that have been cited include a possible reluctance on the part of seniors to discuss their pain (believing that pain must simply be endured), fear of addiction to opioids, and the belief that pain is a natural part of aging (Hadjistavropoulos & Craig, 2004).

The various explanations that have been provided for the under-management of pain among older adults are largely based on the opinions of researchers in the field. We decided to take a novel approach and seek the perspectives of seniors and front-line nursing staff on the current status of pain assessment and management. We also chose to solicit the opinions of nursing-home administrators and informal caregivers of seniors with dementia. We believed that the view from the grass roots would represent a fresh perspective and complement the views of experts in the area. We anticipated that, while some of these explanations and potential solutions concerning the under-treatment of pain in seniors would echo those found in the literature, they would also point to factors

and avenues that have not been given formal consideration. It was our hope that our findings would pave the way for the development and implementation of more effective ways of assessing and managing pain in this population. To achieve our objectives we chose to explore both pain assessment and management separately for seniors with and without dementia.

## **Method**

Focus groups consisting of up to nine participants were used to study concerns about pain assessment and treatment among seniors. We sought the perspectives of care recipients (i.e., seniors experiencing pain), informal caregivers of seniors with dementia, and health professionals. Focus-group discussions are a commonly used method in qualitative research. This method allows for the spontaneity of group interaction while maintaining the structure of an individual interview through the use of a moderator (Krueger, 1994). The dynamic interactions of the group allow for depth and insight into an issue (Seal, Bogart, & Ehrhardt, 1998).

### ***Focus-Group Participants***

Indices of saturation (i.e., repetition of material, confirmation of material across the groups) signified that we had a sufficient number (six) and variety of focus groups (Morse, 1994); that is, during analysis of the data, the themes would be repeated among the six groups and new material would not be uncovered towards the end of the analysis. Separate focus groups were formed for seniors, informal caregivers, and health professionals. There were two groups of seniors, one comprising those living independently in the community ( $n = 8$ ) and the other comprising cognitively intact nursing-home residents ( $n = 4$ ). There was one group of informal caregivers (persons providing care in their homes for relatives diagnosed with dementia) ( $n = 8$ ). Finally, three groups of health professionals were formed; two of these ( $n = 9$ ,  $n = 10$ ) included roughly equal numbers of registered and practical nurses (11–31 years' experience), while the third comprised nursing-home supervisors and administrators ( $n = 6$ ).

The group of community-dwelling seniors was recruited through advertisements at a seniors' centre inviting the participation of those with past or current pain problems. The group of nursing-home residents was formed via contacts (i.e., nominations) provided by the facility's administrator; the administrator identified residents with pain problems who would be well enough to participate in a focus-group discussion. The informal caregivers were recruited through the provincial Alzheimer society. Both groups of nursing staff were recruited through local nursing

homes via nomination (as it is often the case in focus-group research — see Patton, 1990); that is, nursing-home administrators were asked to nominate experienced staff members who had worked with seniors experiencing pain. The nursing-home administrators themselves were recruited through an announcement made during a meeting of administrators of long-term-care facilities in a mid-sized metropolitan area. The voluntary nature of participation was stressed in all cases.

### ***Procedure***

The researchers developed moderator guides (i.e., predetermined sets of open-ended questions regarding the assessment and treatment of pain) for each of the focus groups.<sup>1</sup> The majority of the questions were similar for all of the groups as they dealt with core topic areas in the assessment and treatment of pain (e.g., “How is pain assessed?”; “What concerns do you have about the way pain is assessed?”). However, some questions were specifically included to gather data pertinent to seniors with dementia.

Following approval by the Research Ethics Board of the university and that of the local health region, verbal and written informed consent (including consent to audiotape) was obtained from all participants. The participants were assured of the confidentiality of the focus-group discussions and were informed that only anonymous quotations would be included in written reports. Finally, they were told that all materials derived from the investigation would be kept securely in keeping with professional standards. A member of the research team acted as the moderator for the focus groups. The moderator encouraged participation from all group members and used scripted probes to stimulate further discussion. In the event that a discussion became tangential, the moderator refocused the dialogue on the question being addressed. The moderator also asked participants to clarify any vague or ambiguous responses. Each 90-minute focus-group session was audiotaped and transcribed verbatim.

### ***Analytic Techniques***

Given the open-ended nature of the focus-group method, we chose a data-analysis technique (i.e., thematic content analysis) that facilitates the identification of central themes from the data by determining the presence of common words or concepts. Specifically, we sought to identify and categorize commonalities (as well as differences) in views on pain assessment/management in seniors. This approach also allows for the classification of words and phrases into more than one category. Prior to

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<sup>1</sup> The complete moderator guides are available from the authors on request.

analyzing the transcripts, we identified meaning units as the most basic component of our analysis. The meaning unit was selected because it is the smallest component of text that conveys a unitary, cohesive idea (e.g., "Medications don't help") (Frontman & Kunkel, 1994). Meaning units varied in length from a phrase to a paragraph.

The qualitative software package NVivo was used to facilitate the analysis (NVivo qualitative data analysis program, Version 1.3, 2000). NVivo was deemed suitable for this investigation because it allows for flexibility in coding the data and allows for searching and assessing relationships in terms of text and coding (Richards, 1999). Moreover, the internal graphical modeller was useful for exploring the relationships between the parts of the framework.

Using thematic content analysis (e.g., Lincoln & Guba, 1985), data analysis proceeded in the following way. First, the data were categorized into broad topics derived from the moderator guides (*pain-assessment issues, pain-treatment issues, impact of pain on quality of life, and issues specific to seniors with dementia*). The data were categorized separately for each focus group. Then, more specific sub-units (domains) were identified within the broad topics. To identify the domains, three members of the research team examined the moderator guides and identified the general areas of inquiry. Moreover, one researcher examined the transcripts to ensure that the focus groups proceeded as indicated by the moderator guides. The data were then categorized into the domains (separately for each focus group). The implications, criteria, and nuances of each topic and domain were discussed among the researchers and guidelines for categorization were developed to ensure trustworthy classification of the meaning units.

The meaning units, coded into the domains, were examined thoroughly for repetition of words, ideas, examples, and key phrases. This allowed for the identification of themes from the initial coding structure. It should be noted that even at this advanced stage of analysis, the data from each focus group were examined separately. This allowed the researchers to continuously clarify unique themes that were emerging from the different focus groups as well as common themes. The last stage of analysis was examination of the themes across the focus groups. To determine whether the themes were common, repetition of words, ideas, examples, and key phrases were considered. The labels associated with each theme were selected through discussion among three of the researchers. To enhance the trustworthiness of the coding process, members of the research team met regularly to resolve any discrepancies in the emerging framework. Throughout the coding process, following the constant comparative method, the framework was continuously revised to reflect the views of the team.

### **Trustworthiness of the Data**

As an index of trustworthiness (e.g., Curtis et al., 2001), a second researcher independently coded a randomly selected portion of meaning units (15% across all transcripts) into the established domains. Initial agreement between coders was reached 84% of the time. All discrepancies in coding were discussed and complete agreement was achieved. As a second index of trustworthiness, member checking was carried out using a procedure adapted from Lark and Croteau (1998). The member checking confirmed the trustworthiness of our analysis.

## **Results and Discussion**

The purpose of our study was to gather information on the assessment and treatment of pain among older adults. Four general topics were identified: *pain assessment among seniors*, *pain treatment among seniors*, *effects of pain on seniors' quality of life*, and *concerns specific to seniors with dementia*. Within each of these topics several domains were coded. The domains were then differentiated into themes (where applicable) and, in some cases, sub-themes. Table 1 illustrates the overall structure of the coding. Two of the topics (i.e., *pain assessment among seniors* and *pain treatment among seniors*) were elaborately coded into domains and themes (and two sub-themes). The other two topics (i.e., *effects of pain on seniors' quality of life* and *concerns specific to seniors with dementia*) were coded only into domains, because the data did not lend themselves to further elaboration (i.e., coding into themes).

### **Pain Assessment Among Seniors**

Analyses of the focus-group discussions on pain assessment among seniors were organized into four domains (*assessment methods*, *ways of improving assessment*, *assessment challenges and concerns*, and *positive aspects of assessment*), 27 themes, and two sub-themes.

**Domain: assessment methods.** Self-report was the most commonly identified means of assessing pain, especially among cognitively intact seniors. Participants reported using self-report to assess pain (in the case of caregivers and health professionals) or to make their pain known to others (in the case of seniors). This finding is not surprising given that most professional assessments of pain entail verbal input from the patient. For example, an informal caregiver stated, "They [the physicians] ask questions: How does it feel? Where does it hurt? What kind of pain is it? When did it start? When do you feel it?" However, most participants did not advocate the use of self-reported information in the assessment of pain among seniors with severe dementia. The participants frequently expressed concern regarding the ability of seniors with dementia to

understand questions about pain and to provide accurate and reliable information. However, nursing staff reported using self-report with both dementia and cognitively intact patients. With regard to assessing pain in seniors with dementia, nurses discussed the importance of asking simple, direct questions that require a "yes" or "no" response. They further indicated that this line of questioning provides a foundation for the remainder of the assessment. This suggests that nurses are aware that seniors with mild to moderate dementia may be able to provide reliable information about their pain (e.g., Hadjistavropoulos, von Baeyer, & Craig, 2001; Huffman & Kunik, 2000).

Other ways of assessing pain that were frequently mentioned (especially in reference to seniors with dementia) included observation of behaviours that signal the presence of pain (e.g., grimacing, furrowing of the brow, guarding, rubbing the affected area, physical withdrawal from touch) and changes in mood (e.g., irritability, impatience, frustration, depression) or behaviour (e.g., sleep patterns, eating patterns). Both self-report and behavioural observation were discussed in all of the focus groups. Even the community-dwelling seniors stated that their friends and family members often identified their pain by observing how they performed tasks. Physical examination and medical testing were mentioned less frequently as methods of pain assessment. Informal caregivers and health professionals said that they often served as an important source of information regarding pain. Caregivers, especially those who are very familiar with the older care recipient such as spouses or children, may be particularly adept at recognizing the more subtle signs and symptoms of pain. The following meaning units illustrate the use of behavioural assessment:

Health professional: *...the change could be shown in any number of ways, from not wanting to get up walking, or there's a change in behaviour, or resistance to care...a change...a cue.*

Health professional: *...body language, facial expressions.*

**Domain: ways of improving assessment.** Improved education of health-care providers was the most frequently identified theme in this domain, especially among health professionals and informal caregivers. Specific suggestions by professionals included continuing education (e.g., increased in-service presentations and satellite training events) and formal academic and supervised training. This theme was not identified within the seniors' groups.

All of the focus-group discussions indicated that a subset of health professionals may embrace myths about aging (e.g., believe that pain is a natural part of aging) that can hamper efforts to carefully assess pain.

**Table 1 Coding Structure of Topics, Domains, and Themes**

**Topic: Pain Assessment Among Seniors**

**Domain: assessment methods**

- Themes*
- pain behaviours
  - emotional and mood changes
  - facial expressions
  - self-report
  - caregiver report
  - medical examination or medical testing
  - change in behaviour

**Domain: ways of improving assessment**

- Themes*
- increased documentation and staff communication
  - improved assessment tools
  - more education
  - shorter waiting lists
  - greater accessibility to services
  - increased patient assistance
  - increased familiarity with person doing the assessment

**Domain: assessment challenges and concerns**

*Themes and sub-themes*

- lack of education
- long waiting lists
- inferior assessment tools
- lack of/inconsistency of staff
- assessments not thorough enough
- physician issues: lack of communication with patient; lack of/inefficiency of referrals
- subjectivity and individual differences in experiencing pain
- problems with self-report: limited communication; underreporting pain; reasons for underreporting pain
- limited documentation

**Domain: positive aspects of assessment**

- Themes*
- good physician-patient relationship facilitates assessment
  - assessment is thorough and fast
  - increased focus on assessment
  - assessment is facilitated by communication and a team environment

**Topic: Effects of Pain on Seniors' Quality of Life**

**Domain: limitation in social activity**

**Domain: limitation in basic life-sustaining activity**

**Domain: loss of independence**

**Domain: mood changes**

**Topic: Pain Treatment Among Seniors**

**Domain: management methods**

- Themes*
- rest and relaxation
  - holistic alternatives
  - information on pain
  - social and recreational activities
  - teamwork
  - exercise
  - attention from family, friends, and caregivers
  - medication
  - not telling others about the pain
  - distraction
  - talking about the pain
  - physical aids/manipulating the environment
  - living despite the pain

**Domain: treatment challenges and concerns**

- Themes*
- treating multiple problems
  - lack of treatment/undermedication
  - inefficiency of medication
  - medication side effects
  - medication options not explored
  - self-medication
  - lack of alternatives to medications

**Domain: positive aspects of treatment/ways of improving treatment**

- Themes*
- education
  - alternative/holistic treatments
  - interdisciplinary team approach
  - nursing staff teamwork/competency
  - medication options
  - willingness to prescribe medications
  - appropriate/specific prescriptions
  - active participation of the patient in treatment
  - positive physician-patient relationships
  - immediacy of treatment

**Topic: Concerns Specific to Seniors With Dementia**

**Domain: communication problems**

**Domain: difficulties in making physical adjustments**

**Domain: behavioural problems and concerns**

**Domain: misattribution of pain behaviours**

Although most medical schools and nursing programs provide some training in special populations, more emphasis may be required to address the specific concerns of seniors and to reduce the prevalence of erroneous beliefs about pain in old age.

Nurses were more likely than other focus-group participants to discuss the need for improvements in the documentation and communication of pain-related information in health-care settings. If the results of a pain assessment are not communicated to other staff members (e.g., documented in the older patient's medical chart), valuable information on pain in seniors may be lost (e.g., the timing, intensity, and correlates of pain). A health-care provider stated the following:

*I do believe that...there is sometimes lack of communication among the staff, because if there is a change...why not pass it on to the other nurses and make them aware? Or put a note that states, "Please continue doing this," and then the assessment can be more accurate.*

Less frequently identified themes (primarily arising in the community-dwelling seniors and informal caregiver groups) in this domain that could be beneficial for assessment included improved access to services (e.g., for assessment of dental pain), shorter waiting lists, and improved patient-physician communication (e.g., informing the physician of all potentially relevant information). Health professionals and informal caregivers expressed a need for better and more accessible assessment tools, especially those suitable for seniors with severe dementia.

**Domain: assessment challenges and concerns.** The most frequently identified theme in this domain was related to self-report. Closer inspection revealed that the meaning units within this theme diverged to form two distinct sub-themes regarding barriers to self-reporting information during pain assessment: difficulty communicating and underreporting pain. All of the groups noted that pain can be underreported by older adults for various reasons (e.g., stoicism, not wanting to bother others). In addition, the health professionals discussed a reluctance on the part of many patients to report pain for fear of being prescribed excessive amounts of medication and having restrictions imposed upon them. Further, all of the focus groups except the group of nursing-home residents noted that seniors may have difficulty describing the intensity and quality of their pain to health professionals.

Other themes included concerns that pain assessments are insufficiently thorough and that subjectivity and individual differences in the experience and expression of pain (e.g., gender differences in reporting pain) make assessment difficult. Participants also expressed the concern that health-care providers may not be receiving adequate education regarding the assessment of pain among seniors.

The following are representative meaning units from this domain:

Moderator: *Do you feel that pain is more likely to be ignored in seniors?*

Senior A: *...because we're grey and wrinkly and over the hill...*

Senior B: *Because you're getting older —*

Senior A: *— they don't —*

Senior B: *— you just get aches and pains when you're older, right?*

Senior A: *Definitely.*

Health professional: *If you talk to them [physicians] about someone with pain, well, "She's old, she's saggy, she's going to die, what can you do for her?" Instead of really looking at what the problem is and giving something that might help, whatever the situation is at the time. But they seem to think, "Oh, she doesn't have much longer to live, she's 80-something or 90-something; she's bound to have pain."*

Themes that emerged less frequently in this domain included long waiting lists for medical appointments to discuss pain-related problems, staff shortages, and the inconsistency of health-care staff in conducting pain assessments. These themes were identified primarily among the health professionals. These larger, contextual issues within the health-care system may result in either the neglect of pain assessments (in the face of more pressing medical issues) or assessments that are conducted quickly and in a cursory fashion. Nursing staff also mentioned staff shortages as a concern, saying they had a limited amount of time to conduct pain assessments. This is problematic given that seniors often need more time than younger people to convey information about their pain. The following statement by a health professional illustrates the time restrictions placed on front-line workers:

*There's not even extra time to talk to that person while you're getting them up in the morning...we don't have enough to give them an extra 5 minutes in the morning per resident so...you could find out that something is sore today. ...they may be telling you but you're not listening because you're so busy doing.*

Poor communication between physicians and patients, limited documentation of pain in medical charts, and the lack of adequate pain-assessment tools for seniors with cognitive impairments were also mentioned as obstacles to accurate pain assessment. For example, although the value of behavioural indicators of pain was discussed frequently, participants (especially nurses) were quick to point to a paucity of formal assessment tools that actually employ this method of pain evaluation.

**Domain: positive aspects of assessment.** Themes within this domain indicated that the pain assessments of many health-care providers are fairly frequent and thorough. Moreover, the participants acknowledged

that inroads have been made in terms of revising the curriculum of medical schools and nursing programs to cover the unique characteristics of older populations. All groups of participants noted that effective pain assessments are facilitated by good patient-physician relationships and a multidisciplinary or team approach. The health professionals discussed the value of having assessments conducted by nurses, physicians, aides, physical therapists and others, who then communicate their conclusions to one another.

### ***Pain Treatment Among Seniors***

The analysis of discussions on this topic revealed three domains (*management methods, treatment challenges and concerns, and positive aspects of treatment/improving treatment*) and 30 themes. In the original structure of this topic, *positive aspects of treatment/improving treatment* was treated as two domains. However, because further coding revealed significant overlap of content (i.e., participants reported that the positive aspects of treatment could often be used to improve the treatment), it was decided to merge the two.

**Domain: management methods.** The theme that emerged most often across all focus groups was the use of medications. The participants acknowledged that physicians have an array of pharmacological interventions at their disposal, including non-opioid analgesics, non-steroidal anti-inflammatory medications, and opioids. For example, one senior commented on the use of medication for chronic pain:

*...that's why I think I look so healthy, but people don't realize that I'm on long-acting medication and I couldn't go without it for...if I missed a dose...I would be in quite severe pain.*

Community-dwelling seniors frequently mentioned the use of assistive devices (e.g., canes) and physical accommodations (e.g., propping up an injured limb) in managing pain, noting that these forms of pain management are easy to implement and cost-effective. Nursing staff said that these methods were useful in managing pain among cognitively impaired and cognitively intact seniors. Alternatives (e.g., massage, acupuncture) to pain medications were discussed in all of the focus groups. This suggests a willingness to explore and incorporate alternative approaches into pain management and may reflect shifts in health-care training and societal attitudes towards pain interventions. Health professionals stated that measures such as massage and music therapy are sometimes implemented. An informal caregiver commented:

*I think that doctors are becoming more willing to refer, too, to some of the more holistic things, like chiropractors and massage therapists, than what they used to be.*

Participants also expressed the view that lifestyle choices may affect pain. This theme was particularly robust among seniors living in the community. For example, appropriate physical activity was seen as beneficial in managing chronic pain. Exercise, in addition to enhancing cardiovascular and musculoskeletal health, was viewed as helpful in maintaining and improving mobility and managing other aspects of chronic pain such as stiffness. Participants also acknowledged that regular physical activity (e.g., gardening, participating in social or recreational pursuits) may be helpful in managing chronic pain indirectly, by maintaining everyday functioning, building self-esteem and self-efficacy, and enhancing mood.

The participants agreed that physical activity should be balanced with rest and relaxation. This reflects an awareness of the value of pacing (i.e., scheduling rest periods before the onset or exacerbation of symptoms) as a coping strategy in chronic pain. Another coping strategy mentioned in all of the focus groups was the use of distraction; for some older adults, focusing on a task can be helpful in shifting their attention and awareness away from their pain. A few participants also noted the value of information on pain, carrying on with one's daily life despite the pain, talking about the pain in order to share the burden, and receiving attention from family, friends, and caregivers.

**Domain: treatment challenges and concerns.** The most commonly identified themes in this domain were untreated pain and under-medicated pain. These themes emerged primarily among the health professionals. The participants spoke of difficulties with "as needed" medications, including inconsistency of administration and lack of systematic protocol. In addition, they were troubled by the reluctance of many physicians to prescribe stronger analgesics (i.e., opioids) when more conventional analgesics cease to be effective. Concerns about under-medication of pain were especially prevalent during discussions of cancer pain in older adults. Nurses discussed the need for an effective dose and type of medication in order to make patients as comfortable as possible:

*We have a resident who has chronic back pain and her family physician told me specifically...we wanted something stronger for her pain...and her family physician told me that the neurologist said that she can't have any, and this lady has a brain tumour and she is dying and she is not very old and I am thinking...why are we worried...isn't it better to give her some quality to make her comfortable?*

Another common theme — identified in all of the groups — was concern about the side effects of pain medications (e.g., drowsiness, sedation). The participants indicated that seniors are more likely than younger adults to be taking other medications, as a result of the increased number of chronic health problems that occur with advancing age, thus

compounding the problems associated with adverse side effects. One senior commented on his difficulties with side effects:

*Give me stronger and stronger medication, making me stupider. The pain is still there. I can go to sleep, sleep for 5 minutes, and it's lucky if I get 5 minutes a night... I can't sleep with the pain... Those guys are so smart, they...kill you, make you sicker...stupid half the time.*

Nurses discussed the need for availability of different medication options. For example, without the option of using an analgesic patch nursing staff may be required to use pain medications in pill form, which could lead to problems with patient compliance, especially among patients with dementia. Themes that emerged less frequently in this domain included the ineffectiveness of many medications, patient self-medication, difficulties associated with treating multiple conditions, and the dearth of non-pharmacological alternatives.

**Domain: positive aspects of treatment/improving treatment.** The most frequently identified theme in this domain was the willingness of a subset of physicians to prescribe potent pain medications, especially stronger narcotics, for the management of severe cancer pain. The participants also noted that pain medications are often available in different forms (e.g., pills, analgesic patches), which enhances their flexibility and utility. These points were stressed primarily by health professionals:

*The doctors seem to be getting more at treating the pain and allowing the treatment to be done. Whereas it was really hard to get a narcotic order for someone who was really ill and...their final stages of life when I first started, but now...most of the doctors are...whatever they need to keep them comfortable.*

*We do have a range of options available to us now. Even in the area of just giving analgesic. At one time it was just oral or IM, but now we've got patches and we've got subcutaneous deliveries... We've got different delivery options as well. So I think that, too, is a positive in pain management.*

Seniors living in the community, informal caregivers, and nursing-home residents made the point that a positive patient-physician relationship is vital for effective pain management. Health professionals mentioned increasing education in pain management. Less commonly identified themes in this domain were the availability of alternative approaches to treatment, the immediacy of treatment, teamwork and competency among nursing staff, interdisciplinary approaches, and the active participation of the patient in treatment.

### ***The Effects of Pain on Seniors' Quality of Life***

During discussions about the effects of pain on quality of life, four domains emerged: *limitation in social activity, limitation in basic life-sustaining activity, loss of independence, and mood changes*. The most commonly discussed of these domains was *limitation in social activity*. All of the focus groups noted that seniors may be discouraged or prevented from engaging in social activities because of their pain. The participants also expressed a concern that older adults may become more reclusive and isolated over time. Common side effects of pain medications such as drowsiness and sedation were also noted as impairing social functioning. Limitation in everyday activities was seen as central. Hobbies (e.g., gardening, woodworking, card-playing) and other enjoyable pursuits (shopping, volunteering) were reported as being negatively affected by pain, as expressed by a senior participant:

*I could sit and play cards and all at once my thumbs, they get stiff. I can't move them... Or the fingers. They just stiffen up and you got to work on them, to loosen them up a bit. It's the golden years, right? Isn't that what it is?*

The participants said that even the most basic activities of daily living such as washing, dressing, and cleaning become difficult when pain is present. Further, they acknowledged that poor quality of life is most evident when functions that are necessary for survival such as sleeping, eating, and breathing become difficult due to chronic pain. The health professionals noted that difficulty sleeping, in particular, creates a cycle that exacerbates pain. One nursing-home resident said, "I can't walk, can't do exercise, can't do anything, so what do you do?" Such concerns were not mentioned by the community-dwelling seniors, likely because they are more prevalent among frail seniors residing in institutions. It was noted in all of the focus groups except the group of informal caregivers that chronic pain forces many seniors to seek support and assistance with everyday tasks. Some seniors perceived having to relinquish such tasks as losing their independence or becoming a burden to friends or family members. The impact of pain on quality of life was also said to cause negative mood shifts and a loss of independence. This was discussed in all of the focus groups. One senior commented:

*My biggest concern was that I was a trouble to my family. That's one thing. And...just why did I have to get this pain. ...I'm a great one in silence. I suffered in silence, I guess I'll put it that way.*

### **Concerns Specific to Seniors With Dementia**

Discussions on this topic yielded four domains: *communication problems*, *difficulty making physical adjustments to manage pain*, *behavioural problems*, and *misattribution of pain behaviours*. The most common of these domains was *communication problems* (i.e., limited ability of seniors with dementia to accurately convey pain-related information), which was prominent within the groups of formal and informal caregivers. The participants said that, because of communication difficulties, pain conditions are more likely to go unrecognized and untreated among seniors with dementia than among other seniors. As a result, seniors with dementia may be at increased risk for escalating symptoms and aggressive behaviours. The literature also suggests that pain problems tend to go undetected in people with limited ability to communicate (Biersdorff, 1991; Sengstaken & King, 1993).

Another prominent domain was *misattribution of pain behaviours* — a concern that overt signs of pain (e.g., behavioural disturbances, mood changes) are being incorrectly attributed to a dementing process, resulting in interventions that are misdirected. For example, several participants commented that seniors with dementia are sometimes given a neuroleptic medication when the underlying cause of their behavioural disturbances is pain. In such cases, the underlying pain may go unrecognized and untreated for long periods, resulting in prolonged and unnecessary suffering.

Less prominent domains were the concern, raised by health professionals, that pain may lead to more severe behavioural reactions among those with dementia, and the related concern that these individuals will have particular difficulty managing their pain (by, for instance, elevating a limb). This point is illustrated in the comments of three health professionals:

*I think the cognitively intact people get treated quicker, because they can tell you what they want and they can ask and the staff are more likely to respond to that, whereas people with dementia, it makes it much more difficult.*

*Well, with the dementia, it is usually the behaviour problems...people saying so and so is being difficult and we have to do something because they are going into everybody's room...no one thinks it is really pain first, because when we are told we think, oh, it's their dementia.*

*Or they might not even know how to compensate or to do something to reduce the pain. A person that has dementia that maybe has a bad knee and is still walking on that knee although they are obviously limping and showing pain, but can't put the process together to sit down, take the pressure off, and reduce the pain, can't say, "I will no longer do this 'cause it hurts."*

## **Conclusions: Towards a Multidimensional Approach to the Assessment and Treatment of Pain in Seniors**

When we cross-referenced our findings with the pain-assessment and pain-management literature, it was evident that the views of front-line workers and seniors themselves are, in many ways, consistent with what has been suggested by authorities in the area. First, there was recognition of both the frequent use of self-report and its limitations (Turk & Melzack, 2001). Moreover, there was recognition by the health professionals that self-report should be attempted with seniors who have mild to moderate dementia although this needs to be supplemented by observational approaches and caregiver reports (e.g., Hadjistavropoulos et al., 2001; Huffman & Kunik, 2000). There was recognition of the paucity of pain-assessment methodologies for seniors with limited ability to communicate but also lack of familiarity with suitable assessment procedures that have been developed recently (Feld, 2000; Fuchs-Lacelle & Hadjistavropoulos, 2004; Hadjistavropoulos et al., 2001). This lack of familiarity underscores the need for continuing staff education. It is incumbent upon health-care facilities to provide staff with adequate release time for such education in order to ensure that quality of care is maximized.

Some of our participants' explanations for the under-treatment of pain in seniors, such as fear of addiction to opioids and myths and beliefs about pain and aging, are frequently cited in the literature (Balfour & O'Rourke, 2003; Craig & Hadjistavropoulos, 2004; Malloy & Hadjistavropoulos, 2004). The seniors in particular discussed societal bias with respect to the expression of pain. The consensus among the group of community-dwelling seniors was that society views pain as a natural part of aging and that they are expected to "put up with it." The seniors said that discussing their pain and asking for relief was analogous to whining: "Just don't tell anyone; that's the way to do it." It is worth noting that some of the explanations for the under-treatment of pain in this population are not cited frequently in the literature; these include, for example, inadequate communication among nursing staff about the assessment and treatment of pain and systemic barriers such as staff shortages and waiting lists.

The participants reported that health-care providers often hesitate to use certain effective medications to control pain. This finding is consistent with those reported in the literature (Gloth, 2000). However, although the participants were concerned about under-medication, they also worried about side effects. Concerns about side effects, as well as frequently unjustified fears about addiction, are often cited in the literature as barriers to pain treatment (Gloth). The participants also pointed to the availability and effectiveness of non-pharmaceutical alternatives, echoing

researchers in the field who increasingly acknowledge the use of alternative medications and other means of pain management (Craig & Hadjistavropoulos, 2004).

The findings of this study give weight to the frequent assertions of pain researchers and clinicians about barriers to pain assessment and management. They also underscore the need for immediate intervention when seniors experience pain. Our professional curricula should conform to the guidelines of such organizations as the International Association for the Study of Pain (IASP), the American Geriatrics Society, and the Canadian Pain Society. Our interventions also need to incorporate development and adaptation of treatment and assessment procedures suited for seniors and especially for those with severe limitations in ability to communicate. The urgent need for coordinated care was clear in the comments of our participants regarding the level of communication among health-care providers. In addition, greater attention should be paid to alternative methods of pain management such as cognitive and behavioural approaches, including self-management strategies. A list of recommendations, based on our focus-group data, is presented in Appendix 1.

Although the focus groups of health professionals discussed more systemic and technical issues such as staff shortages and the availability of analgesic patches than our other participants, generally the views expressed were consistent across groups. Our group of nursing-home residents consisted of only four participants. It is possible that a larger group would have produced richer material. Moreover, the concerns and experiences of our sample of caregivers, recruited with the aid of the provincial Alzheimer society, could differ somewhat from those of caregivers not connected to such an organization. It would be useful for future research to assess for the presence of such differences.

We are humbled by the task ahead but remain optimistic in light of recent developments in our field. These developments include changes in the conceptualization of pain to better accommodate the needs of persons with communication difficulties (see, for example, the note that has been added to the IASP's conceptualization of pain: <http://www.iasp-pain.org/terms-p.html#Pain>) and attempts to incorporate specific relevant guidelines into the current revision of the IASP's curriculum for professional pain education. Moreover, longitudinal studies with seniors are beginning to systematically incorporate the study of pain concerns (Canadian Longitudinal Study of Aging) and the literature is increasingly focusing on clinical issues affecting these populations. Our next challenge is to integrate all of the latest developments into practice in a way that will have a strong impact on both seniors and front-line caregivers.

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## **Appendix 1 *Recommendations for Pain Assessment and Management***

- Pain assessment should include both self-report and observational procedures.
- Self-report approaches to pain assessment should be attempted with patients with mild to moderate dementia, because many of these patients are likely to provide useful information; in this population, self-report should be used in conjunction with patient history, the results of physical examinations, caregiver reports, and observational assessment procedures.
- Training programs for health professionals should cover more pain assessment and management of seniors, including seniors with dementia.
- Health-care providers should keep more systematic records of pain complaints and concerns in order to enhance continuity of care.
- Additional staffing can enhance pain assessment and management.
- Multidisciplinary approaches to pain management should be used where possible.
- Communication between patients and health-care providers should be improved in order to enhance pain assessment and management.
- Continuing education for health professionals should put more emphasis on pain management, including issues related to effective use of opioids and medication side effects.
- Non-pharmaceutical alternatives to pain management should be included in routine patient care as much as possible.
- Seniors should be encouraged to discuss their pain complaints with health-care providers and to not assume that pain is a natural consequence of growing old.
- Research in pain assessment and management among seniors should be encouraged; one area that warrants special attention is pain assessment and management in those with severe dementia and communication difficulties.