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**CJNR**



Volume 39, N° 2

June/juin 2007

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GUEST EDITORIAL

# The Challenge of Unrelieved Pain in the 21st Century

**Kate Seers and Judy Watt-Watson**

The management of unrelieved pain continues to be a challenge in the 21st century. Evidence from pain research is not always effectively and consistently applied in practice. New ways of examining issues and strategies to meet this challenge need to be explored with regard to people with pain across the lifespan, special pain issues, and different types of pain. We need to consider whether we are including all pertinent aspects when we strive to understand and manage pain. In the Discourse published in this issue of the Journal, Sioban Nelson makes the point that effective pain management requires skilled and knowledgeable practitioners and includes the scientific, technological, and interpersonal domains. This pain-focused issue of *CJNR* is particularly exciting for those interested in improving pain management, because it addresses ways of effecting improvements in several especially challenging areas and provides a range of perspectives that makes us think and reappraise our approach. The various contributors report on many innovative clinical and theoretical approaches to pain issues in the 21st century.

Pain issues across the lifespan are addressed, from those that affect neonates to those that concern older people in long-term care. At one end of the spectrum, the pain management of older people in long-term care is often far from ideal. Kaasalainen, DiCenso, Donald, and Staples examine the role of the nurse practitioner in optimizing pain management within an interdisciplinary model in long-term care. These authors highlight the importance of effective collaboration and mutual trust within the team. Working collaboratively in an environment of respect is clearly an essential element in improving pain management in long-term care, reminding us why both knowledge and relationship-building are so central to effective pain practices in nursing.

Valid pain assessment is the cornerstone of good pain management. Getting this right in extremely premature infants of low birth weight, who are severely ill or at risk for neurological impairment, is a real challenge. The innovative study by Stevens, Franck, Gibbins, McGrath, Dupuis, and Yamada looks at the assessment of acute pain in these most

vulnerable neonates. Recognizing that existing pain measures have been validated in the healthiest neonates in the neonatal intensive care unit and in older populations, the authors investigate their appropriateness for use with vulnerable infant populations in the NICU. Stevens et al. question whether the acute pain response in vulnerable neonates is similar to that in the other populations with whom the measures were developed. This issue is fundamental to valid pain assessment with this vulnerable group.

Effective pain management requires an understanding of what the pain represents for the person who is experiencing it. The importance of the meaning of pain to the person involved is addressed from a different perspective in the study by McGillion, Watt-Watson, LeFort, and Stevens. These authors demonstrate how perceptions of the meaning of angina pain as burdensome and debilitating could be shifted by psychoeducation to perceptions of angina as a pain problem requiring ongoing self-management in order to retain life goals and functioning. This reframing of the meaning of pain has great potential. Its impact on other outcomes is an area for future work.

How we judge pain is crucial to pain management, and so too are the factors we take into account when seeking to understand a person's pain. Most student essays on pain will tell you that pain is a biopsychosocial experience. One aspect of pain management that has received little attention is the impact of spirituality and/or religion on the pain experience. The study by Anita M. Unruh demonstrates that a consideration of spirituality is generally not part of the therapeutic context. Unruh argues that religious and spiritual beliefs affect the way in which the meanings of pain and its management are constructed. She points out that patients want their health-care providers to acknowledge and respect the possible effects of these beliefs on health needs. Unruh makes a strong case for the inclusion of a spiritual perspective in the management of pain, to enable the provision of more sensitive, appropriate, and person-centred pain management.

Health professionals are routinely exposed to pain in others, and it is essential that the processes by which they evaluate that pain be understood. The review by Prkachin, Solomon, and Ross addresses the issue of underestimation of pain by health-care providers and discusses the gatekeeper role that they play in determining who receives pain treatments and how these treatments are administered. The authors look at how health professionals judge the pain of others and present a conceptual model of the decoding process involved. Evaluations of the amount of suffering endured are critical in determining the final treatment decision. Prkachin et al.'s framework is a unique attempt to summarize current research and to give direction for future work in this area.

This issue of *CJNR* shows clearly that ground-breaking pain research is being undertaken — research that addresses issues of key importance in improving people’s experience of pain. Working together across the professions, thinking about how we assess and judge pain, and the impact of people’s constructions of pain are common themes that are bound to foster serious reflection as we strive to deepen our understanding of pain and its management in the 21st century. Understanding the science, as well as being “caring,” is essential to the provision of sensitive and appropriate care to people who are in pain.

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## Discourse

# When Caring Is Not Enough: Understanding the Science of Pain

Sioban Nelson

Effective pain management requires skilled and knowledgeable practitioners. Is the traditional preoccupation of nursing with “care” implicitly undervaluing “science” and interfering with our ability to successfully manage pain issues?

Much has been written on the cultural and social significance of pain, on the differing responses to pain dictated by social mores, on the association between pain and purification rites, and on the moral value of pain and suffering — pain in childbirth and pain in death (Cassell, 1991). Scientific changes and practice shifts in areas of high cultural and social significance (such as childbirth, death, and pain) tend to be accompanied by a re-evaluation of moral issues. Moral constraints on anything that appears to interfere with the “natural” (however painful) order of events are not only of ancient historical relevance. As recently as the post-war period, controversy over developments in anesthesia and opioid analgesia made it necessary for Pope Pius XII to formally approve the administration of pain relief. According to a papal decree on the matter:

The patient, desirous of avoiding or relieving pain, may, without any disquietude of conscience, use the means discovered by science which in themselves are not immoral.

(Pius XII, cited in Jaros, 1991, p. 8)

Sixty years on, a papal clearance to receive analgesia may seem odd. Nonetheless, the very existence of this position statement reveals widespread “disquietude” at cultural shifts in relation to pain and illustrates that questions of morality and pain relief have been closely linked down through the ages.

Nursing has its own cultural history with respect to pain. It is a history that bears heavily on both the science of pain and the application of that science in everyday practice. As one of the quintessential areas of nursing care, nursing has long been associated with comfort and support for the sick and suffering. For patients in early hospitals, religious nurses

provided comfort through whatever means were at hand. The spiritual support, along with the comforting rhythm of religious rituals, helped the sufferer to endure. Highly esteemed in this Christian context were stoicism and the offering up of pain and suffering for one's sins or for the sins of the world.

One does not have to search far in the multitude of contemporary nursing narratives to see that nurses still view comfort for the patient in pain as one of their key purposes and, in truth, satisfactions — see, for example, Canfield, Hansen, Mitchell-Autio, and Thieman's 2001 *Chicken Soup for the Nurse's Soul* or Briskin and Boller's 2006 *Daily Miracles: Stories and Practices of Humanity and Excellence in Health Care*. Yet while nurses declare their importance to the patient with respect to pain, we have ample evidence of the fact that patients in pain remain poorly managed. Why so?

In a recent book, *The Complexities of Care: Nursing Reconsidered* (Nelson & Gordon, 2006), Suzanne Gordon, an American journalist and health commentator, and I, along with our contributors, consider this and other apparent paradoxes in contemporary nursing discourse and practice.

Our argument comes down to two clear issues. The first concerns the way in which nursing is represented, and in fact represents itself, in moral terms — what Gordon and I coin the “virtue script.” The second rests with the observation that nursing appears to be increasingly uncomfortable with the scientific and biomedical domain in which it is practised. Through a phenomenon that Gordon terms “the new Cartesianism,” nursing's overarching “human science” framework paradoxically serves to downplay and undervalue the scientific and technical knowledge of nurses as “medical” and thus of secondary importance to the human and relational skills that the nurse brings to the patient encounter.

As Gordon and I argue, the problem with the ministering angel image of nurses is that it is an image for another time, when it served particular ends. Yet today, no less than in the 19th century, nurses cling to the virtue script, with an emphasis on their virtues rather than on the knowledge and concrete contributions of their work, and eschew claims to biomedical and scientific expertise as secondary or “medical.” And while nurses are often comforted by the fact that the public feels it owes them a debt of gratitude, it is clear that the same public does not think of nurses as particularly knowledgeable or as highly skilled. Hence the issue of the low professional status of nurses has remained very much alive despite the countless strategies that over the decades were thought to have addressed it (university-based education, baccalaureate entry to practice, graduate education, research-based knowledge, and so forth).

If we apply the virtue script to pain care, we find the widespread idea that the patient is best served by a kind and attentive nurse, one who



helps the patient to voice his or her feelings, supports families, and puts energy and sensitivity into determining the meaning of the illness and the pain for the patient. This is the tenet of patient-centred care. Of course all of these principles are central to good practice, but what concerns me is what is missing from this model of excellent nursing. Where is the science? Gordon argues that in its efforts to differentiate itself from medicine, and to adhere to the traditional value attached to nursing as moral work, nursing has become increasingly uncomfortable with the scientific “half” of holistic care. Biomedical knowledge is frequently dismissed as “merely” medical and ranked a distant second in importance to interpersonal skills.

With respect to pain management, this can lead to caring and resourceful nurses believing they are providing excellent patient-centred care, with patients and their families reinforcing this view in gratitude for the nurses’ support yet in ignorance of the rapidly evolving science of pain, which could make the caring nurse a key contributor not only to poorly managed pain but also to its sequelae, including chronic pain. Effective pain management by nurses is more than “caring” and carrying out procedures ordered by others. Furthermore, when nurses do not articulate a biomedical understanding of pain assessment and management approaches, they risk being perceived as less than full members of the interprofessional team that is so important to collaborative pain management.

In many respects, the field of pain provides a paradigm case for several of the arguments presented in *The Complexities of Care*. A false dichotomy between nursing and medicalized knowledge undervalues the science that nurses need to possess and to practise; a lack of focus on science in the discourse on nursing means that the public is unaware that the nurse needs to be more than a nice person and is led to believe that all clinical decisions of consequence are made by medical members of the care team. Most concerning of all, nurses may believe they are doing a great job, in ignorance of the science and the consequences of poorly managed pain.

Gordon and I argue that proper uptake of the science of pain calls for nursing educators, administrators, and researchers to reclaim the scientific, medical, and technical knowledge of skilled nursing, without apology, unconcerned that it might be viewed as a sign of an “uncaring” nurse or a “wannabe” doctor. The revolution in pain management will not occur unless nurses feel comfortable talking with colleagues, patients, and peers about the scientific and technical realm in which they practise, as well as talking more effectively about the human, interpersonal domain. We do not have to choose between these domains but we do

have to reject the false polarity so often set up by curricula, professional, and even scientific discourse.

Pain management is a science, and one in which nurses are key. The virtue script may have served nurses and their patients well in the past, but in the field of pain, as in so many other domains of care, we need to move beyond angels and practise as knowledgeable scientific and compassionate professionals.

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Résumé

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## **L'optimisation du rôle de l'infirmière praticienne en matière d'amélioration de la gestion de la douleur en soins de longue durée**

**Sharon Kaasalainen, Alba DiCenso,  
Faith C. Donald et Eric Staples**

Cette étude vise à examiner le rôle de l'infirmière praticienne (IP) dans le cadre d'un modèle interdisciplinaire de la gestion de la douleur, en soins de longue durée (SLD). Dans une enquête ponctuelle, un questionnaire a été soumis à 16 IP pratiquant dans la province canadienne de l'Ontario (89 %) dans le but d'identifier celles qui exécutaient actuellement ou devaient exécuter 33 activités liées à la gestion de la douleur, et de cerner les obstacles qui les empêchaient de mener à bien leur rôle d'intervenantes quant à la gestion de la douleur. La majorité des IP (81,3 %) ont signalé qu'elles utilisaient des outils d'évaluation de la douleur. Par contre, moins de la moitié bénéficiaient de lignes directrices en matière de pratiques cliniques portant sur la gestion de la douleur. Les IP (a) effectuaient moins d'activités liées à la prescription et à la modification du dosage de médicaments contre la douleur, (b) occupaient moins de fonctions de leadership en gestion de la douleur, et (c) étaient moins nombreuses à mener des initiatives de recherche traitant de la douleur. Toutefois, la plupart ont exprimé le désir de participer davantage à ces activités. Les contraintes de temps, les restrictions en matière d'ordonnance, le manque de connaissances, la difficulté à évaluer la douleur, les réserves des médecins, du personnel, des bénéficiaires et des familles quant à l'utilisation des opioïdes, et le peu de collaboration des médecins figurent parmi les obstacles qui entravent la participation des IP à la gestion de la douleur. Les résultats de l'étude indiquent que les compétences des IP ne sont pas utilisées pleinement en ce qui a trait à la gestion de la douleur chez les bénéficiaires âgés recevant des SLD.

Mots clés : gestion de la douleur, infirmière praticienne, soins de longue durée

# **Optimizing the Role of the Nurse Practitioner to Improve Pain Management in Long-Term Care**

**Sharon Kaasalainen, Alba DiCenso,  
Faith C. Donald, and Eric Staples**

The purpose of this study was to examine the role of the nurse practitioner (NP) within an interdisciplinary model of pain management in long-term care (LTC). In a cross-sectional survey, 16 NPs in the Canadian province of Ontario (89%) indicated whether they currently performed and whether they should be performing 33 activities related to pain management and identified barriers to the fulfilment of their pain-management role. Most NPs (81.3%) reported use of pain-assessment tools, but less than half reported use of pain-management clinical practice guidelines. NPs were less involved in activities related to (a) prescribing and adjusting pain medications, (b) providing leadership in pain management, and (c) engaging in pain-related research initiatives. However, most felt that they should be more involved in these activities. Barriers to NP management of pain included time constraints; prescribing restrictions; lack of knowledge; difficulties with assessing pain; MD, staff, resident, and family reservations about use of opioids; and poor collaboration with physicians. The results indicate that NPs are not being used to their full potential in managing pain among elderly LTC residents.

Keywords: Pain management, nurse practitioners, long-term care, older adults

## **Background**

Pain management is a significant problem in older adults. In long-term care (LTC), the majority of older adults with or without cognitive impairment experience pain (Desbiens, Mueller-Rizner, Connors, Hamel, & Wenger, 1997; Fox, Raina, & Jadad, 1999; Kaasalainen & Crook, 2003; Moulin, Clark, Speechley, & Morley-Forster, 2002; Proctor & Hirdes, 2001; Simons & Malabar, 1995). Pain in the elderly has been associated with various chronic health problems including degenerative joint disease, osteoarthritis, skin ulcers, back pain, cancer, angina, neuralgia, diabetes, chronic sinusitis, and fractures and other injuries sustained through falls (Feldt, 2000; Ferrell, 1996; Marzinski, 1991).

Despite high rates of pain in older adults, pain is being undertreated, especially in those with cognitive impairment (Horgas & Tsai, 1998; Kaasalainen et al., 1998; Mezinskis, Keller, & Luggen, 2004; Sengstaken

& King, 1993). In a correlational study, Horgas and Tsai examined the use of analgesics among 339 residents of four nursing homes. The residents with cognitive impairment were prescribed and administered significantly less analgesic medication than those without cognitive impairment. Based on a chart review of 307 residents with cognitive impairment in 14 LTC facilities, Mezinskis et al. found that fewer medications were ordered for residents with greater cognitive impairment. In a recent qualitative study examining pain management decision-making in LTC, physicians and nurses described a reluctance to use opioids with residents who had cognitive impairment because they were uncertain about the accuracy of their pain assessments, specifically related to (a) the inadequacy of currently used tools in practice, and (b) inability to discriminate between pain and other problems such as delirium and dementia (Kaasalainen et al., in press). Clearly, LTC residents with cognitive impairment are particularly vulnerable to unrelieved pain and suffering.

In most LTC settings, physician coverage is limited to a few hours per week, resulting in restricted ability to individualize and monitor pain treatments. A potential solution is to utilize the nurse practitioner (NP) more effectively in the management and evaluation of pain treatments when the physician is unavailable onsite to attend to residents' needs.

In 2000 the Ministry of Health and Long-Term Care (MoHLTC) in the Canadian province of Ontario funded 20 full-time primary health care (PHC) NP positions in LTC, in response to the complex needs of this population and the inability of the health-care system to support those needs. These NP positions in LTC, licensed in the extended class, were funded 2 years after the NP role had been legislated in Ontario and require a 12-month post-baccalaureate certificate from a university. Primary health care NPs are uniquely qualified to provide individualized and holistic care for pain management considering their scope of practice (i.e., authority to prescribe certain medications), their educational preparation, and the health model under which they practise (Cumbie, Conley, & Burman, 2004; Schober & Affara, 2006).

To date, minimal research has been conducted on the effectiveness of this new NP role in LTC settings in Ontario or in the other Canadian provinces that employ NPs in LTC. In the United States, however, there is a developing body of knowledge that supports the role of NPs in LTC (Aigner, Drew, & Phipps, 2004; Burl, Bonner, Rao, & Khan, 1998; Intrator, Castle, & Mor, 1999; Kane, Keckhafer, Flood, Bershadsky, & Siadat, 2003; Rosenfeld, Kobayashi, Barber, & Mezey, 2004). NPs have been shown to reduce hospital admissions, visits to the emergency department, and costs, while increasing access to PHC (Burl et al.; Intrator et al.; Kane et al.). In a survey of physicians, all of whom were members of the American Medical Directors Association, Rosenfeld et al.

found a high level of satisfaction with the NP role in LTC on the part of physicians (90%), residents (87%), and families (85%). However, the low response rate (19%) leads one to question the validity of these findings. In addition, it is unclear how the satisfaction reports were obtained, but it appears that the physicians reported on behalf of residents and families. There are no reported findings related to NP management of pain in these studies.

The role of NPs in pain management in Canadian acute-care settings has recently been studied (Kohr & Sawhney, 2005). Musclow, Sawhney, and Watt-Watson (2002) found that interdisciplinary collaboration, including NP-improved pain management in acute-care settings, provides opportunities for consulting on difficult pain-management issues, disseminating research findings, providing ongoing staff education, and advocating for greater accountability within nursing for pain management. Research is needed to determine whether improving interdisciplinary collaboration within a model of care that includes a well-defined role for the NP would fill gaps in care, ultimately improving the quality and efficiency of pain management in LTC.

However, the NP role in both acute-care and LTC settings is not well delineated within an interdisciplinary model of care, likely due to the recent emergence of the NP role in Ontario. Bryant-Lukosius and DiCenso (2004) developed the Participatory, Evidence-Based, Patient-Focused Process for Advanced Practice Nursing (APN) Role Development, Implementation, and Evaluation (PEPPA) framework, which can be used to guide NP integration. According to this framework, it is important to clearly define the role of the NP and address any barriers to its implementation before conducting an evaluation of the effectiveness of the NP role. Applied specifically to pain management in LTC, the PEPPA framework suggests that the high prevalence of poorly managed pain in older adults and the recent introduction of the NP role in LTC warrant the delineation of a pain-management role for NPs, which, once properly implemented, should be evaluated. This framework provided the impetus for this study — an examination of role delineation of the NP in LTC around pain management.

In summary, pain management is a serious problem in LTC. The emergence of the NP role in Canadian LTC settings may provide a mechanism for improving pain-management practices. However, prior to examining the effectiveness of the NP role in pain management in LTC, we conducted a role delineation study, the purpose of which was to examine the role of the NP in pain management in LTC. We designed the study to (1) *examine the practice patterns of NPs in LTC with a particular focus on pain management*, and (2) *identify the barriers to and facilitators of NP role implementation in pain management*.

## Methods

This study used a cross-sectional survey design to gather information about the current role of NPs in pain management in LTC homes across Ontario. The survey involved both qualitative and quantitative approaches to data collection and analysis.

### *Instrumentation*

The survey comprised four sections: (1) demographic information, (2) practice patterns, (3) activities related to pain management, and (4) barriers to and facilitators of pain management in LTC. Demographic information included age, education, years of practice as both a registered nurse and a licensed NP, and type of position held (i.e., full-time, part-time, casual, contract).

The second section, that on practice patterns (e.g., allocation of time spent on clinical and non-clinical duties and on specific types of services such as wellness care/health promotion, care of minor acute illness, monitoring of chronic illness, care of major acute illness, and palliative care; use of pain-assessment tools or clinical practice guidelines [CPGs] for pain management), gathered information about the context of NP practice within which pain management occurred. Most of the questions for this section were taken from a previous survey administered to NPs across Ontario (DiCenso, Paech, & IBM Corporation, 2003) and based on a comprehensive literature review and existing survey instruments; that survey had been assessed for face and content validity by NPs and representatives of nursing and physician organizations and had been pretested on a small number of NPs, with revisions made based on their feedback.

The third section included a list of pain-management activities based on (a) the competencies in the Canadian Nurses Association (2002) framework of advanced practice nursing, namely clinical practice, consultation/communication, education, leadership/change agent, advocacy, and research; (b) a review of the literature related to pain management and older adults; and (c) CPGs for pain management developed by the Registered Nurses Association of Ontario (2002), the American Medical Directors Association (2003), and the American Geriatrics Society (1998). The NPs were asked to indicate whether they (a) performed each of these pain management activities, and (b) should be doing so.

Finally, in the fourth section NPs were asked to identify the barriers and facilitators they experienced while managing pain among LTC residents.

The face and content validity of the four-part survey were assessed by a panel of experts in both pain management and advanced practice

nursing. The survey was pretested with two NPs with expertise in pain management and elder care and was modified based on their feedback and responses.

### **Procedure**

The study was approved by a university research ethics board in south-central Ontario. The survey was mailed to all MoHLTC-funded NPs working in LTC facilities in Ontario ( $n = 18$ ) along with a coupon for a national chain of coffee shops to enhance response rates and a self-addressed, stamped envelope. NPs were asked to complete the survey and return it the self-addressed, stamped envelope. The survey was designed to be completed in 15 to 20 minutes. A modified Dillman's approach was used to increase response rate: a second mailing of the survey was made 2 weeks after the first, followed by a telephone call or e-mail message 1 week later (Dillman, 1978).

### **Data Analysis**

The quantitative data from the survey were summarized using descriptive statistics. Frequency distributions, means, and standard deviations were calculated. Content analysis was used to analyze the survey data obtained from the open-ended questions.

## **Results**

Sixteen NPs returned the completed survey, for a response rate of 89%. The respondents had an average age of 45.3 years ( $SD = 8.6$ ). They had been practising as NPs for an average of 3.8 years ( $SD = 2.3$ ) and as RNs for an average of 20.7 years ( $SD = 9$ ). The majority of the NPs had a bachelor's (56.3%) or master's (26.3%) degree in nursing and worked full time (87.5%).

The respondents reported spending on average 76% of their time on clinical duties ( $range = 30-95\%$ ), 14.1% on non-clinical activities ( $range = 5-50\%$ ), 8% on clerical duties ( $range = 0-20\%$ ), and 1.5% travelling ( $range = 0-10\%$ ). In addition, NPs reported spending on average 31% ( $range = 2.5-60\%$ ) of their time treating minor acute illnesses and 26.3% ( $range = 5-60\%$ ) monitoring chronic illnesses (see Table 1).

The majority of NPs (81.3%) reported that they used pain-assessment tools in their practice. However, only 50% of the NPs ( $n = 8$ ) indicated using CPGs to direct their pain-management activities for LTC residents. It is not known if the remaining NPs ( $n = 8$ ) used CPGs, as they did not respond to this survey question.

At least 93.75% of the NPs reported that they engaged in activities related to the assessment and diagnosis of pain in their clinical practice



**Table 1** *Time Spent by NPs in Providing Services in LTC (n = 15<sup>a</sup>)*

	Mean % of Time (Range)
<b>Duties</b>	
Clinical	76.0 (30–95)
Non-clinical	14.1 (5–50)
Clerical	8.0 (0–20)
Travel	1.5 (0–10)
<b>Services</b>	
Wellness care/health promotion	14.5 (0–50)
Care of minor acute illness	30.8 (2.5–60)
Monitoring of chronic illness	26.3 (5–60)
Care of major acute illness	9.2 (0–30)
Palliative care	10.5 (2–30)
Other <sup>b</sup>	14.0 (0–70)
<sup>a</sup> One missing response.	
<sup>b</sup> Admissions, histories, physicals.	

(Table 2). In addition, 93.75% indicated that they prescribed non-opioid analgesics, such as acetaminophen and aspirin, and non-pharmacological pain interventions. However, only 62.5% of NPs reported prescribing NSAIDs and 12.5% of NPs reported prescribing opioid analgesics from a defined list, whereas 87.5% and 93.75%, respectively, reported that they should be able to prescribe these medications.

Given the large number of missing responses to the question “Should you be performing this activity?,” we asked two of the NPs who had not responded to it to explain why. Both said they did not respond because they thought the question was intended to be answered only by those who responded negatively to the previous question (“Do you currently perform this activity?”) for each item in the survey. Therefore, for NPs who indicated that they performed these activities and did not respond to the question about whether they *should* perform them, we interpreted the missing response as “yes.”

With regard to consultation and communication, most of the NPs reported that they collaborated with physicians, other nurses, families, and residents about pain management. Only 75% of the NPs, however, reported that they collaborated with pharmacists, whereas 93.75% reported they should be collaborating with pharmacists in LTC around pain management. The respondents indicated that they were less engaged than they should be in leadership activities related to pain management, such as serving on committees (56.25%), assisting in the development of

Table 2 NP Involvement in Pain Management Activities (n = 16)

Activity	“Do you currently perform this activity?” Yes <sup>a</sup> % (n)	“Should you be performing this activity?” Yes <sup>b</sup> % (n)
<p><b>Clinical Practice</b></p> <p>1. Assess pain  <i>If yes, do you base this on:</i>                      (a) physical examination                      (b) health history                      (c) assessment tools</p> <p>2. Order diagnostic tests to determine pain diagnosis (e.g., x-ray, blood &amp; urine)</p> <p>3. Diagnose the cause of residents’ pain</p> <p>4. Prescribe NSAIDs (e.g., ibuprofen, naproxen)</p> <p>5. Prescribe analgesics (e.g., acetaminophen, aspirin)</p> <p>6. Prescribe a defined list of opioid analgesics</p> <p>7. Prescribe nonpharmacological pain interventions</p> <p>8. Adjust a defined list of non-opioid analgesics</p> <p>9. Adjust a defined list of opioid analgesics</p>	<p>93.75 (15)<sup>1</sup></p> <p>100 (16)</p> <p>93.75 (15)</p> <p>87.5 (14)</p> <p>87.5 (14)<sup>1</sup></p> <p>93.75 (15)</p> <p>62.5 (10)</p> <p>93.75 (15)</p> <p>12.5 (2)<sup>1</sup></p> <p>93.75 (15)</p> <p>62.5 (10)<sup>1</sup></p> <p>25 (4)<sup>1</sup></p>	<p>93.75 (15)<sup>3</sup></p> <p>100 (16)<sup>4</sup></p> <p>100 (16)<sup>4</sup></p> <p>100 (16)<sup>4</sup></p> <p>93.75 (15)<sup>4</sup></p> <p>100 (16)<sup>4</sup></p> <p>87.5 (14)<sup>4</sup></p> <p>100 (16)<sup>4</sup></p> <p>93.75 (15)<sup>3</sup></p> <p>93.75 (15)<sup>5</sup></p> <p>93.75 (15)<sup>4</sup></p> <p>100 (16)<sup>3</sup></p>

Continued on next page

<i>Clinical Practice (cont'd)</i>	<b>Currently perform</b>	<b>Should perform</b>
10. Prescribe a defined list of adjuvant therapies to manage pain and its side effects	62.5 (10)	93.75 (15) <sup>3</sup>
11. Assess side effects of pain treatments	93.75 (15)	100 (16) <sup>3</sup>
12. Assess effectiveness of pain medications	93.75 (15)	100 (16) <sup>3</sup>
13. Assess effectiveness of nonpharmacological interventions	93.75 (15)	100 (16) <sup>3</sup>
14. Document findings about pain management	93.75 (15) <sup>1</sup>	93.75 (15) <sup>3</sup>
<b>Consultation and Communication</b>		
15. Collaborate with pharmacists about pain management	75 (12)	93.75 (15) <sup>3</sup>
16. Collaborate with physicians about pain management	93.75 (15)	100 (16) <sup>3</sup>
17. Collaborate with RNs about pain management	100 (16)	100 (16) <sup>3</sup>
18. Collaborate with RPNs about pain management	100 (16)	100 (16) <sup>3</sup>
19. Collaborate with HCAs about pain management	93.75 (15)	93.75 (15) <sup>3</sup>
20. Collaborate with other health care professional (HCP) about pain management	93.75 (15)	93.75 (15) <sup>3</sup>
21. Collaborate with family about residents' pain	100 (16)	100 (16) <sup>3</sup>
22. Collaborate with residents about their pain	100 (16)	100 (16) <sup>3</sup>
<b>Education</b>		
23. Educate staff nurses about pain management	100 (16)	100 (16) <sup>2</sup>
24. Counsel residents and/or families about pain	100 (16)	100 (16) <sup>3</sup>

<p><b>Leadership/Change Agent</b></p> <p>25. Participate in committee work related to pain management</p> <p>26. Assist in the development of policies and procedures about pain management</p> <p>27. Liaise with regulating bodies about pain management activities</p> <p>28. Implement or evaluate a pain management program</p>	<p>56.25 (9)</p> <p>43.75 (7)</p> <p>25 (4)</p> <p>31.25 (5)</p>	<p>93.75 (15)<sup>3</sup></p> <p>81.25 (13)<sup>3</sup></p> <p>75 (12)<sup>2</sup></p> <p>87.5 (14)<sup>3</sup></p>
<p><b>Advocacy</b></p> <p>29. Advocate for patients/families related to pain management</p> <p>30. Advocate for staff related to pain management</p>	<p>87.5 (14)<sup>2</sup></p> <p>81.25 (13)<sup>2</sup></p>	<p>87.5 (14)<sup>4</sup></p> <p>93.75 (15)<sup>3</sup></p>
<p><b>Research</b></p> <p>31. Identify researchable questions related to pain management</p> <p>32. Participate in research studies related to pain management</p> <p>33. Disseminate research findings related to pain management</p>	<p>31.25 (5)<sup>2</sup></p> <p>43.75 (7)<sup>2</sup></p> <p>43.75 (7)<sup>2</sup></p>	<p>81.25 (13)<sup>3</sup></p> <p>93.75 (15)<sup>1</sup></p> <p>93.75 (15)<sup>2</sup></p>
<p><sup>a</sup> Missing responses for each item are interpreted as the NP does not perform those activities.</p> <p><sup>b</sup> Missing responses for each item are interpreted as the NP should be performing those activities <i>only</i> if the NP has indicated "yes"; he/she does perform these activities.</p> <p><sup>1</sup> One missing response.</p> <p><sup>2</sup> Two missing responses.</p> <p><sup>3</sup> Three missing responses.</p> <p><sup>4</sup> Four missing responses.</p> <p><sup>5</sup> Five missing responses.</p>		

policies and procedures (43.75%), liaising with regulating bodies (25%), and implementing or evaluating a pain-management program (31.25%). Regarding advocacy, 87.5% of the NPs reported advocating for patients and families and 81.25% advocating for staff related to pain management. Less than half of the NPs were involved in research activities related to pain management, such as identifying researchable questions (31.25%), participating in studies (43.75%), and disseminating research findings (43.75%). Large proportions of the sample felt that they should be more involved in these activities, particularly with regard to (a) leadership activities such as committee work (93.75%) and implementation of a pain-management program (87.5%), and (b) research activities (93.75%).

Using content analysis, themes were developed from responses to the open-ended question "In your opinion, what are the major barriers and facilitators to effective pain management in LTC settings?" The themes that emerged as barriers were (a) difficulty assessing pain due to lack of tools, especially for residents with dementia; (b) poor collaboration with physicians; (c) lack of time/heavy workload; (d) limited scope for prescribing opioids; (e) lack of staff education; and (f) reservations about the use of opioids (i.e., not wanting to use narcotic medication for non-palliative pain). One NP commented:

*Doctors refuse to have a list of pain medications that NPs can prescribe [independently]. I have to have them [doctors] cosign it. This hinders me from ordering because I am afraid that the doctor may choose not to cosign it when he comes in.*

NPs also reported a number of facilitators of pain-management practices. These included: (a) the use of CPGs and standardized tools for pain management; (b) interdisciplinary collaboration among nurses, physicians, and pharmacists; (c) staff education and support; and (d) strong collaboration with physicians embedded in a trusting relationship.

## Discussion

The NPs appeared to spend most of their time (76%) engaged in clinical activities in LTC. This finding is congruent with those of other research. DiCenso et al. (2003) found that PHC NPs spent on average 73% of their time on clinical activities. The implementation of the NP role was inconsistent across the LTC homes. The range of the percentages of time spent on clinical activities was quite wide, with some NPs spending as little as 30% and others as much as 95% of their time engaged in clinical activities. As well, the extent of their time spent on non-clinical activities varied from 5 to 50%. These findings provide some context regarding the extent to which NPs are engaged in clinical activities as opposed to, for

instance, travelling between LTC settings or engaged in non-clinical activities. This information is important if consideration is to be given to increasing the NP's role in pain management.

The wide variation in amount of time spent on clinical activities may indicate that some NPs are not utilizing their skill set fully and are spending time on activities that may be more appropriately performed by other members of the health-care team or by administrative personnel. While we did not measure NP job satisfaction in this study, DiCenso et al. (2003) found that those NPs who spent more time on clinical duties were more likely to be satisfied with their scope of practice than those who spent less time on these duties. Similarly, Sidani et al. (2000) found that acute-care NPs viewed their involvement in clinical care as a positive, enjoyable, and rewarding aspect of the NP role. It seems reasonable to speculate that the relationship between time spent on clinical activities and job satisfaction will be similar for LTC NPs, but future work is needed to confirm this assumption. In light of the PEPPA recommendation that the role be evaluated once successful implementation is achieved, further work is also needed to examine the reason for the inconsistency in the NP role across LTC homes, so that the effectiveness of NPs in LTC, particularly around pain management, can be evaluated fairly and systematically.

The scope of practice for NPs in terms of prescribing and adjusting certain pain medications, namely NSAIDs and opioids, appears limited. Yet the majority of NPs reported that they should be able to prescribe these types of pain medication in their practice. Even though there are NSAIDs on the approved list for NP prescribing, there may be some concern regarding the side effects of these medications, especially for the older population (e.g., gastrointestinal bleeding, stroke). Further research is needed to examine why NPs are not prescribing NSAIDs to the extent permissible.

Kohr and Sawhney (2005) found that NPs dealt with prescribing restrictions by offering suggestions or advice to physicians and pharmacists, implementing medical directives, and discussing options with patients and families. However, these prescribing restrictions can cause delays in the effective treatment of residents' pain, fragmentation of care, and inefficient use of health-care funding (DiCenso et al., 2003). Efforts should be directed at extending the scope of practice for NPs around the prescribing of pain medications or at developing alternative strategies so that NPs can function more autonomously and pain can be alleviated in a more timely and efficient fashion for LTC residents.

Respondents commented on the usefulness of pharmacists as a resource in LTC. While some NPs reported currently collaborating with pharmacists, almost all NPs reported that they should be doing so. By

developing stronger collaboration with LTC pharmacists, NPs may be better positioned to treat pain.

Another apparently weak aspect of the NP role is the extent to which NPs are engaged in leadership and research activities related to pain management. Although the majority of NPs indicated that they should be engaged in leadership and research activities, slightly less than half reported that they were. Given the demands of the NP position in LTC, this finding is not surprising. Sidani et al. (2000) found that, although NPs believed they should be involved in all aspects of their role, they stated that patient care took precedence over other activities, including leadership and research. In addition, the relative novelty of the NP role in LTC may limit the scope of its implementation. However, DiCenso et al. (2003) report that NPs expressed an interest in participating in evidence-based practice and research. Perhaps the limited involvement in research and leadership is reflective of the NPs' level of education: most of the participants in the present study were baccalaureate-prepared. As the level of education required for NPs increases (i.e., master's), it will be interesting to examine whether their involvement in leadership and research also increases. This aspect of the NP role in LTC around pain management needs to be further developed.

The NPs reported a number of barriers to and facilitators of their pain-management practices in LTC. Similarly, Kohr and Sawhney (2005) found that advanced practice nurses, including NPs, reported barriers to their pain-management practices. These included lack of prescriptive authority; lack of knowledge across all health professionals and patients; lack of clear guidelines; practitioner resistance; inaccurate assessment of pain; and concerns about addiction, substance abuse, and side effects.

The challenges associated with assessing pain in residents with dementia are not unique to the practice of advanced practice nurses; they have been reported by other health practitioners as well (Kaasalainen et al., in press; Martin, Williams, Hadjistavropoulos, Hadjistavropoulos, & MacLean, 2005; Marzinski, 1991). A number of pain-assessment tools for use with residents with dementia have been developed over the past decade, although many of them require further psychometric testing before they can be fully recommended for practice. However, in a recent systematic review, the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC; Fuchs-Lacelle et al., 2003) was recommended as an appropriate tool for assessing pain in older adults with severe dementia (Zwakhalen, Hamers, Abu-Saad, & Berger, 2006).

Clinical practice guidelines can also be useful in pain management. However, only 50% of the NPs in the present study reported using such guidelines in their practice. This finding is concerning, as CPGs for pain management have been developed by a variety of professional organiz-

ations, including the Registered Nurses Association of Ontario, the American Geriatrics Society, and the American Medical Directors Association. Perhaps this finding is reflective of the challenges inherent in implementing CPGs. For example, Resnick, Quinn, and Baxter (2004) found that only 45% of participating LTC facilities implemented CPGs. As a result, they recommend implementing one CPG at a time and “tooling staff” — providing staff members with a tool to guide them with CPG implementation. Despite these challenges, the NPs in the present study acknowledged CPGs as a facilitator in their pain-management practices, a finding that is also reported elsewhere (Kohr & Sawhney, 2005). Future work is needed to examine innovative ways of implementing CPGs within an interdisciplinary model of care that includes NPs.

Some NPs indicated that the current attitudes of nurses and physicians around opioid use for LTC residents formed a barrier to the effective treatment of pain. Other researchers have reported similar attitudes among health professionals, highlighting reasons for the underutilization of opioids in older adults, such as poor quality of pain assessments and concern about polypharmacy, opiophobia, addiction, and other adverse effects (Ardery, Herr, Hannon, & Titler, 2003; Auret & Schug, 2005; Kaasalainen et al., in press; McCaffery, Ferrell, & Pasero, 2000). Weissman and Matson (1999) observe that there is a widespread fear of treating pain without knowing its exact cause, along with concern about overmedication and drug toxicity, especially in seniors with cognitive impairment. In a recent qualitative study of pain-management decision-making in LTC, physicians described the need to tailor pain treatment so that side effects can be balanced with the amount of pain relief desired (Kaasalainen et al., in press). These findings highlight the need for education of health-care providers so that pervasive misconceptions about pain and aging can be overcome.

A major facilitator of pain management identified by the NPs was effective collaboration within the interdisciplinary team, particularly with regard to physicians. A collaborative relationship is critical to effective pain management and is especially important in LTC because of the lack of onsite coverage by physicians. Nurses and physicians alike have commented on the need for a trusting relationship. Physicians have described the significant influence of a trusting relationship with the nursing staff on their prescribing patterns around pain management in LTC (Kaasalainen et al., in press). Physicians are concerned about prescribing appropriate pain medications when they are working with a nurse who lacks clinical skills and experience, because they depend on the nursing staff to assess resident pain and evaluate the side effects of pain medications in an accurate and therapeutic manner. Clearly, improvements are



needed in collaborative relationships between nurses and physicians, within new models of care delivery to facilitate effective pain-management practices in LTC. The NP with advanced clinical skills may present a viable opportunity to make such improvements. The quality of care for LTC residents, particularly around pain management, might thus be improved.

The high response rate is a strength of this study, with 16 of 18 NPs returning completed surveys (89%). However, the small number of NPs currently employed in LTC homes in Ontario limits the generalizability of the findings. In addition, the settings in which the NPs were employed may not be typical of LTC facilities. Since these LTC homes were the first to employ NPs, they could represent the “best-case scenario” in terms of their receptivity to the role. On the other hand, they served as the pilot sites for NP role implementation and may need to further refine the role within the interdisciplinary team. A further limitation of the study is the absence of responses for some of the survey items (e.g., demographic information, use of CPGs), which may have skewed the results or limited the interpretation of the findings.

In summary, the findings from this study help to delineate the role of the NP related to pain management and provide insight into the current implementation and practice patterns of LTC NPs around pain management. The survey identified a number of factors that limit the NPs’ pain management practices; these barriers need to be addressed before the NP role in pain management can be evaluated. However, as the number of NPs working in LTC homes increases, and as the emphasis on multi-disciplinary collaboration increases, it is anticipated that the NP role in pain management will be better utilized, ultimately improving the way in which pain is managed in long-term care.

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**Authors' Note**

Dr. Sharon Kaasalainen was supported by a Canadian Health Services Research Foundation (CHSRF) postdoctoral fellowship during this study.

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Résumé

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## **Analyse de la structure des réponses à la douleur aiguë chez des nouveau-nés vulnérables**

**Bonnie Stevens, Linda Franck, Sharyn Gibbins,  
Patrick J. McGrath, Annie Dupuis et Janet Yamada**  
et par (en ordre alphabétique) Joseph Beyene, Carol Camfield,  
G. Allen Finley, Celeste Johnston, Karel O'Brien et Arne Ohlsson

Le but principal du projet était de déterminer la structure sous-jacente de la réponse du nouveau-né vulnérable à une intervention causant une douleur aiguë. Son but secondaire était d'analyser l'influence du contexte (p. ex. risque d'affection neurologique [AN] et âge gestationnel [AG]). L'étude d'une cohorte descriptive a permis d'établir le rôle des indicateurs sélectionnés relativement à la structure de la douleur chez le nourrisson. On a effectué une analyse de variance sur 19 indicateurs de la douleur à l'aide de trois analyses factorielles chez 149 nouveau-nés. La structure factorielle préliminaire comprenait des indicateurs comportementaux (p. ex. mouvements faciaux) et physiologiques (p. ex. saturation en oxygène, fréquence cardiaque). Les mouvements faciaux ont obtenu la variance la plus élevée pour toutes les solutions factorielles (29-39 %). Les indicateurs physiologiques expliquent 8 à 26 % de la variance additionnelle. On n'a observé aucune différence systématique entre les structures factorielles dans l'analyse des facteurs contextuels.

Mots clés : Nourrisson, douleur, évaluation, indicateurs, analyses factorielles

# **Determining the Structure of Acute Pain Responses in Vulnerable Neonates**

**Bonnie Stevens, Linda Franck, Sharyn Gibbins,  
Patrick J. McGrath, Annie Dupuis, and Janet Yamada**

and (in alphabetical order) Joseph Beyene, Carol Camfield,  
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The primary purpose was to determine the underlying structure of the vulnerable infant's response to an acute painful procedure. The secondary purpose was to explore the influence of context (e.g., risk for neurological impairment [NI] and gestational age [GA]). A descriptive cohort design determined contributions of selected indicators to the structure of infant pain. The magnitude of variance for 19 pain indicators was assessed using 3 exploratory factor analyses in 149 neonates. The basic exploratory factor structure included behavioural (e.g., facial actions) and physiological (e.g., oxygen saturation, heart rate) indicators. Facial actions accounted for the greatest variance across all factor solutions (29–39%). Physiological indicators explained 8 to 26% additional variance. There were no consistent differences in the factor structures when contextual factors were explored.

Keywords: Infant, pain, assessment, indicators, factor analyses

## **Introduction**

Pain assessment has become a standard of care for hospitalized patients. Although there has been a rapid proliferation of infant-pain measures over the past 2 decades, many of these instruments fall short of rigorous psychometric standards and are proliferated at the expense of refining existing measures that show promise. The most reliable and valid measures have been used to systematically evaluate pain-relieving interventions (Bellu, de Waal, & Zanini, 2005; Shah, Aliwalas, & Shah, 2006; Stevens, Yamada, & Ohlsson, 2004) and to provide evidence for the development of professional infant-pain guidelines and standards (Anand et al., 2006; Batton, Barrington, & Wallman, 2006). However, as clinicians become increasingly challenged with assessing acute pain in populations of infants who are extremely premature, of low birth weight, severely ill, or at risk for neurological or physical impairment, the question arises as to whether the way in which existing acute-pain

measures are constructed is appropriate for assessing and managing pain in these vulnerable populations. To address this issue, contributions of indicators in real pain situations experienced by vulnerable infants can be examined and the underlying structure of existing measures explored.

Most frequently, measures of acute infant pain consist of multiple behavioural indicators or a composite of behavioural and physiological indicators. In the development of these measures, individual indicators of pain have been carefully generated, evaluated, and reduced based on observations of healthy preterm (Craig, Whitfield, Grunau, Linton, & Hadjistavropoulos, 1993; Holsti, Grunau, Oberlander, & Whitfield, 2004), term (Gibbins & Stevens, 2003), and older infants (Johnston, Stevens, Craig, & Grunau, 1993; Johnston, Stevens, Yang, & Horton, 1996), most often using heel lance as the pain stimulus. The majority of these measures consist of behavioural (e.g., facial actions, cry, body motions) and physiological (e.g., heart rate, respiratory rate, oxygen saturation, blood pressure) indicators. A few infant measures, such as the Premature Infant Pain Profile (PIPP; Stevens, Johnston, Petryshen, & Taddio, 1996), take contextual factors (e.g., gestational age [GA] and behavioural state) into account. Other examples include the Neonatal Infant Pain Scale (NIPS; Lawrence et al., 1993) where state of arousal is considered and the Neonatal Pain, Agitation and Sedation Scale (NPASS; Hummel, Puchalski, Creech, & Weiss, 2003) where pain scores are adjusted for GA, similar to the PIPP.

Consistent with the development of pain scales for individuals across all age groups, developers of most infant-pain scales have assumed that individual behavioural, physiological, and contextual indicators contribute equally to the infant's pain experience, as depicted in the particular instrument's scoring system. This assumption of equal contributions may preclude a comprehensive understanding of the underlying pain construct, which is known to be multidimensional (e.g., sensory, affective, and cognitive dimensions) in adults (Melzack & Casey, 1968; Price, 1999), or how indicators may be individually or collectively influenced by contextual factors (i.e., GA at birth and NI risk) that render the infant vulnerable. Thus, we are uncertain whether existing pain measures, which were most often developed with more mature and healthy neonates, are appropriate for use with vulnerable infant populations in the NICU.

The primary purpose of this study was to determine the underlying structure of the infant's response to an acute painful event. The secondary purpose was to explore the influence of two contextual factors: risk for NI and GA. Ultimately, the aim was to determine whether existing pain measures can be used with vulnerable infants.

## **Methods**

### ***Study Design and Sample***

A descriptive cohort design was employed. Data were originally collected to compare the behavioural and physiological responses to painful procedures in infants at high, moderate, and low risk for NI (Stevens, McGrath, et al., 2007).

The sample comprised 149 neonates (GA > 25–40 weeks) at high (cohort A:  $n = 54$ ), moderate (cohort B:  $n = 45$ ), and low (cohort C:  $n = 50$ ) risk for NI from three tertiary-level NICUs in Canada. Eligible neonates were: (a) hospitalized in the NICU, (b) > 25 weeks gestational age at birth, and (c) < 6 weeks of postnatal age. Maternal heroin or methadone addiction (defined by a history of active drug intake within 72 hours before delivery or a positive urine test from maternal urine) and pharmacologically induced paralysis in the infant precluded inclusion in the study.

Infants who met the inclusion criteria were stratified into three previously validated cohorts for NI (Stevens et al., 2003) defined as:

Cohort A: at high risk for NI — for example, perinatal asphyxia, IVH (Grade III or IV), or a syndrome or chromosomal anomaly

Cohort B: at moderate risk for NI — for example, acute disease processes such as persistent pulmonary hypertension of the newborn, severe meconium aspiration, meningitis, hydrocephalus, necrotizing enterocolitis

Cohort C: at low risk for NI — for example, respiratory distress requiring ventilation, sepsis.

Estimating inclusion of approximately 30 behavioural (facial actions, body movements, cry) and physiological (heart rate, oxygen saturation, heart rate variability [HRV]) indicators and using five subjects per variable, we concluded that 150 infants, or 50 per risk group, were required.

### ***Pain Response Indicators***

Of the originally estimated 30 indicators, 19 formed the basis for this analysis — 10 behavioural (7 facial action indicators, 3 cry indicators) and 9 physiological (3 oxygen saturation, 3 heart rate, 3 HRV). These indicators were selected based on their repeated validation across infant-pain measurement research. Each indicator was assessed in response to a routine heel-lance procedure in a standardized method described previously by Stevens, McGrath, et al. (2007). Of the original 30 indicators, 11 were excluded, for a variety of reasons. For example, although previous studies may have included all possible facial actions in the Neonatal Facial Coding System (NFCS) (Craig, Hadjistavropoulos, Grunau, & Whitfield,



1994; Grunau, Johnston, & Craig, 1990; Lilley, Craig, & Grunau, 1997), we included only 7 (brow bulge, eye squeeze, nasolabial furrow, open lips, vertical mouth stretch, horizontal mouth stretch, and taut tongue). Chin quiver and lip purse were removed from the analysis as 132/138 non-missing values recorded for this group of infants were 0 (indicating no facial action). Total facial action was excluded as this variable is obtained from a linear equation of other variables and therefore did not add any new information to the factor analysis. Body movements were excluded due to the poor feasibility of collecting data on body movements while bundling or containing the infant to conduct the heel lance and to accurately collect physiological data, in particular HRV data.

### **Data Collection**

Data on behavioural and physiological indicators were collected using procedures previously developed and validated by Stevens and others (Stevens et al., 2003; Stevens, Pillai Riddell, Oberlander, & Gibbins, 2007). *Facial actions* were videotaped using an 8mm camcorder (Sharp, Panasonic, or Sony). Facial actions were coded according to the NFCS coding scheme (Grunau & Craig, 1987) by two trained research assistants on a second-to-second basis using videotapes replayed in real time. Each session was scored repeatedly for each facial action using laptop computer software written in BASIC that recorded the scores and allowed for information on artifacts to be included. A final score was calculated based on percentage of time the action was present for the block of time of interest. Intrarater and interrater reliability of 95% in videotape scoring has been consistently reported (Stevens et al., 2003).

*Cries* were audiotaped using a Sennheiser unidirectional microphone connected to a Sony 500 high-frequency audiotape recorder with an event-marking tone generator. A research assistant conducted cry analyses using CSPEECH (Milenkovic, 1998). The first cry from the stick phase of the heel lance was digitized at 20 kHz using a 16-bit analogue-to-digital converter and low-pass filtered with a high-frequency cut-off of 10 kHz to avoid aliasing. Cry analysis from Fast-Fourier transform spectroscopy was performed using a Pentium microcomputer with C-SPEECH SP that was modified to accommodate fundamental frequencies up to 4 kHz. Cries were analyzed by pitch, which is precisely measured as fundamental frequency ( $F_0$ ). Intrarater reliability was 98%. Mean, minimum, and maximum  $F_0$  were included in the analysis.

To collect *physiological indicators*, disposable ECG electrodes and pulse oximetry probes were placed on the infants and ECG, respiratory rate, and oxygen saturation were continuously recorded using a cardio-respiratory monitor and personal computer (1000 Hz sampling rate). Physiological indicators were recorded using a pulse oximeter (Nellcor

Pulse Oximeter, Model N-3000, Hayward, CA) and the SATMASTER data-collection system (EMG, Los Angeles). ECG segments of 128 seconds in the baseline/warming and immediate post-procedure/return to baseline phases were edited, linearly detrended, and analyzed for power spectral density using HRView software (Boston Medical Technologies, Boston). Data were recorded second-to-second and sampled at 100 Hz. Signals, digitalized in the pulse oximeter, were downloaded onto a personal computer. Standards defining specific frequency bandwidths commonly used to characterize and study power spectral analysis of HRV in infants were followed. Normalized power spectral values were calculated and reported for high-frequency power (0.15–1 Hz), low-frequency power (0.04–0.15 Hz), and the ratio of low-/high-frequency power.

Data on GA and NI risk status were retrieved from the infant's medical record.

### ***Data Management and Statistical Analyses***

A careful examination of all data indicators was undertaken and reasons for missing and unavailable data were ascertained. Data existed on 148/149 babies for all heart-rate indicators and on 146/149 babies for oxygen-saturation indicators. A difference score was created comparing baseline and stick phases of the heel-lance procedure and reported as such (e.g., mean HR difference). Of the 149 babies, HRV data were available for 106. Missing HRV data were attributable to movement artifact.

Complete facial action data were obtained on 135/149 babies with exclusion of the Taut Tongue indicator, where data existed for 129 babies. As Taut Tongue can be visualized only when infants have their mouth open, it is understandable why the coders could not view Taut Tongue in some infants. Cry data were available for 82/149 infants; the remainder did not cry. The incidence of crying in response to heel lance in preterm and sick babies has been noted previously as approximately 50% (Gibbins, Stevens, McGrath, & Yamada, 2007; Harrison, Johnston, & Loughnan, 2003).

A series of exploratory factor analyses with orthogonal transformation and varimax rotation were conducted. All factors with eigenvalues greater than 1.00 were included in the analyses; all indicators loading on factors  $> 0.4$  were reported (Streiner & Norman, 2003). Factor analyses were first conducted on the total population of infants to address the primary research purpose. Sub-analyses were conducted by NI cohort groups and by GA age (i.e., two cohorts above and below the median number of weeks GA (31 weeks) to begin to explore the influence of contextual factors.

Table 1 Summary of Factor Solutions Using Total Infant Samples

Sample	Factor Solution	Eigenvalue	Rotated Factor Patterns, Indicators, and Proportion of Factor Variance
<b>1. Total Sample</b> with FA, HR, O2 ( <i>n</i> = 124)	4 factors accounting for 93% of total variance	Factor 1 = 3.87 Factor 2 = 2.46 Factor 3 = 1.92 Factor 4 = 1.06	Factor 1 (FA) = 39% Factor 2 (O2 diff) = 25% Factor 3 (HR diff) = 19% Factor 4 (FA) = 11%
<b>2. Total Sample</b> with FA, HR, O2, HRV ( <i>n</i> = 83)	5 factors accounting for 95% of total variance	Factor 1 = 4.29 Factor 2 = 2.66 Factor 3 = 1.64 Factor 4 = 1.55 Factor 5 = 1.02	Factor 1 (FA + min HR diff) = 36% Factor 2 (O2 diff) = 22% Factor 3 (FA) = 14% Factor 4 (HRV) = 13% Factor 5 (mean/max HR diff) = 8%
<b>3. Total Sample</b> with FA, Cry, HR, O2, HRV ( <i>n</i> = 40)	5 factors accounting for 89% of total variance	Factor 1 = 4.51 Factor 2 = 3.95 Factor 3 = 1.94 Factor 4 = 1.74 Factor 5 = 1.32	Factor 1 (FA + min/mean HR diff) = 29% Factor 2 (Cry) = 26% Factor 3 (min/mean/max O2 diff + mean HR diff) = 13% Factor 4 (HRV) = 11% Factor 5 (FA) = 8%

FA = Facial Actions; HR = Heart Rate; O2 = Oxygen Saturation; HRV = Heart Rate Variability; diff = difference.

## **Results**

Due to missing and unavailable data (i.e., from infants who did not cry and where HRV data were not available because infants were moving or crying), three separate factor analyses were performed on the total sample based on available data to address the primary research objective: sample 1, based on no missing data when the three cry and three HRV indicators were excluded ( $n = 124$ ); sample 2, with no missing data when the three cry indicators were excluded ( $n = 83$ ); and sample 3, with no missing data on any of the 19 variables ( $n = 40$ ). Factor solutions, eigenvalues, the percentage of variance accounted for, rotated factor patterns, and the specific indicators (and proportion of additional variance) loading on individual factors are described in Table 1.

The factor solution from sample 1 was considered the most defensible due to the adequacy of the sample size. This solution represented the basic exploratory factor structure; key factors represented behavioural (i.e., facial activity) and physiological (i.e., oxygen saturation, heart rate) components of the infant's pain response. All three factor analyses involving the total sample resulted in either four or five factor solutions and accounted for 89 to 95% of the total variance. In each analysis, Facial Actions constituted the factor that accounted for the most variance (29–39%). In two of these analyses, this factor also included one of the heart-rate variables. Factors representing Oxygen Saturation, Cry, and HRV accounted for less variance in the factor solutions than Facial Actions but added anywhere from 8 to 26% additional variance to that resulting from Facial Actions.

To address the secondary research objective, we explored the influence of contextual variables (i.e., NI risk status and GA) on factor solutions. Individual factor analyses were conducted on sample 1 of the total sample only where 50 infants were in cohort A (high risk for NI), 39 were in cohort B (moderate risk for NI), and 35 were in cohort C (low risk for NI) (Table 2). Consistent with the basic exploratory factor structure, in each NI risk cohort Facial Action accounted for the most variance (38–42%) in infant pain response, with oxygen saturation and heart rate representing 20 to 27% and 11 to 20%, respectively, of the additional variance. Cry indicators and HRV indicators were not included in these factor solutions due to the limited amount of data on these variables.

A similar analysis was conducted to determine whether factor solutions varied by GA for infants who were less than and more than 31 weeks GA. No differences in factor solution or structure existed between the groups.

**Table 2 Summary of Factor Solutions Using Cohorts by Neurological Impairment (NI) Risk Status**

Sample	Factor Solution	Eigenvalue	Rotated Factor Patterns, Indicators, and Proportion of Factor Variance
<b>Total Sample with EA, HR, O2 (n = 124)</b>			
<b>Cohort 1:</b> high risk for NI (n = 50)	4 factors accounting for 93% of total variance	Factor 1 = 4.28 Factor 2 = 2.02 Factor 3 = 1.98 Factor 4 = 1.14	Factor 1 (FA) = 42% Factor 2 (FA) = 20% Factor 3 (min/mean/max O2 diff) = 20% Factor 4 (min/mean/max HR diff) = 11%
<b>Cohort 2:</b> moderate risk for NI (n = 39)	4 factors accounting for 90% of total variance	Factor 1 = 4.03 Factor 2 = 2.26 Factor 3 = 2.06 Factor 4 = 1.20	Factor 1 (FA) = 38% Factor 2 (min/mean/max O2 diff) = 21% Factor 3 (min/mean/max HR diff) = 20% Factor 4 (FA) = 11%
<b>Cohort 3:</b> low risk for NI (n = 35)	3 factors accounting for 85% of total variance	Factor 1 = 4.46 Factor 2 = 2.82 Factor 3 = 1.64	Factor 1 (FA) = 42% Factor 2 (min/mean/max O2 diff) = 27% Factor 3 (min/mean/max HR diff) = 16%
FA = Facial Actions; HR, diff = Heart Rate difference; O2 diff = Oxygen Saturation difference; HRV = Heart Rate Variability.			

## **Discussion**

The development of infant pain assessment measures has expanded greatly in the past 2 decades, in response to demands for increasingly comprehensive standards of care and the need to increase our understanding of pain in neonates. However, many of these measures are devastatingly shy of being satisfactorily validated. The general developmental approach has been to utilize either multidimensional behaviour measures or a composite of behavioural and physiological indicators that, if validated, was undertaken in the healthiest infants in NICUs or from older populations where the most appropriate indicators are customized into measures for neonates. For example, the multidimensional behavioural NFCS (Grunau & Craig, 1990), consisting of 10 facial actions, was developed from the 44-facial-action Facial Coding System (Ekman & Friesen, 1978). Other researchers further adapted the original measures, added or deleted indicators, and established the construct validity with a different population of infants or a new pain paradigm. Stevens et al. (1996), in the PIPP, combined the three most frequently displayed facial actions from the NFCS with physiological (i.e., heart rate, oxygen saturation) and contextual (i.e., GA, behavioural state) indicators where sufficient evidence existed to support the construct of pain or factors known to influence it. In the original PIPP, factor analyses were performed on 124 preterm infants aged 32 to 34 weeks GA to determine the underlying structure of selected pain indicators. The three facial actions (Brow Bulge, Eye Squeeze, Nasolabial Furrow) accounted for 42.4% of the variance. An additional 35.8% of the variance was explained by physiological activity (19.1%) and behavioural state (16.7%), explaining 78% of the total variance (Stevens et al., 1996). These findings are consistent with those of the current study on the underlying structure of pain indicators, where up to 40% of the variance was explained by Facial Actions.

Pain assessment is now a standard component of care for all infants, including more vulnerable populations of infants (e.g., infants with low, very low, and extremely low birth weight; infants who are neurologically, physically, and pharmacologically compromised; and infants who may be critically ill or receiving end-of-life care). However, questions remain as to whether the underlying structure of the acute-pain response is similar in the population with whom the measures were developed. Ultimately, this knowledge could assist in determining whether existing measures are applicable for assessing pain in these infants or whether new indicators are warranted.

In the present analyses, Facial Actions consistently accounted for the maximum amount of variance amongst all indicators examined, across all factor solutions. These Facial Action factors were not identical in terms

of the indicators that loaded onto them or their individual indicator weightings. Most often, Brow Bulge, Eye Squeeze, and Nasolabial Furrow had amongst the highest loadings on the Facial Action Factor. However, given the limited sample sizes and the varying amounts of missing or unavailable data, it would not be prudent to delve into this depth of analysis or to make broad and sweeping conclusions about particular Facial Actions from these data. Similar and consistent results across these analyses and previous analyses (Stevens, McGrath, et al., 2007) suggest with some certainty that Facial Actions are the most important but not the only contributors to the assessment of acute pain in neonates.

In two of the factor solutions, one or more of the Heart Rate indicators loaded with the most heavily weighted facial actions. However, Heart Rate indicators also loaded on a separate factor that accounted for varying amounts of significant variance. This result may reflect the lack of specificity in pain responses in infants, especially in distinguishing it from the more global concept of stress.

Although predominant, the leading factor containing the Facial Action indicators (and sometimes one or more of the Heart Rate indicators) accounted for approximately 40% of the total variance, when up to 95% of total variance was explained by the three to five factors in the factor solutions. Indeed, the remaining two to four factors, in any given solution, contributed important additional information in terms of the total explained variance, up to approximately 25% and rarely less than 10%. This finding was consistent across factor solutions, supporting the claim that a composite of indicators contributed to the overarching construct of infant pain.

Until recently, our knowledge of the mechanisms of pain in neonates was limited primarily to our understanding of nociception and pain responses at the periphery and at the level of spinal activation. Recently, Bartocci, Bergqvist, Lagercrantz, and Anand (2006) and Slater et al. (2006) explored cortical responses to a painful stimulus using Near Infrared Spectroscopy (NIRS). The primary hypothesis in each of these studies was that acute pain would cause hemodynamic changes associated with activation of the somatosensory cortex. Slater et al. noted that noxious stimulation via heel lance produced a clear cortical response, measured as an increase in total hemoglobin concentration in the contra-lateral somatosensory cortex in infants as young as 25 weeks GA. Similarly, Bartocci et al. noted increases in hemoglobin concentrations in both hemispheres following tactile stimulation with further significant increases followed by noxious stimulation (i.e., venipuncture). These data suggest that noxious information is being transmitted to the neonatal cortex from 25 weeks GA, highlighting the potential for higher-level pain processing and potentially pain perception. Therefore, determination

of specific pain indicators at very early GA may be necessary to supplement or replace existing acute-pain indicators.

No categorical differences were noted in factor loadings or factor solutions by either GA or NI risk status in this study. This suggests that, in this early exploratory work to determine the influence of contextual variables, there is no difference in the underlying structure of the responses, although the magnitude of actual responses is not captured. We need to be very cautious in interpreting this result due to the limited sample sizes for the subanalyses involving these cohorts. In our previous research (Stevens, McGrath, et al., 2007), using regression analyses, the magnitude of facial actions in infants at the least risk for NI (cohort C) was greater following the pain stimulus. A significant cohort by phase (of the heel lance) interaction existed for total facial expression ( $F[6, 409] = 3.50, p = .002$ ), and four individual facial actions. Cohort B had higher minimum ( $F[2, 79] = 3.71, p = .029$ ) and mean ( $F[2, 79] = 4.04, p = .021$ ) cry pitch. A significant phase effect existed for low- and high-frequency HRV ratio ( $F[2, 216] = 4.97, p = .008$ ), with the greatest decrease in cohort A. Significant cohort by phase interactions were found for low- and high-frequency HRV. Overall, all infants responded to the most painful phase of the heel lance; however, infants at moderate and high risk for NI demonstrated decreased intensity of responses on some indicators. These results indicate that the underlying structure of the response was consistent. Factors such as severity of illness, time since previous painful procedures, and current medication status may be important to consider in terms of the situational context.

No differences in factor solutions were noted in the two groups of infants defined by GA greater than and less than 31 weeks. Gibbins et al. (2007) report that responses to painful procedures in infants with extremely low birth weight (i.e., < 28 weeks GA) were similar across behavioural and physiological responses, compared to older infants, but the responses were proportional to GA, with the youngest infants showing the least amount of change. Infants less than 28 weeks GA had significantly lower minimum oxygen saturation and higher minimum heart rate following a heel lance than infants greater than 28 weeks GA. When controlling for NI risk status, GA was still a significant factor in responsiveness. The categorization of age cohorts (i.e., greater than and less than 31 weeks GA) or the particular pain indicators used for the comparisons, although developmentally defensible, may have influenced these analyses in light of the small cohort sizes.

Overall, the results are generally consistent with the underlying structure of the PIPP and with the multivariate composition of existing composite infant-pain measures. Greater variance was explained when additional indicators such as cry characteristics and HRV were added in



the factor solutions, although the populations examined in relation to the influence of context were small. Therefore, the conclusions need to be considered with caution. The results are limited by the contextual variables included in these analyses. Further research, including additional and novel pain behavioural and physiological indicators and contextual variables beyond NI risk status and GA, should be considered, especially with infants who are the most immature, critically ill, fragile, or vulnerable.

The research is also constrained by the pain indicators that were selected for entry into this factor analysis in consideration of the sample size. Many other behavioural and physiological variables could have been included; behavioural indicators such as finger splay and fisting (Holsti et al., 2004) and physiological indicators such as cortisol, hemodynamic intracranial pressure changes, and palmer sweating may also be important to consider in the youngest age group of infants. In previous measurement research by Stevens and others (Stevens et al., 1996), the potential list of available indicators was minimized based on sensitivity and specificity, high correlations with other indicators, and feasibility (for an in-depth discussion on selection of pain indicators in infants, see Stevens, Pillai Riddell, et al., 2007).

Indicators (e.g., cry) that were included in this study are also problematic when assessing pain in infants. Except for mechanical ventilation, which precludes the infant's ability to voice a cry, we continue to be perplexed as to why particular infants fail to cry following a heel lance. The complexity of issues surrounding cry has frequently rendered cry a questionable indicator for inclusion in infant pain-assessment measures. This rationale is not sufficient for removing cry from our potential list of infant-pain indicators and for failing to study other cry characteristics in addition to fundamental frequency (pitch) and duration. Peak spectral energy, phonation, jitter, and other temporal characteristics (latency, expiration, pause, inspiration, rhythmicity) should also be explored in future cry analyses.

This research is relevant in light of the directions for research proposed by Anand et al. (2006), where the search for a gold standard in pain assessment is still paramount. At present, this research, in addition to work by Gibbins et al. (2007) and others, suggests that these infants' pain responses in terms of facial expression, heart rate, and oxygen saturation are consistent (although dampened) with their more mature counterparts and therefore may serve as a useful starting point for assessment of acute pain. Results from our explanatory factor analyses can also be helpful in guiding future confirmatory factor analyses that may be undertaken to test specific hypotheses regarding the number of factors, factor loadings, and factor intercorrelations.

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### Authors' Note

Funding was provided by the Canadian Institutes of Health Research (MOP-37884) and the Bloorview Children's Hospital Foundation. We also acknowledge financial support in the form of a Career Scientist Award from the Ontario Ministry of Health, the award of the Signy Hildur Eaton Chair in Paediatric Nursing Research at the Hospital for

Sick Children to Bonnie Stevens, and a Canada Research Chair award to Patrick McGrath.

We would like to acknowledge the contributions of Drs. Lynn Breau, Alexandra Howlett, and Patricia McKeever as co-investigators in this program of research.

We are grateful to the research nurses who participated in the collection and management of data: Anne Jack, Marie Bagg, Mary Anne Fagan, Janet Narciso, Kim Caddell, Janet Chee, Salena Mohammed-Breault, Sandy Lin, and Karolina Kupczyk.

Finally, we are grateful to the families of the infants for their willingness to participate in the study.

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## **Évolution positive de la perception des patients à l'issue d'un programme de psychoéducation pour angine stable chronique**

**Michael McGillion, Judy Watt-Watson,  
Sandra LeFort et Bonnie Stevens**

La présente étude vise à analyser la perception de la douleur thoracique associée à l'angine stable chronique (ASC) chez des patients inscrits à un programme de psychoéducation standardisé de six semaines, axé sur l'autogestion de la maladie. Aux première et sixième séances, on a demandé aux patients d'expliquer comment ils voyaient l'apparition de cette maladie dans leur vie. À la première séance, les sujets ont décrit l'angine comme un bouleversement majeur, caractérisé par la peur, la frustration, les restrictions et la colère. À la sixième, ils ont dit la considérer comme un problème général et permanent, nécessitant une autogestion continue pour s'assurer la meilleure qualité de vie possible. Les données indiquent que la perception des patients évolue au cours du processus de psychoéducation : d'un changement de vie pénible et débilitant, l'angine devient un problème de douleur exigeant une autogestion assidue pour qui veut préserver ses objectifs de vie et son mode de fonctionnement. D'autres recherches devront être menées pour déterminer en quoi ces changements de perception contribuent de manière générale à l'utilité de la psychoéducation.

Mots clés : angine stable chronique, douleur, perception, psychoéducation

# **Positive Shifts in the Perceived Meaning of Cardiac Pain Following a Psychoeducation Program for Chronic Stable Angina**

**Michael McGillion, Judy Watt-Watson,  
Sandra LeFort, and Bonnie Stevens**

This study examined the meaning of cardiac pain for chronic stable angina (CSA) patients who participated in a standardized angina psychoeducation program. The patients documented what angina meant to them at sessions 1 and 6 of a 6-week standardized psychoeducation program aimed at enhancing CSA self-management. At session 1, angina was described as a major negative life change characterized by fear, frustration, limitations, and anger. At session 6, angina signified a broad and ongoing pain problem requiring continual self-management in order to maximize quality of life. The findings suggest that the perceived meaning of angina as a burdensome and debilitating life change shifts, during psychoeducation, to one of angina as a broad pain problem requiring ongoing self-management in order to preserve life goals and functioning. How such perceptual shifts in the meaning of cardiac pain might contribute to the overall effectiveness of psychoeducation warrants further investigation.

Keywords: Chronic stable angina, pain, meaning, psychoeducation

## **Background**

Chronic stable angina (CSA) is the most common and debilitating symptom of ischemic heart disease (IHD). More than 33% of Canadians with IHD suffer from CSA, which has a large negative impact on health-related quality of life (HRQOL), causing poor general health status, restricted activity and role functioning, and decreased capacity for self-care (Erixon, Jerlock, & Dahlberg, 1997; Gardner & Chapple, 1999; MacDermott, 2002). Chronic stable angina is characterized by pain or discomfort in the chest, arm, jaw, shoulder, and or/back (Podrid, 2000). This pain is thought to be triggered by transient myocardial ischemia caused by inadequate perfusion relative to the needs of the heart (Ganz & Ganz, 2001).

Although neurophysiological evidence has long supported the involvement of the spinothalamic tract, neocortex, and related excitatory mechanisms in the afferent processing of cardiac pain, there is also

substantial evidence pointing to the variability of cardiac pain for persons with IHD, where angina can occur in the absence of myocardial ischemia and, conversely, ischemic episodes can be painless (Procacci, Zoppi, & Maresca, 1999). The equivocal nature of the relationship between myocardial ischemia and angina is due to the variable nature of pain. Melzack and Wall's seminal Gate Control Theory (1965) led to the understanding that injury, such as ischemia, produces neural signals that enter an already active nervous system that is a substrate of past experience, cultural background, context, and emotion (Melzack & Wall, 1965, 1973, 1982). Pain is modulated centrally through continuous interactions among complex ascending and descending central nervous system mechanisms that actively participate in the selection, abstraction, and synthesis of information from the total sensory input (Melzack & Wall, 1965, 1973, 1982). The amount and quality of pain experienced is therefore dynamic and variable for each person. More recently, the critical role of plasticity of the nervous system in peripheral and central sensitization has also been recognized, along with the individuality of the pain experience and related response (Basbaum & Bushnell, 2002; Bielefeldt & Gebhart, 2005). Pain mechanisms in the peripheral and central nervous systems can change in response to continued noxious stimulation so that they transmit spontaneous discharges and respond at lowered thresholds to both noxious and non-noxious stimuli. These advancements in the understanding of pain have led to growing recognition that angina is not simply the end product of a linear transformation of a noxious, ischemic stimulus. Like other pain problems, CSA is complex and multidimensional, with sensory-discriminative, motivational-affective, and cognitive-evaluative components (Melzack & Casey, 1968). As well, the meaning of the pain stimulus can contribute to the pain experience (Arntz & Claassens, 2003) and anxiety and fear have been identified as potential intensifiers of perceived pain and related burden (Arntz & de Jong, 1993).

The meaning of pain is of critical importance to the care of CSA patients, as these patients are at risk for misinterpreting the meaning and consequences of their angina. Our previous work, like that of others, has found that CSA patients (a) are poorly informed about their condition; (b) experience continued fear and anxiety due to common misbeliefs (e.g., each angina episode reflects further damage to the heart); and (c) lack the knowledge and skills necessary to engage in daily symptom monitoring, interpretation, and decision-making about when to seek emergency assistance (Erixson et al., 1997; Furze, Lewin, Murberg, Bull, & Thompson, 2005; Gardner & Chapple, 1999; MacDermott, 2002; McGillion, Watt-Watson, Kim, & Graham, 2004; Miklaucich, 1998). Recent studies have examined the impact of psychoeducational interventions designed to address CSA patients' misconceptions, learning

needs, and perceived HRQOL burden. A recent systematic review found that while a few small randomized controlled trials (RCTs) demonstrated positive effects somewhat related to exercise tolerance, angina symptoms, and stress (McGillion, Watt-Watson, Kim, & Yamada, 2004), none examined the impact of their interventions on the meaning of cardiac pain.

The purpose of this study was to examine potential shifts in the meaning of cardiac pain following participation in a 6-week standardized angina psychoeducation program, the Chronic Angina Self-Management Program (CASMP).

### **Method**

We aimed to derive low-inference descriptions of CSA patients' expressed meaning of their cardiac pain, remaining as close to the data as possible without imposing our own theoretical position on their meaning. The chosen method for this study was qualitative description as outlined by Sandelowski (2000). According to this approach, investigators can derive the latent meaning of their findings by preserving a mandate to produce a descriptive summary supported by verbatim illustrative quotes without extensive accompanying narrative and/or intentional "interpretive spin" on the data collected:

Basic qualitative description is not highly interpretive in the sense that a researcher chooses to describe an event in terms of conceptual, philosophical, or other highly abstract framework of system. The description in qualitative descriptive studies entails the presentation of the facts of the case in everyday language. (Sandelowski, p. 336)

Qualitative description was deemed the most appropriate method for the study, as a straight description of participants' responses was desired for this initial exploration of the impact of our program on the meaning of cardiac pain.

### ***Inclusion Criteria***

The study included CSA outpatients who (a) had a medical diagnosis of IHD; (b) had angina symptoms for at least 6 months; and (c) were able to speak, read, and understand English. Patients were excluded if they (a) had sustained a myocardial infarction and/or undergone a coronary artery bypass graft revascularization procedure within the preceding 6 months, (b) had CCS (Canadian Cardiovascular Society) class IV angina, or (c) had a major cognitive disorder precluding participation in a group setting.



### **Sample**

As part of a larger RCT ( $N = 130$ ), the study included 66 participants from three university-affiliated teaching hospitals in central Canada with large cardiac outpatient programs. This subsample had a mean age of 67 ( $SD = 11$ ) and had been living with angina for an average of 6 years ( $SD = 6$ ). The majority were male (80%), married or cohabitating (67%), and Caucasian (73%). Individuals of East Indian and Pakistani origin constituted the second-largest racial group (17%). Most participants were either retired (70%) or working full time (24%). The majority had completed high school (89%) and/or had postsecondary education (64%). The majority reported having a co-morbid condition (98%), typically a minor medical problem (52%) or diabetes (27%).

### **Intervention**

Participants were randomly allocated to the intervention group or to a 3-month waitlist control group. The CASMP was delivered by a nurse facilitator in 2-hour sessions weekly, over a 6-week period, using a small-group format (8–15 participants). Participants were permitted to bring a family member or friend if they wished. The program integrated strategies known to enhance self-efficacy, including skills mastery, modelling, and self-talk. The program was designed to (a) maximize discussion and group problem-solving; (b) encourage individual experimentation with various cognitive-behavioural self-management techniques; and (c) facilitate mutual support, optimism, and self-attribution of success. Content included self-help principles; myths and information about chronic angina pain; benefits of exercise, such as walking; angina-management strategies, including symptom interpretation and decision-making; energy conservation; pacing of activities and practice of four relaxation techniques; discussion of depression and anxiety; nutrition; communication skills; review of medications; fatigue/sleep; evaluation of non-traditional therapies; problem-solving; and weekly individual goal-setting.

### **Data Collection and Analysis**

Ethical approval was obtained from participating centres, including one university and three university-affiliated teaching hospitals. As a part of our intervention protocol, at sessions 1 and 6 of the program the nurse facilitator asked the CASMP participants to document what their angina meant to them with respect to their perceived HRQOL and self-efficacy to manage their angina symptoms; these qualitative data were then analyzed for the current study. The constructs of enabling skill and life quality in Braden's Self-Help Model: Learned Response to Chronic Illness Experience (Braden, 1990a, 1990b) guided the outcomes of our

larger RCT. Prior to documentation of the responses, the facilitator defined enabling skill and life quality for the participants. Enabling skill, or one's perceived ability to manage adversity, was defined as the ability to manage one's angina symptoms (Bandura, 1997). Life quality, or level of satisfaction with one's current life situation, was defined as the participant's perceived disease-related burden. Analysis of the qualitative data was ongoing once the first group of participants had documented their responses. Axial coding and constant comparison were used to derive key themes for the qualitative content analysis. Axial coding is a technique that allows the researcher to organize data around more central themes that emerge, once they have been organized into preliminary categories (Creswell, 1998). The frequency, extensiveness, intensity, and specificity of comments were guiding principles for the principal investigator (PI) and research assistant engaged in reducing the data into central themes (Morgan, 1993; Sandelowski, 2000).

### ***Credibility***

Descriptive credibility refers to the "degree to which a description of human experience is such that those having the experience would recognize it immediately and those outside the experience can understand it" (Baxter & Eyles, 1997, p. 512). Sandelowski (2000) argues that despite best efforts to generate inference-free descriptions via qualitative description, some level of interpretation is unavoidable: data are confronted and processed through the perceptions of an investigator with a particular subjective position. The PI was a full-time doctoral candidate in nursing with 5 years' experience working with CSA patients in emergency room settings. He had a strong commitment to understanding the experience of CSA, with the intention of describing the impact of the CASMP on the meaning of cardiac pain for CSA patients.

The sampling technique for this study was purposive in nature, as we sought to elicit the meaning of cardiac pain from experienced CSA patients already enrolled in a larger RCT. Purposive sampling can enhance descriptive credibility through the obtainment of "information-rich" cases that will adequately reflect the realities of the group under study (Patton, 1990). Because this study was conducted within a larger RCT, we were confident that we would have an adequate number of participants to achieve data saturation.

Bracketing and prolonged engagement were additional strategies used to enhance credibility (Lincoln & Guba, 1985). Bracketing, also known as disciplined subjectivity, refers to the fact that the PI and research assistant made a conscious effort to put aside their preconceived beliefs regarding the meaning of cardiac pain when analyzing the data separately and when coming to a consensus on major descriptive themes (Lincoln

<b>Table 1 The Meaning of Angina for Participants</b>		
	<b>Session 1</b>	<b>Session 6</b>
<i>What does your angina mean to you with respect to your life quality?</i>	<p>Major negative life change</p> <p>Slowed down</p> <p>Life curtailed</p> <p>Warning sign, constant reminder of ill health</p> <p>Fear of sudden death</p> <p>Source of altered role functioning and relationship tension</p>	<p>Not curable but manageable</p> <p>Acceptance of limitations</p> <p>A broad and ongoing health problem</p> <p>Can maintain quality of life</p> <p>Can have some control</p>
<i>What does your angina mean to you with respect to your self-efficacy to manage your symptoms?</i>	<p>Lack of knowledge about angina management</p> <p>Cannot meet own expectations</p> <p>Wake-up call to take better care of one's health</p>	<p>Need for continual self-management</p> <p>Staying informed</p> <p>Communicating and asking for help</p> <p>Lifestyle changes</p> <p>Priority-setting for self-management</p> <p>Pacing</p>

& Guba). Prolonged engagement calls for the investigator to spend sufficient time with participants to establish rapport, develop an understanding of the key issues faced by the group under study, and monitor for misconceptions, either self-imposed or from the group, that could distort reality (Lincoln & Guba). Prolonged engagement was a pre-existing condition of the larger RCT in which the study took place; the PI was part of each CASMP small group, working with the participants in 2-hour sessions over the course of 6 weeks. Further, as part of the CASMP protocol, each participant read aloud and discussed his/her responses to the research questions in the small-group setting. The sharing of individual meanings of cardiac pain was part of the intervention design and also served as an additional means for the PI to validate the data. Finally, to enhance the validity of our data codes, an outside individual with expertise in qualitative description was asked to review the data; agreement was reached on the identified descriptive themes.

## Results

The data collected at sessions 1 and 6 of the CASMP were thematized under the constructs of HRQOL and self-efficacy, as participants were asked to document what angina meant to them with respect to these constructs. A summary of these results is presented in Table 1. In keeping with the principles of low-inference analysis, we have chosen a number of illustrative quotes in order to represent our data under key themes, rather than selecting fewer quotes augmented by a more extensive interpretive narrative (Sandelowski, 2000).

### *CASMP Session 1*

**HRQOL.** With respect to HRQOL, or the perceived burden of CSA, most participants indicated that their angina signified a major negative life change, characterized by frustration, limitations, and/or anger or shock over how angina had negatively impacted their day-to-day functioning. The following are typical participant remarks reflecting the experience of angina as a major negative life change:

*Frustration. It's a major change in my life. [I] had bypass surgery in '95, had a 75% blockage. Now the pain is unpredictable — some days good, some days bad. I've had major decreases in my physical activity. Really bothers me. I don't feel good, feel very limited.*

*Angina means to me a change in my lifestyle, not being able to go out as often, working at a slower pace with my household duties, and even changing the type of person that I am — I now have major mood swings.*

*My life has been changed completely. I can't do what I was able to do. Every step of my life has been changed.*

*Chronic angina is for me a constant hindrance and severe roadblock to enjoying my day and planning each 24-hour period. To me it's a curse that I have this affliction. Therefore, I have to constantly monitor my physical exercise habits, and I sort of exist in a physical strait-jacket.*

Angina also meant a slowing down and curtailment of life:

*[Angina] restricts my movement, makes me more susceptible to stress and strain, and I have to take medication that makes me tired and slows me down.*

*I have to go slowly on stairs or uphill when walking. If the pain is severe I use my nitro, which will give me a severe headache, so I try to take my time when out.*

*It significantly curtails physical activity that I want to engage in.*

Angina was also understood as a warning sign and a constant reminder of ill health. Some participants felt that angina, as a warning, was a direct result of their own behaviour. Uncertainty about the future also emerged in contemplations of angina as a reminder of ill health:

*Angina is a warning sign, given to me by my body to say that I was pushing myself too hard. This was a warning. Should I continue with my lifestyle, I could have a stroke or a heart attack.*

*A warning that my heart is not getting sufficient oxygen or is otherwise stressed, probably caused by something I am doing at that time.*

*It's a constant reminder that life as I know it could change in an instant.*

*A reminder of my condition and my pain, caused by impaired heart functioning as a result of my heart attack.*

The contemplations of other participants resulted in frank expression of the fear of death:

*I expect the condition to worsen. [I am] very likely to experience a heart attack and die. The heart condition I have is to some degree hereditary. This sounds "fateful" and I expect that, subconsciously, this is my attitude.*

*Another issue is the fear of what will happen if I do not control this angina — will I die?*

*It's a constant reminder of my mortality, a disheartening, limiting, constant companion.*

The fear of death was also seen as a factor negatively impacting one's role functioning within the family and as a contributor to tension within the family and within spousal relationships:

*Fear of having the pain comes again and again. [I] don't enjoy the normal activities that a normal dad does with his kids. I'm always thinking thoroughly of what will be my future and my family's future if more serious things happen.*

*Sometimes, if he snaps at me or is in a bad mood, he tells me it's because of his chest pains. Then I know he's scared.*

**Self-efficacy.** With regard to self-efficacy, or one's perceived ability to manage symptoms, participants predominantly expressed a lack of knowledge about angina and how best to manage their angina symptoms. Some also expressed confusion about when to seek emergency assistance and frustration that past attempts to obtain help there had been fruitless:

*[Angina] is severe pain that I don't know how to handle, especially living alone.*

*How can I improve my condition? I don't know what to do.*

*Pain in [my] chest — not always in the same spot. Do I go to the emerg[ency]? I'll waste a day there. I hate hospitals after spending a month [there] after my heart attack and having my bypass. What's worse? Dropping dead on the street or spending another week, month, et cetera, in hospital?*

A lack of knowledge about how to manage was coupled with feelings of disappointment about no longer being able to meet one's own goals and expectations with respect to physical or emotional functioning; some participants blamed themselves for this:

*Basically it's become quite restrictive in the sense of my energy levels and ability to live at [a] level which I had become accustomed and to which I have performed in the past.*

*If I exercise on the treadmill I constantly have to be alert to dizziness. It means I can't walk as quickly as I'd like.*

*I cannot do many things I used to be able to... I also do not keep a good and happy disposition.*

*[Angina] is a restriction placed on my body, probably due to ignoring my symptoms over the years. It has now become a roadblock to exercise and activities I enjoy.*

Finally, angina was seen as a wake-up call, alerting participants to learn to take better care of their bodies:

*To me, angina was a wake-up call for a better lifestyle — healthy eating and more exercise and less of a stressful lifestyle.*

*I was not taking care of health and my body. It's time for me to learn.*

### **CASMP Session 6**

**HRQOL.** With respect to perceived HRQOL at session 6, many participants said angina meant living with a condition that is not curable but manageable and that it was important to come to an acceptance of the resulting limitations:

*Although my angina will never be cured, I now understand the condition better and I'm not as frightened as I used to be of my attacks... When I had attacks I was paralyzed with fear — sometimes I was even afraid to fetch my nitro-spray. Now I know how to manage an attack and how to administer my nitro.*

*My angina is not curable but I can assist myself to live a less limiting lifestyle.*

*I'm trying not to get angry so I will not [have] angina discomfort. I will have to live with angina as my companion and accept life as it is.*

*It means acknowledging that there are some things I cannot do. Staying positive and accepting the illness is very important.*

A number of participants indicated that angina represented a broad and ongoing health problem in their lives. They thought that angina was something one can live with and that, with time and effort, quality of life could be maintained:

*[Angina is] an ongoing, potentially restrictive but manageable occurrence that makes you well aware of life.*

*I think that angina means to me that I have a chronic condition that needs my day-to-day attention in the form of self-management. I find that the best thing for me to do is realize that angina need not prevent me from having what would be considered a normal life. It can be a hindrance to things in life, however; but if it is properly managed, then I can work with the symptoms to the extent that I can live a happy life and enjoy each day.*

*Angina is a condition that afflicts me and has to be dealt with in order to maintain a reasonable quality of life. Living with angina means I have to practise all the methods and procedures that will give me the opportunity*

*to obtain a better life and cope with the anxieties and side effects of the disease.*

*Angina tells me that life is not forever, but there are ways and means to ameliorate the symptoms to make life enjoyable, to make life a pleasant experience.*

*[Angina] is a condition which, through appropriate actions on my part, can be maintained in a stable state so that I can continue to enjoy life.*

Finally, angina was seen by participants as a pain problem over which they could exert some control:

*[Angina] means that I have a health problem. That problem is heart-related and can be controlled up to a point with sensible diet, exercise, positive self-talk, and careful attention to my medications.*

*I now understand that [spouse] has frustrations over the things he can't do. I also realize now that my panic level can be reduced because he can do things to have control of his angina.*

*It limits me emotionally. I have felt that I am not in control, but I do feel now that I have some control... On the up side, when I can do things to relieve my angina I appreciate the moments I do have.*

**Self-efficacy.** Contemplating the meaning of angina related to managing symptoms at session 6, participants emphasized their need for continual self-management and the importance of staying informed in order to avoid angina-related pitfalls:

*[Angina] means that I have a disease that is not going to go away and could restrict my lifestyle, but with continual self-management techniques I can lead close to a normal life.*

*I need to monitor for precursors to angina — fatigue, tension, depression, stress, anxiety, and anger. For me, watching for these and using techniques...will help me to avoid angina.*

*I must continue to take steps to improve my physical and mental condition. Studying more about angina and knowing the latest treatments for my condition helps... I need to keep reading and asking questions — it helps me to understand.*

Communicating and seeking help were also expressed as important aspects of angina self-management:

*One essential element that is required to live with angina is to use the support of my loved ones, by revealing my concerns and worries to them.*



*Keeping in touch with family every day to let them know how I am is important, as I live alone.*

*Letting my doctor know when I am having trouble and checking in regularly will help me to be safe.*

Angina also meant the need for lifestyle changes characterized by change in diet and exercise, planning ahead, realistic goal-setting, and pacing in order to manage symptoms:

*Angina means the need to change my lifestyle, to manage eating and drinking habits, and getting regular exercise.*

*Now I look at it [angina] as a need for a lifestyle change. I'm not as afraid of it as I used to be. I know that I must be careful about lifestyle because it affects my angina.*

*If I'm involved in any physical activity I must plan it so that I don't bring on my angina attacks. For example, I must carry my nitro wherever and whenever.*

*Angina is part of my life, and with sensible exercise and walking I can increase the amount of activities I can do over time. I know that I must lose weight to reduce heart stress and achieve overall better health.*

Finally, angina was also thought of as a condition requiring careful attention to pacing and selection of individual priorities for self-management:

*I have to be careful not to do too much, to not rush around, as I get tired as a result and this brings on my angina. Leading my life with pacing is very important.*

*This course has taught me to pace myself more realistically, in accordance with my age and condition. Now I try not to over-schedule myself and to intersperse work with periods of rest.*

*I have learned that there are techniques I can do for myself. Most important for me are the breathing and relaxation exercises. I can pick what works for me.*

*It means using what works for me. I have made mild exercise part of my routine. I am going to eat more frequently and reduce meal size, and have my medications re-evaluated periodically to confirm dosages.*

*Deep breathing and pacing help me to overcome the feeling in the chest and to promote relief.*

*Documenting symptoms and health concerns for a planned and productive appointment with the doctor is also what I need to do.*

## **Discussion**

These results indicate that, following their participation in the Chronic Angina Self-Management Program, CSA participants experienced positive shifts in the meaning of their cardiac pain. At session 1, angina was described as a major negative life change characterized by frustration, limitations, and anger; angina also meant that life was curtailed and served as a warning sign and reminder of ill health. The fear of death was also a concern, coupled with the stress that this fear can impose upon role functioning and relationships. Lack of knowledge about the management of angina symptoms and frustration over unsuccessful attempts to obtain help were also identified as concerns. However, meaning had changed by session 6. Patients described angina as a broad and ongoing pain problem and indicated that angina meant the need for continual self-management. Lifestyle changes with respect to diet, planning, and realistic goal-setting, as well as asking for help, were viewed as critical in order to live with angina, maximize quality of life, and retain desired life goals.

Our session 1 findings support those of previous work examining the self-management learning needs of CSA patients. McGillion, Watt-Watson, Kim, and Graham (2004) found that CSA patients had a critical need to deal with their illness-related uncertainty, learn how to reduce the impact of symptoms, and cope with their angina-induced limitations. Results of other studies examining CSA patients' HRQOL also resonate with our findings with respect to angina's signifying a major negative life change, fear of death, and uncertainty about self-management. For example, Gardner and Chapple (1999) found that CSA patients continually struggled with their angina-induced limitations and interpretation of their symptoms. Gardner and Chapple found that a common strategy for dealing with limitations was to adopt a sedentary lifestyle, relinquish control of normal activities, and "give in" to the pain. Their participants also reported being in a quandary over whether to seek emergency help during an angina episode, as the pain was often confused with severe heartburn, anxiety, or indigestion. Similarly, Miklaucich (1998) found that fear and anxiety were central to the experiences of CSA; inpatient participants consistently reported an insoluble circle wherein angina caused feelings of fear, anxiety, and uncertainty, which created tension between wanting to be secure in the familiar home environment and wanting to be safe in hospital.

Session 6 findings support the quantitative data of our larger RCT ( $N = 130$ ) (McGillion, Watt-Watson, Stevens, LeFort, & Coyte, 2006). We found that the CASMP resulted in clinically significant short-term improvements in HRQOL self-ratings of physical functioning [ $F = 11.75 (1,114), p < 0.001$ ] and general health [ $F = 10.94 (1,114),$

$p = 0.001$ ], symptom profile with respect to angina frequency [ $F = 5.60$  (1,115),  $p = 0.02$ ] and stability [ $F = 7.37$  (1,115),  $p = 0.001$ ], and perceived self-efficacy to manage angina [ $F = 8.45$  (1,115),  $p = 0.004$ ] at 6 weeks post-intervention (McGillion et al., 2006). Although our current qualitative data cannot be directly compared with the quantitative outcomes of our RCT, the shift in perception of angina to a broad and ongoing manageable health problem suggests that engaging with the meaning of one's angina may be critical to the enhancement of perceived self-efficacy, functional status, and angina symptom profile. Furze et al. (2005) also found that a supportive psychoeducational intervention for newly diagnosed angina patients ( $N = 130$ ) resulted in a positive change, over 1 year, in angina-related beliefs; these beliefs were the most significant predictor of improved physical functioning ( $\Delta R^2 = .064$ ,  $p = 0.024$ ).

Cumulative evidence from well-designed RCTs has established that standardized psychoeducation programs improve HRQOL-related outcomes for chronic conditions, including chronic pain, by virtue of enhancing perceived self-efficacy (LeFort, Gray-Donald, Rowat, & Jeans, 1998; Lorig & Holman, 1993). What remains unclear is how the meaning of cardiac pain may have contributed to the overall short-term effectiveness of our program for improving CSA patients' perceived self-efficacy, symptoms, and functional status. At an operational level, part of the answer to this question may lie with participants' decision-making processes while acquiring the skills for angina self-management. In a future study, we will examine the relationship between perceptual shifts in the meaning of cardiac pain and participants' decision-making with respect to how they gauge self-efficacy and identify their individual priorities for self-management during psychoeducation.

A limitation of this study may be social desirability bias. However, the sharing of data took place in a group setting of 8 to 15 participants, which included the researcher. Madriz (2000) argues that data collection within a focused group setting can serve to mitigate the influence of the researcher on participants by allowing for the balance of power to be oriented towards the larger group. The study, as an initial investigation of the meaning of cardiac pain, also relied solely upon content analysis of written accounts to derive key themes. Additional qualitative methods, such as participant observation, would allow for a broader range of information, including verbal communication and body language. Higher-inference analytic techniques might also enhance our understanding of meaning beyond what can be gleaned from qualitative description.

A major strength of the study was the large number of experienced CSA participants with varying degrees of angina severity (i.e., CCS classes I-III), thereby enhancing the transferability of findings to the CSA

population. Moreover, treatment integrity of the RCT program was maximized using a theoretically sound and standardized intervention protocol that was verified by an external auditor who monitored session audiotaping. Techniques used to enhance descriptive credibility included purposive sampling, bracketing, and prolonged engagement.

In conclusion, to our knowledge this is the first study to use qualitative methods to examine shifts in the perceived meaning of cardiac pain following participation in a standardized CSA psychoeducation program. The findings suggest that the perceived meaning of angina as a burdensome and debilitating life change shifts, during psychoeducation, to one of angina as a broad pain problem requiring ongoing self-management in order to preserve life goals and functioning. How such perceptual shifts in the meaning of cardiac pain might contribute to the overall effectiveness of psychoeducation warrants further investigation.

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### **Authors' Note**

We are grateful to the participants in this study, who generously gave of their time and input. We would also like to thank Drs. Denise Gastaldo, Elizabeth Peter, and Jan Angus for their comments and Ms. Josephine Mullally, MA, for her external audit of our data and major themes.

This study was made possible by a Canadian Institutes of Health Research fellowship (#452939) and a University of Toronto Centre for the Study of Pain Clinician-Scientist fellowship.

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## Spiritualité, religion et douleur

Anita M. Unruh

Les rapports entre spiritualité et santé occupent une place de plus en plus importante en recherche, y compris dans le domaine des sciences infirmières. Peu de travaux de recherche ont porté sur la spiritualité, la religion et la douleur jusqu'ici, même si, tout au long de l'histoire, certaines croyances spirituelles ont été empreintes de notions relatives à la souffrance. Ces croyances peuvent avoir un effet sensible sur la façon dont un patient perçoit la douleur et sur les décisions qu'il prendra relativement à sa gestion. L'auteure propose une synthèse de la recherche sur ces questions dans une perspective historique. Elle analyse en quoi la spiritualité et la religion ont servi à construire une idée de la souffrance qui se reflète sur la perception de la douleur, l'adaptation à celle-ci et sa gestion. Cette approche comporte des implications cliniques, notamment en ce qui concerne les points suivants : la communication entre soignant et patient sur les questions liées à la spiritualité et à la douleur; l'intégration de ce thème dans les programmes d'éducation et d'aide; le respect des préférences spirituelles en matière de gestion de la douleur, là où cela est possible et justifié; la consultation avec les équipes de conseillers spirituels; la réflexion que mène l'infirmière sur la place qu'occupe la spiritualité dans sa propre vie. L'article se termine sur une discussion des implications pour la recherche.

Mots clés : spiritualité, religion, douleur

# **Spirituality, Religion, and Pain**

**Anita M. Unruh**

Understanding the relationships between spirituality and health has become increasingly important in health research, including nursing research. Very little of the research thus far has focused on spirituality, religion, and pain even though spiritual views have been intertwined with beliefs about pain and suffering throughout history. Spiritual views can have a substantial impact on patients' understanding of pain and decisions about pain management. The author reviews the research literature on spirituality and pain from a historical perspective. The analysis is concerned with how spirituality and religion have been used to construct a meaning of pain that shapes appraisal, coping, and pain management. The clinical implications include respectful communication with patients about spirituality and pain, inclusion of spirituality in education and support programs, integration of spiritual preferences in pain management where feasible and appropriate, consultation with pastoral care teams, and reflection by nurses about spirituality in their own lives. A discussion of research implications is included.

Keywords: Spirituality, religion, pain

## **Introduction**

Considerable progress has been made since the publication of Melzack and Wall's (1965) effort to reframe pain from a biomedical to a more comprehensive biopsychosocial perspective. There is a substantial body of research examining the interactions between physiological and psychological mechanisms of pain (for a review, see Fields, Basbaum, & Heinricher, 2006). More recently, attention has also been given to understanding the social context of pain, including ethnic and cultural issues (e.g., Craig & Riddell, 2003). Nevertheless, very little attention has been focused on the impact of spirituality and religion on patients' pain experience, despite a growing concern in the health literature with spirituality and health.

Increased interest in spirituality and health is related to researcher and practitioner interest in how people construct meaning when faced with serious life issues (Clarke, 2006). Koenig, McCullough, and Larsen (2001) propose three additional reasons for this interest in spirituality and health. First, despite the increased secularization of society, spirituality and religion continue to play a role in the daily lives of many people. Second, populations are rapidly aging and consuming more health care with its



associated costs, leading to greater concern with the factors that promote health and resilience. Third, traditional biomedical models of practice have brought significant challenges for health professionals who are more comfortable with technological care and patients who seek more humane, compassionate care. This tension between traditional health care and the preferences of patients has resulted in increased opportunities for alternative and complementary therapies, in part because many of these therapies incorporate a spiritual framework.

Spirituality and religion have a significant bearing on patients' beliefs about pain, strategies for coping with pain, and approaches to pain management. Often, these beliefs are unknown to health professionals because spiritual issues are perceived as personal and private (Koenig et al., 2001). Although interest in spirituality and pain is relatively recent in terms of pain research, spirituality and pain have historically been intertwined, since the causes of pain are often elusive and persistent pain may lead to suffering. Pain and suffering are not interchangeable terms. Suffering is the perception of serious threat or injury to the self that emerges when there is a discrepancy between what one expects of oneself and what one does or what one is (Chapman & Gavrin, 1999). This discrepancy in the construction of self-identity is associated with loss and grief, which may be experienced as suffering (Unruh, 2004). Suffering can lead one to wonder about the meaning and purpose of one's life. For a person living with chronic pain, suffering may occur as a result of the pain, but it may also occur for other reasons or may not occur at all. In this paper I will examine the spiritual and religious meanings associated with pain — and suffering when it concerns pain — with an emphasis on Christianity as the dominant religion in Western countries. Next I will address the spiritual or religious tensions that can arise for the patient experiencing pain, and then conclude by focusing on practical considerations for clinicians and researchers.

### **Distinction between Spirituality and Religion**

Although there is no generally accepted definition of spirituality in the health literature, there are common themes in proposed definitions, as illustrated in recent reviews (Chiu, Emblen, Van Hofwegen, Sawatzky, & Meyerhoff, 2004; Tanyi, 2002; Unruh, Versnel, & Kerr, 2002). Spirituality is often defined as the experience of transcendence, connectedness, meaning, and purpose in life, integrating aspects of the self or a search for the sacred. These definitions reflect a construction of spirituality that is individualistic and not necessarily associated with traditional religion. Such secularization of spirituality reflects a growing tendency in Western societies to retain some aspects of religiosity, such as transcendence, while

rejecting the institutional and doctrinal aspects of organized religion (Hill et al., 1998; Tanyi). Religion is usually used to convey a set of beliefs and practices around the existence of something sacred or divine such as God, a higher power, or an ultimate truth (Koenig et al., 2001). Neither spirituality nor religion has received much attention in pain research even though spiritual views have for centuries been intertwined with beliefs about pain and suffering (Unruh, 1992). Although early biblical writings suggest that religion might provide comfort and solace to those living with pain and suffering (Koenig, 2003), in ancient religions, and in Christianity until relatively recent times, pain was regarded primarily as a consequence of sin and misfortune or as a human condition that could be mastered to achieve a higher spiritual state.

### **Historical Perspectives on Spirituality, Religion, and Pain**

Most if not all ancient civilizations believed that pain and disease were caused, sustained, and cured by supernatural entities. Spiritual leaders were believed to be the only people capable of carrying out divine will through medicine (Castiglioni, 1975). Treatment consisted of appealing to the gods through incantation, religious ritual, sacrificial offering, prayer, or exorcism (Castiglioni). Although there was a greater understanding about the physiology of pain and disease among the ancient Greek and Arabian physicians of the Middle Ages, the early Christian Church exerted a strong influence on the management of pain and disease. Physicians had little power since all cures were believed to be miraculous and there were religious proscriptions against some pain-relieving drugs (Todd, 1985). Monastic medicine, with its reliance on drugs, surgery, spells, incantation, prayer, exorcism, and relics, prevailed (Haggard, 1929; MacKinney, 1937). For example, a physician's handbook written in the year 1000 BCE includes a recipe for Holy Salve, a wound dressing made by combining butter with 60 different herbs while reciting spiritual incantations, following which the following prayer was said over the salve:

Holy Lord, Omnipotent Father, Eternal God: by the laying on of my hands may the enemy, the Devil, depart from the hairs, from the head, from the eyes, from the nose, from the lips, from the tongue, from the undertongue, from the neck, from the breast, from the feet, from the heels, from the whole framework of his members, so that the Devil may have no power over him, neither in his speech nor in his silence, neither in his sleeping nor in his waking, neither by day or by night, neither in resting nor in running, neither in seeing nor in sleeping, neither in writing or in reading; So be it in the Name of the Lord Jesus Christ, Who redeemed us with His Holy Blood, Who liveth with the Father and Reigneth God, world without end. Amen. (Cartwright, 1977, p. 12)

According to Kinsley (1996), the linking of pain, suffering, and disease with sin and divine punishment and visitation was at times so strong that physicians were instructed not to treat patients who did not first confess their sins to a priest. In 1215 the Church declared that because sickness was caused by sin the physician's first duty was to summon a priest (Fourth Lateran Council). In the 16th century physicians had to swear that they would stop treating a patient if, after 3 days, he or she had not made a confession (Kelsey, 1973), and in the 18th century Catholic physicians were forbidden to practise medicine if they treated patients who had not confessed.

In the 19th century this tension between medical advances and religious beliefs was manifested in the suspicion surrounding the development of anesthesia. Both the medical literature and the popular press featured heated debate about the benefits and drawbacks of pain and painlessness (Glucklich, 2001; Pernick, 1985). There were threats that babies delivered through painless childbirth would be refused the sacrament of Baptism (Glucklich). There were arguments that pain was necessary for healing, that pain was God's will, that pain was spiritually uplifting (Fulop-Miller, 1938; Gardner, 1987). To eliminate pain was to do the work of the devil. This was the view held by William Atkinson, the first president of the American Dental Association:

I think anesthesia is of the devil, and I cannot give my sanction to any Satanic influence which deprives a man of the capacity to recognize the law! I wish there was no such thing as anesthesia! I do not think men should be prevented from passing through what God intended them to endure. (Quoted in Raper, 1945, p. 105)

Aside from religious objections, there were concerns that ether and chloroform were intoxicants and should be rejected on moral grounds (Glucklich, 2001). Anesthetics were thought to mask symptoms and thus to subvert the natural healing process (Porter, 1852) and possibly the life force needed to give birth during labour (Smith, 1847). These drugs were believed to compromise medical ethics by reducing the patient's autonomy (Pernick, 1985). They were costly and exacerbated problems associated with discrimination and prejudice (Glucklich). These issues were intertwined with religious objections to the use of anesthetics.

Caton (1985) and Sauerbruch and Wenke (1963) argue that it was the eventual acceptance of anesthetics that fundamentally shifted attitudes towards a secular view of pain. They conclude that the ability to alleviate pain resulted in an unwillingness to adapt to and live with pain, which in turn increased feelings of helplessness in situations where pain could not be relieved.

The view that pain and suffering were sent by God nevertheless persisted. In 1940, C. S. Lewis, author of *The Chronicles of Narnia* among other works, wrote:

Until the evil man finds evil unmistakably present in his existence in the form of pain he is enclosed in illusion. Once pain has roused him he knows that he is in some way or other “up against” the real universe; he either rebels with the possibility of a clearer issue and deeper repentance at some later stage, or else makes some attempt at an adjustment, which, if pursued, will lead him to religion... No doubt pain as God’s megaphone is a terrible instrument; it may lead to final and unwanted rebellion. But it gives the only opportunity the bad man can have for amendment. (Lewis, 1940, p. 83)

Lewis’s views were not very different from other Christian perspectives of the period. The Office for the Visitation in the *U.S. Book of Common Prayer* (Anglican), 1928 to 1978, also expresses the view that pain and sickness are sent by God to teach a lesson, to punish, or to correct sinful ways:

Wherefore, whatsoever your sickness is, know you certainly that it is God’s visitation...to try your patience for the example of others...or else be sent unto you to correct and amend in you whatsoever doth offend the eyes of your heavenly father... (<http://justus.anglican.org>)

But these views were changing. The 1979 *U.S. Book of Common Prayer* is concerned not with pain as an instructive spiritual experience but with comforting the person in pain through religion. It includes the following prayer for the person experiencing pain:

Lord Jesus Christ, by your patience in suffering you hallowed earthly pain and gave us the example of obedience to your Father’s will: Be near me in my time of weakness and pain; sustain me by your grace, that my strength and courage may not fail; heal me according to your will; and help me always to believe that what happens to me here is of little account if you hold me in eternal life, my Lord and my God. Amen. ([http://justus.anglican.org/resources/bcp/formatatted\\_1979.htm](http://justus.anglican.org/resources/bcp/formatatted_1979.htm))

Another spiritually influenced perspective is that pain can be experienced as transcendental, mystical, or religious. Throughout history there have been religious devotees (e.g., monks, nuns, mystics) who have sought out pain as a means of hurting the body for the sake of the soul, a form of what Glucklich (2001) refers to as sacred pain. Enduring pain in the physical world is thought to ensure salvation, bringing the sufferer closer to the suffering of Christ or some other spiritual leader. Pain enables the person to reach a higher plane of spiritual or religious experience, as illustrated by the comment of a religious pilgrim quoted by

Glücklich: “At one moment everything is pain. But at the next moment everything is love. Everything is love for the Lord” (p. 38). According to Brena (1972), “religion teaches that the human individuality is not fulfilled until God-communion is realized, when the ontological unity with our Creator is experienced as an expanded sense of awareness, love and supernatural joy” (p. 131). Brena argues that prayer behaviours, which are central to all religious doctrines, are opposite to pain behaviours, because they break down feelings of isolation and focus the individual on love and service to others. Brena (1978) expresses the view that it is ultimately possible to go beyond pain, to reach a mystical union with a divine being — that indeed pain makes this possible. Brena’s writings are strongly influenced by his own Christian convictions.

Other writers argue that pain that is transformed into a spiritual experience is no longer pain but something else. For example, Scarry (1985), in an interview with Geddes (2000), maintains that pain is always negative and that to put a religious construction on the experience of pain would be counter-intuitive:

If I will myself into a situation of pain such as a medical therapy, and I agree to go to a doctor and let her do something to me that hurts (or seek out pain for religious reasons), then it’s already very different. And it’s not just different as an interpretative act, but, rather, to say that more clearly, the act of interpretation is so deeply grounded in the felt experience itself that if I am actually seeking it, it already has a kind of power to transform the pain. That is, it is no longer pain, since pain is centrally the experience of aversiveness. (<http://www.virginia.edu/iasc//hh/THRtoc2-2.html>)

Pain that is sought out is likely to be physiologically, psychologically, and spiritually different from pain that is experienced involuntarily as is the case in most instances of acute or chronic pain. Although science, medicine, and the secularization of spirituality have changed the ways in which people regard their pain, there is increasing evidence showing that spirituality and religion are important to how people experience their pain and suffering (Bartlett, Piedmont, Bilderback, Matsumoto, & Bathon, 2003; McCaffrey, Eisenberg, Legedza, Davis, & Phillips, 2004; Rippentrop, 2005; Rippentrop, Altmaier, Chen, Found, & Keffala, 2005).

### **Religion and the Meaning of Pain**

Very little is known about how 21st-century patients use their spiritual or religious views in constructing the meaning of their pain. Koenig, a nurse and psychiatrist specializing in chronic pain, lives with chronic pain himself and self-identifies as a Christian. In his book on spiritual

approaches to chronic pain, Koenig (2003) quotes some of his Christian chronic pain patients:

I feel like God doesn't put any more on you than you can bear.... The Lord picks you for this because you can take it. He doesn't give you more than you can handle. (pp. 79, 83)

It's given me the ability, not only the ability but the desire, to see God in a different way than I would if the pain wasn't there. (p. 94)

... it's like the Lord is telling me, "This is a burden that you're going to have to carry. I carried the cross and your sin, and you're going to have to carry this." (p. 46)

Although these views are Christian, their underlying meaning may not be unique to Christianity. Thomas (1992), in a study with Hindu religious renunciates, found similar health attitudes and behaviours among his respondents. The most dramatic attitude was one of classic detachment and separation from pain. When asked what he did for his pain, one renunciate replied:

Think that you are different from the pain. If a tree in front of you is being cut, you are just the observer. You know that the body is going to perish. So whenever you are ill bear it by your knowledge that you do not belong to this particular body. You have renounced it. (p. 501)

Other Hindu respondents expressed an acceptance of pain as the will of God, similar to the Christian view expressed in Koenig's (2003) work: "Whatever God wants to give, He can give me. He can do anything according to his desire. Human desire can't do anything" (p. 501). They also saw in pain a similar opportunity for spiritual growth:

Suffering is necessary. When you have this suffering, you begin to feel deeper. Each moment of pain or suffering enables you to understand what it means when others suffer from it. This wideness of consciousness is a very important thing. (p. 501)

Käppeli (2000) also found fewer differences than might be expected in the religious meaning that Christian and Jewish cancer patients gave to their suffering, despite the differences in the structures underlying their religion. The patients explained their suffering in stories of retribution and a return to a better life, stories of wrestling with God, apocalyptic stories in which their experience was part of the disintegration of the world and the coming of the Messiah, and stories of mystical transfiguration. In the three monotheistic religions, Islam, Judaism, and Christianity, pain and suffering are linked with perceptions about the nature of humankind; pain is a punishment for the flawed nature of humankind and a means to improve one's nature (Koenig et al., 2001).

Koenig et al. (2001) suggest that the difference with Christianity is that pain as punishment is seen as relievable through atonement and redemption. Further, the image of a crucified Messiah who understands pain and suffering may provide guidance and comfort in one's living a meaningful life with chronic pain (Koenig, 2003, 2004). Despite some similarities among religions, there may be considerable differences between and within spiritual perspectives and religions. Such differences are not well understood with respect to how they shape a conceptualization of pain (Low, 1997). There has been little comparative research in this area.

### **Religion and Coping**

There is a significant body of research examining the influence of spirituality and religion on mental health concerns, physical health issues, and addiction (Koenig et al., 2001). Much of this research has focused on prayer and coping (e.g., McCaffrey et al., 2004), but attendance at religious services has a stronger association with positive health outcomes than prayer (Koenig et al., 2001).

There is a small body of research on spirituality and religion and coping with pain (Conway 1985/86; Koenig, 2002). These studies have begun to identify the potential positive and negative associations of spirituality and religion with pain. For example, Bush et al. (1999) examined positive and negative religious coping and non-religious cognitive-behavioural coping in 61 chronic pain patients. They found that positive religious coping was significantly associated with positive affect and religious outcomes (spiritual growth, satisfaction with religious life, relationship to God). They found no association between negative religious coping and other study outcomes. Harrison et al. (2005), in a sample of 50 African-American patients with sickle cell disease, found that church attendance (weekly or more often) was associated with lower pain measures. This outcome is similar to the results of an earlier study by Yates, Chalmers, St. James, Follansbee, and McKegney (1981), in which having religious beliefs was found to be positively associated with measures of well-being and less pain in patients with advanced cancer. Rippentrop et al. (2005), in a study with 122 patients with chronic musculoskeletal pain, report that patients with poorer physical health engaged in more private religious behaviours such as prayer, reading religious material, and meditation, perhaps to cope with more serious health problems. Spirituality and religion were found not to be related to pain intensity or interference of pain in daily life. Patients in this sample were also more likely to report feeling abandoned by God than participants in a sample without chronic pain. In a prospective study with people with rheumatoid arthritis, Keefe et al. (2001) found that partici-

pants reported much more frequent use of positive rather than negative spiritual coping strategies. Individuals with frequent daily spiritual experiences had more positive mood and higher levels of social support. The findings were similar in another sample of patients with rheumatoid arthritis (Bartlett et al., 2003) and in a sample of nursing home residents (Koenig, Weiner, Peterson, Meador, & Keefe, 1998). Cronan, Kaplan, Posner, Lumberg and Kozin (1989), in an earlier study with arthritis patients, found that prayer was the most common unconventional coping strategy, 54% reporting it to be very helpful. These studies suggest that, for patients living with pain for whom spirituality is a part of daily life, spirituality is important to successful coping.

Integral to coping with persistent pain or living with pain may be the ability to accept pain. Risdon, Eccleston, Crombez, and McCracken (2003) examined the meaning of acceptance of chronic pain and found that for some participants spiritual strength was an important aspect of acceptance. Participants who had a spiritual view of acceptance saw living with pain day-to-day as based not on personal or motivational strength but on spiritual strength. They endorsed such statements as “I can identify with myself on a spiritual level,” “God has been telling me to change,” and “I have been rewarded for all the suffering I have gone through in the past.” Koenig (2003) suggests that a spiritual attitude towards pain, based on submission, acceptance, understanding, and calling, enables a person with religious views to live a meaningful life with chronic pain. He conceptualizes “submission” as having submitted one’s life to God, “acceptance” as having turned pain over to God and not worrying about it, “understanding” as believing that positive emotions are possible despite pain, and “calling” as serving God and others.

An issue related to spirituality, religion, and pain is the impact of these views on patients’ preferences with respect to pain management.

### **Religion and the Management of Pain**

Religious views may influence a person’s acceptance of various pain-management approaches and her or his treatment goals. Koenig (2003) lists four misconceptions about pain management that might be held by patients with strong religious views:

- 1) reluctance or refusal to take pain medication (or to take sufficient medication) because of addiction fears; 2) belief that pain should be dealt with only in spiritual terms, and taking medication for pain relief would be relying on something other than God; 3) belief that pain should not be relieved because pain may result in spiritual growth; and 4) persistent pain may be regarded as a sign that the patient’s faith is not strong enough. (p. 3)



Such misconceptions can have a significant impact on patients' use of medications for pain, especially persistent pain, pain associated with disease, or pain during palliative care (Bosch & Banos, 2002). Refusal of pain medication may also be associated with a desire to feel closer to the suffering of a spiritual leader, as is the case with some Christian patients. The Catholic Church allows the use of medication to relieve pain even if it may hasten death, but, as elaborated by O'Rourke (1992), the Church also maintains that to voluntarily endure pain in the last stage of life is to share in the suffering of Christ and to prepare for death:

Suffering, especially suffering during the last moments of life, has a special place in God's saving plan: it is in fact a sharing in Christ's passion and a union with the redeeming sacrifice which he offered in obedience to the Father's will. Medication, coma, reduce opportunity to share or experience in this way. Nevertheless, the church recognized the ideal cannot be a general rule...would be imprudent to impose a heroic way as a general rule... If possible, a person should have the opportunity "to moderate the use of pain killers, in order to accept voluntarily at least part of their sufferings and thus associate themselves in a conscious way with the suffering of Christ." (p. 488)

Koenig (2003) suggests that religious views may also affect the acceptability of management strategies such as relaxation, hypnosis, guided imagery, and mindfulness meditation, if these strategies are seen as possibly inconsistent with the patient's spiritual beliefs. Such strategies may be perceived as a kind of New Age spirituality and therefore potentially unacceptable to a religious person. The literature contains no empirical research on the extent to which spiritual or religious views influence patients' use of pharmacological strategies or their preferences with respect to non-pharmacological interventions such as cognitive-behavioural therapies.

Spiritual beliefs, attitudes about pain, and decisions with respect to pain management may seem contradictory as the patient endeavours to reconcile beliefs, needs, and treatment options. For example, Thomas (1992) found that even though the attitudes of Hindu renunciates suggested that pain should be borne rather than relieved, all but one renunciate did use some type of medical relief for pain. The men struggled to reconcile their pursuit of medical care with their beliefs, especially among the most conservative group. For example, they justified seeking relief for severe pain. They also accepted pain relief if it would be more injurious not to treat pain than to treat it in order to help others. The most conservative participant saw the active pursuit of treatment as a violation of his vows of renunciation. Only if a physician said to him, "Take it for my sake" would he agree to do so, and then only traditional medicine and not allopathic or Western medicine. In Judaism and Islam,

pain relief is acceptable because pain may impair quality of life and proper functioning (Bowker, 1978; Koenig et al., 2001). In Christianity, Islam, and Judaism, pain relief near the end of life may cause concern should it risk causing death but is acceptable if unrelieved pain is likely to hasten death (Puchalski & O'Donnell, 2005).

Refusal of pain medication and other management approaches due to religious beliefs can be a source of stress for health professionals, especially nurses and physicians (Kumaska & Miles, 1996). Referral to and consultation with a pastoral care team or other spiritual counsellors, if desired by the patient, is recommended (Koenig, 2003). Open discussion with the patient and her or his family about spiritual views and how they can be incorporated into the management plan will likely be beneficial for both the patient and the team. Patients with spiritual or religious views about pain may also need to examine and possibly challenge their beliefs with the assistance of a trusted health professional, in order to determine which pain-management strategies are acceptable given the person's spiritual worldview.

Another issue that has not been widely examined in pain research is whether spiritual practices can be incorporated into pain management and whether this would have a positive effect on the patient's care.

### ***Spiritual Approaches***

Spiritual approaches to pain management can take many forms, from prayer, to participation in religious services and rituals, to therapeutic touch, spiritual healing, mindfulness meditation, Reiki, and other strategies. Some of these strategies are explicitly religious, whereas others take a more secular spiritual approach. In some cases the strategy will have roots in religious tradition but will have been modified to make it more amenable to a diverse group of people. For example, mindfulness meditation has roots in Buddhism but is typically used in Western culture separately from its traditions within Buddhism (Baer, 2003).

Research on the effectiveness of most spiritual therapies is inconclusive and is complicated by the many different approaches to spiritual therapy and the situations in which they are used. Nevertheless, reviews of this research indicate that while the evidence is not definitive, positive outcomes are possible. Roberts, Ahmed, and Hall (2003) conducted a Cochrane review of the effectiveness of prayer as a complementary intervention for those with health problems being treated with standard medical care. They report that the data were too inconclusive to guide those wishing to uphold or refute the effect of intercessory prayer on health-care outcomes (achievement of desired goals, death, illness, quality of life or well-being) but that the findings thus far do justify further study. Astin, Harkness, and Ernst (2000) reviewed randomized clinical

trials of interventions using some form of “distant healing” (e.g., therapeutic touch, Reiki, prayer, spiritual healing) and report that 57% of trials found some positive benefit.

Many spiritually based therapies have not been examined in the context of chronic pain. Abbott et al. (2001) examined healing approaches in a sample of 100 chronic pain patients whose pain was resistant to conventional treatments. The primary outcome measure was the total pain rating index score on the McGill Pain Questionnaire (Melzack & Katz, 1992). The study was a randomized clinical trial comparing face-to-face healing or simulated healing and distant healing or no healing in a series of weekly 30-minute sessions over 8 weeks. Healing was defined as direct interaction between a healer and a patient for the purpose of improving or curing the condition (Hodges & Scofield, 1995). The therapeutic benefit was thought to result from the channelling of energy from source via the healer to the person to promote self-healing (Fulder, 1996). The authors conclude that no specific effect could be demonstrated. Mindfulness meditation is essentially a secular spiritual application of meditation and has been used in pain management following initial work by Kabat-Zinn (1982). There is growing evidence of the effectiveness of mindfulness meditation for some patients with chronic pain (e.g., Wachholtz & Pargament, 2005; Weissbecker, Salmon, Studts, Dedert, & Sephton, 2002).

### **Clinical Implications**

There are a number of surveys reporting that patients want their health-care providers to consider their spiritual or religious preferences when offering services (e.g., Daaleman, Cobb, & Frey, 2001; Daaleman & Nease, 1994). It is unclear how these preferences should be taken into consideration, however, especially within the parameters of responsibility specific to a profession. Florin, Ehrenberg, and Ehnfors (2005) found that when nurses and patients in an acute-care setting were asked to identify which problems were most important to patients, the nurses often missed the patients’ emotional and spiritual concerns. There are important ethical considerations for professionals and patients in addressing spirituality. Sensitivity and respect for patients’ spiritual needs is likely to be beneficial, but harm is possible if discussion causes health professionals to defend or assert a particular religious perspective (Unruh et al., 2002). Benefits are much more likely to result if the patient’s spiritual views, whether secular, sacred, or religious, are respected rather than ignored or challenged and if care can be provided in such a way that the patient’s spiritual needs are not violated. A person-centred approach is key to

ensuring that the patient's spirituality is understood from her or his perspective.

Embarking on a discussion about spirituality can be intimidating. Health professionals who are comfortable with their own spiritual journeys may be more willing than others to engage in spiritual discussions about pain with their patients (Unruh et al., 2002). Brockopp et al. (1998), in a discussion about barriers to good pain management, argue that the spiritual views of physicians and nurses may affect their beliefs about the pain management of their patients. For this reason, it may be useful for nurses to reflect on their own spiritual beliefs and values and what they mean to the nurse-patient relationship and to the nurse's beliefs about pain management.

There are many instruments available to measure spirituality or religion (Tanyi, 2002; Unruh, Versnel, & Kerr, 2003). These may be used to initiate discussion about spirituality. It is essential that health professionals first consider what information about the patient's spirituality would be helpful and how it can be used within the parameters of professional responsibilities. One way to begin is to ask the patient about what she or he finds meaningful or important in life and whether her or his spiritual views have relevance for these issues. It may be helpful to ensure that the patient has access to spiritual counsellors as well as to a pastoral care team. It may also be beneficial to discuss with the patient and family how their spiritual practices can be incorporated into the care provided by the medical team. Newshan (1998) and Tanyi discuss some of the ways in which nurses can incorporate spirituality into their care, emphasizing awareness of the nurse's own spiritual views, discussion and acceptance of the patient's perspectives, and the importance of a compassionate therapeutic relationship. Such discussion may be particularly critical if the patient is in acute pain, refuses pain medication, or is receiving palliative care. Inclusion of questions about spiritual needs and preferences in intake assessment will ensure that this area is not forgotten.

The Canadian Pain Society's 1997 *Position Statement on Pain Relief* ([www.canadianpainsociety.ca/policy.html](http://www.canadianpainsociety.ca/policy.html)) asserts that patients have the right to the best pain relief available and that unrelieved acute pain complicates recovery. For some patients, the best pain relief will be that which is consistent with their spiritual or religious views. Some patients may choose to rely partly or wholly on their religious views to manage pain. Engaging in dialogue with patients about their spiritual and religious views with respect to pain is a good beginning; recognizing that these views may influence preferences and decisions about treatment will have clinical implications. Patients stand to benefit from pain education that not only examines the interrelationships between physiological and psychological mechanisms of pain and pain management but also

considers the ways in which their spiritual and religious views can affect their ability to manage their pain and to live a meaningful life with pain. Consideration of positive and negative aspects of religious coping in education/support programs may help patients to use their spiritual and religious views in ways that will enhance their pain-management strategies. Patients may need to be shown that they are better able to serve others as part of their spiritual or religious commitments when their pain is well managed using pharmacological, psychological, and spiritual approaches. It may also be possible to integrate some of the patient's spiritual or religious views with other therapies. Music can be deeply meaningful to patients across secular, spiritual, or religious perspectives (e.g., Krout, 2001; Magill, 2001). Relaxation interventions and guided imagery can incorporate spiritual or religious music, readings, or images that are meaningful to the patient. Patients may have spiritual readings, prayers, or music that can be recorded and played to assist with pain management. A patient may be open to having a nurse recite prayers or readings with her or him, especially if patient and nurse share a particular spiritual view. If spiritual counsellors from diverse backgrounds are available, patients will have an opportunity to speak with respected individuals who share similar beliefs and staff will have ready access to a rich resource.

These clinical implications suggest avenues for nurses to examine how spirituality and religion may be addressed in pain care. However, the potential benefits of these implications need to be examined more closely in pain research.

### **Research Directions**

Many efforts have been made to define spirituality and religion in ways that provide more clarity for research in this area, but there are no agreed-upon definitions. Agreement would enable comparison of findings across studies. Much of the epidemiological research on spirituality, religion, and health, including pain, is correlational in nature and provides limited information about causal relationships between spirituality and pain outcomes. Prospective studies are needed, to examine how spirituality and religion influence coping and adjustment to pain and whether such influences differ among diverse spiritual and religious views. It is important to determine whether the positive and negative aspects of spiritual coping bear out for most patients and whether they remain consistent across different spiritual perspectives. It is essential to determine the extent to which spiritual and religious views about pain influence the acceptability of pharmacological and non-pharmacological pain interventions. Underreporting of pain and non-compliance with

interventions may be related to the incompatibility of interventions with spiritual or religious beliefs or misunderstandings about their mutual benefits for pain management. It is not known whether or how the integration of spiritual views into acute or chronic pain management leads to better outcomes. Further research is also needed to determine whether the influence of spiritual or religious views on appraisal of pain, pain coping, and preferences in pain management is related to patient gender, age, ethnic group, or socio-economic class.

Although it is evident that spirituality and religion influenced conceptualizations about pain and suffering in the past, little is known about how various spiritual and religious beliefs influence appraisal of pain and pain management in the modern era, or how these beliefs might be communicated by families or within spiritual communities. There has been no research on what patients with pain want from pain professionals with respect to spiritual issues, and no research on what might be the best strategies for ensuring that spiritual needs are met in pain clinics. Lastly, spiritual needs are often heightened in palliative care, but there is limited research on how spiritual views about pain affect pain-management preferences in palliative care. Nurses have a critical role to play in developing knowledge in this area, because they are intimately involved in the immediate pain and suffering of their patients.

### **Conclusion**

Spirituality is often seen as a private and subjective area that lies outside of the therapeutic context, but patients' beliefs can have a substantial, if hidden, impact on construction of the meaning of pain, coping behaviour, and preferences in pain management. Patient surveys have indicated that patients want their health-care providers to ask about their spiritual beliefs and to show sensitivity with respect to how these beliefs might affect their health needs. There are many opportunities to integrate spirituality and religion into clinical practice. Much more research in the area of spirituality and pain is needed, to examine the impact of diverse spiritual and religious views on patients' appraisal of and coping with pain, their beliefs about pain management, and their preferences.

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## **La sous-estimation de la douleur par les prestataires de soins : vers la conception d'un modèle d'inférence pour évaluer la douleur chez autrui**

**Kenneth M. Prkachin, Patricia E. Solomon et Joan Ross**

Les professionnels de la santé sont régulièrement exposés aux manifestations de la douleur chez autrui. Il est donc important de comprendre les processus par lesquels ils évaluent celle-ci. Les auteurs présentent une synthèse des travaux de recherche récents sur les moyens d'évaluer la douleur et proposent un modèle conceptuel de ce processus. Ils analysent les questions méthodologiques et conceptuelles découlant de la conduite des recherches sur l'évaluation de la douleur. Les travaux menés dans ce domaine depuis 40 ans révèlent chez les soignants une tendance à sous-estimer l'intensité de la douleur, si on compare leurs évaluations à celles des patients eux-mêmes. Les auteurs analysent le rapport entre cette tendance et des variables comme la nature de la douleur ressentie par le patient et l'expérience clinique du sujet qui pose le jugement. Ils examinent également les variables expérientielles et cognitivo-perceptives censées influencer sur le degré de sous-estimation, tels que la fréquence d'exposition aux manifestations de la douleur et les doutes à l'égard des motifs du patient. Enfin, ils présentent un modèle décrivant le processus de décodage de la douleur. Ils réfléchissent aux conséquences de la sous-estimation sur les résultats thérapeutiques et cernent des priorités pour les recherches futures.

Mots clés : douleur, évaluation, sous-estimation

# **Underestimation of Pain by Health-Care Providers: Towards a Model of the Process of Inferring Pain in Others**

**Kenneth M. Prkachin, Patricia E. Solomon,  
and Joan Ross**

Health professionals are routinely exposed to evidence of pain in others. It is important that the processes by which they evaluate pain be understood. The purposes of this article are to review and synthesize recent research on how health professionals judge the pain of others and to present a conceptual model of this process. Methodological and conceptual issues in the conduct of pain judgement studies are addressed. Research in this field over the last 40 years has indicated that, when compared with the pain judgements of patients themselves, health professionals tend to underestimate pain. The authors review the relation of this underestimation bias to such variables as the nature of the patient's pain and the clinical experience of the judge. They also review experiential and cognitive-perceptual variables found to influence the degree of underestimation bias, such as the amount of exposure to evidence of pain and suspicion about the motivations of the patient. A model of the pain decoding process is presented. The issue of whether underestimation has implications for treatment outcome is addressed and priorities for future research are identified.

**Keywords:** Pain, judgement studies, expression, assessment, bias

Like effective human relations, effective health care depends on the ability to understand the physical, sensory, and affective experiences of other people. Health-care providers — nurses, physicians, therapists from various disciplines — help to improve health or minimize suffering by deploying technical and personal skills. Often, it is possible to evaluate whether health goals are being advanced by measuring objective indicators — a test reveals that lipid levels have improved, or a patient demonstrates increased functional capacity. Sometimes, however, health-care providers must infer how things are on the strength of complex and subtle evidence concerning the behaviour of the patient. Prototypic examples include the patient presenting in emergency complaining of chest pain, the patient with back pain participating in a rehabilitation program, and the nursing home resident with dementia who protests loudly during transfers. The question of whether these individuals are in pain or whether the nature and degree of their painful distress warrants

intervention is so basic that we are often unaware that it exists and guides our actions.

Evaluating others' pain is a classic case of decision-making in uncertainty. The difficulty of the task is complicated by the fact that the clinician must try to "look inside" another person. In an ideal world, the clinician would be able to use some kind of "mental dipstick" to slide inside the patient's consciousness, capture her or his current state, and, on the basis of this reading, recommend further action. Although no mental dipstick exists, people are able to infer, sometimes with what appears to be surprising accuracy, the feelings, thoughts, and experiences of others (Ambady & Rosenthal, 1992; Ickes, 2003). What are the properties of inferences about others' suffering, and on what basis are they drawn?

Of the dimensions that influence inferences about pain, several are obvious and some have been subject to considerable study. Certainly, direct evidence of injury, such as the presence of a burn, plays a part in determining our judgements. Findings of medical testing procedures also contribute. A key role, however, is played by the behaviour of the sufferer — verbal descriptions, complaints, protective behaviour, and other phenomena such as facial expressions whose evolutionary function appears to be largely communicative (Williams, 2002).

The purpose of this article is to present the empirical basis and framework for a model of the processes that unfold when people draw inferences about the pain of others. The particular focus is the correspondence between pain from the perspective of the patient and pain from the perspective of health professionals and other judges with a stake in interpreting pain. This article expands on a previous review of research on agreement between the ratings of pain by health professionals and by patients up to the turn of the 21st century (Solomon, 2001). This review covers more recent research and observations that address inferences by health-care providers about pain in others. Attention is restricted to studies that evaluate responses to complex but natural evidence of pain, such as reports of patients in clinical situations or judgements of actual pain-related behaviour (as opposed to vignette studies, which ask judges to respond to hypothetical scenarios presented in verbal form).

Because the goal of the article is to articulate a model, our review of the literature is selective, though not unrepresentative. In preparing the article we undertook searches in the PsycLit and Medline databases covering the years 2000 to 2006 using the keywords *pain*, *judgement*, *judgement study*, and *bias*. Reference sections from articles identified in this manner were also reviewed for relevant articles.

## **The Phenomenon of Pain Underestimation**

A considerable amount of research has investigated health-care providers' ratings of others' pain and has documented a particular phenomenon: pain underestimation. One of the most widely cited early studies was conducted by Teske, Daut, and Cleeland (1983). The participants were nurses who rated the pain of acute and chronic pain patients using a visual analogue scale (VAS). The patients had independently provided their own ratings on the same scale. The nurses' ratings were significantly correlated with those of the patients. The magnitude of the correlation (Pearson's  $r = .38$ ) was quite low, however, suggesting that, although there was some sensitivity among the nurses to variation in patients' pain states, it was far from optimal. More important is the fact that the nurses' overall ratings were lower than those of the patients, significantly so for patients with chronic pain. In this example, nurses based their evaluations on a complex array of evidence, including knowledge about the patients' conditions and prior ratings that had been made of their pain-related behaviours.

These findings, taken at face value, imply that nurses underestimate patients' pain. In the years since the publication of that report, several studies have compared the pain ratings of patients suffering from various conditions and those of various groups of judges. Observer groups that have been studied include nurses, physicians, other health-care providers, and relatives of the sufferers. In the following sections we will review and synthesize the general findings of such studies.

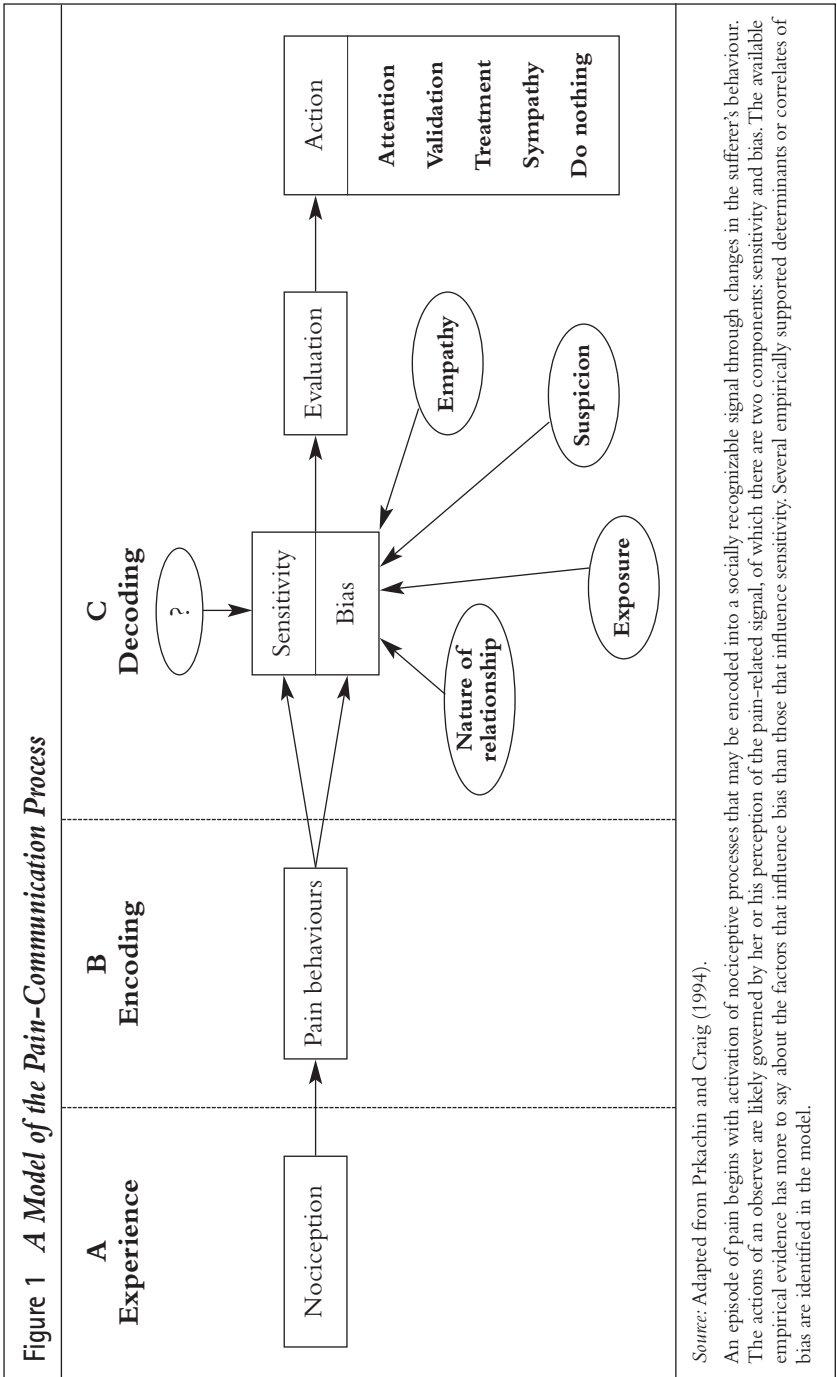
### **Judging Pain in Others**

#### ***Methodological Issues***

A patient presents in emergency following a rear-end motor vehicle collision. There are no abrasions or contusions. He is sent for X rays, which reveal no fractures. Functional tests and records indicate that he has not lost consciousness and he has limited range of motion in the cervical spine. He complains of stiffness and aching in the neck and the back of the head and says he has a headache coming on. How much pain is the patient experiencing?

The question cannot be answered directly, of course, because of the dipstick problem described above. Yet people readily draw an inference. Two issues are then raised: How valid is that inference, and what are its other properties? Empirical studies have attempted to shed light on this by comparing the inferences of observers with other evidence from the patient.

Several techniques can be employed in conducting such studies. Minimally, investigators must have a way of measuring pain in the





sufferer, a way of measuring an observer's judgement of the sufferer's pain, and a way of comparing the two. Rosenthal (1984, 2005) has provided a useful description of the components of any process involving the communication of internal states. He distinguishes three: A – the internal state of the subject, B – the behaviours that provide evidence about the internal state, and C – the inferences made by the observer about the internal state based on the evidence. In the present context, we can conceive of A as the subject's pain, B as the subject's pain-related behaviour, and C as the observer's inference about the subject's pain. Figure 1 presents a conceptual model illustrating some of the key processes and variables involved in the pain-communication process. We have modified it from an earlier model (Prkachin & Craig, 1994) to emphasize aspects of the pain-communication process that are the focus of this article.

The process by which the sufferer's pain is translated into behaviours that communicate pain is called *encoding* and the process by which the sufferer's communicated behaviours are translated into an observer's inference is called *decoding*. Providing that one has measures of each of the three components, it is possible, by making these distinctions, to independently evaluate A→B relations (encoding studies), B→C relations (decoding studies), and A→C relations (inference studies).

The literature on the judgement of pain in others typically makes use of some kind of numerical, verbal descriptor or visual analogue scale when information about the subjective experience of the sufferer (A in Rosenthal's [1984] model) is being collected. Judges, in turn, typically make use of the same scales to record their inferences about patients' pain (C in Rosenthal's model). There is considerable variation in the behaviour that is sampled to provide a basis for judges' evaluations (B in Rosenthal's model). Occasionally, the evidence base is holistic. In such cases, patients undergoing a health-care procedure, for instance, are asked at some point to rate their pain. Providers involved in their care are asked to give their own judgements based on their experiences with the patients. These judgements can, in principle, be based on what the providers have heard, seen, or inferred from independent evidence such as the patients' medical records. Occasionally, a particular type of behaviour is used. In our studies, for example, video records of facial expression are provided to judges as a basis for their inferences.

Measuring the correspondence between the sufferer and the judge requires the setting of some kind of evaluation criterion. One way of doing so is to establish a benchmark for "accuracy." In an influential study by Iafrazi (1986), accuracy was defined as existing when a judge's rating on a numerical scale falls within plus or minus one point of the patient's.

A rating falling outside that range thus becomes identified as an under- or overestimate.

This type of definition has several problems, apart from arbitrariness. The first is that it is dependent on the use of a particular numeric rating scale. Several techniques for quantifying patients' pain reports are commonly employed. They include the 0–10 numerical rating format used by Iafrafi (1986), 0–100 scales, and categorical and scaled verbal descriptor scales. The equivalent range for categorizing a response as in agreement on a 0–100 scale or a verbal descriptor scale is not self-evident. For example, Cremeans-Smith et al. (2003) studied patient, spouse, and physician agreement on a patient's pain using a five-category Likert scale. To be considered in agreement, patients' and observers' ratings had to be the same.

The second problem is that, by reducing the comparison to qualitative categories, information available on the magnitude of the discrepancy between patients' and observers' judgements is lost.

The third problem is that the method does not allow for the evaluation of the observer's judgement processes to be as discriminating as possible. When examining the performance of the observer, it is possible to distinguish two processes that are involved in the inference about another's pain: sensitivity and response bias.

Sensitivity refers to the ability to tell the difference between levels of pain, independent of the overall level of pain present. This is indicated by covariations between the magnitude of the observer's judgement and either the behavioural referent or the patient's report. Sensitivity can be evaluated in two ways: by measuring the correlation between an observer's rating and the subject's rating or behaviour, such as reported by Teske et al. (1983), or through the use of signal detection procedures that allow calculation of direct measures of the ability to discriminate states of the patient (Deyo, Prkachin, & Mercer, 2004). Response bias refers to the likelihood of imputing or being prepared to impute pain to others (Swets, 1996). It can also be measured in two ways: by finding a measure of the central tendency of observers' ratings, such as the mean, or by calculating specific signal detection parameters (cf. Prkachin, Mass, & Mercer, 2004). Underestimation and overestimation of another's pain, the type of judgement we are focusing on in this article, are types of response bias.

Sensitivity and bias are independent parameters that contribute to an overall evaluation of the intensity of the sufferer's pain. In the model, such evaluations serve as the basis for several possible courses of action (including taking no action). Undoubtedly, further social-cognitive processes mediate the relation between evaluation and action.

### ***Findings and Concepts***

Solomon's (2001) review of research on the pain judgements of health professionals (mostly nurses) indicates that, although it is possible to overestimate, underestimate, or accurately judge another's suffering, professionals' ratings tend to be lower than those of the patients themselves. This is consistent with the conclusion that there is an overall bias towards underestimation of pain (Ferguson, Gilroy, & Puntillo, 1997; Grossman, Sheidler, Swedeen, Mucenski, & Piantadosi, 1991; Guru & Dubinsky, 2000; Hall-Lord, Larsson, & Steen, 1998; Rundshagen, Schnabel, Standl, & Schulte am Esch, 1999; Stephenson, 1994; Teske et al., 1983; Thomas, Robinson, Champion, McKell, & Pell, 1998; Zalon, 1993). Several studies using correlation techniques found that sensitivity to variations in patients' pain was low to non-existent (McKinley & Botti, 1991; Singer, Richman, Kowalska, & Thode, 1999; Thomas et al.; Van der Does, 1989).

There have been some exceptions to the finding that judges, whether health professionals or not, underestimate pain relative to the ratings made by sufferers. When patients' ratings are comparatively low, the ratings of health professionals are occasionally higher than those of the patients (Olden, Jordan, Sakima, & Grass, 1995; Zalon, 1993). Heikkinen, Salanterä, Kettu, and Taittonen (2005) studied prostatectomy patients during postoperative recovery. Patients and nurses independently completed numerical pain ratings. In addition, the patients completed VAS ratings and their direct verbal expressions of pain were categorized on an intensity scale. On the numerical scale, nurses' ratings were significantly lower than those of the patients. However, when numerical rating-scale points were re-categorized into ranges of approximately three points, nurses appeared to overestimate approximately as often as they underestimated. Overestimation was most likely to occur when patients were reporting no pain, underestimation when patients were reporting pain ranging from mild to intense.

The type of pain in question appears to have some influence on the tendency towards underestimation or overestimation or on the degree of underestimation. Studies with burn patients, for example, have tended to find comparable degrees of underestimation and overestimation among professionals (Choinière, Melzack, Girard, Rondeau, & Paquin, 1990; Iafrati, 1986). Indeed, Everett et al. (1994) report approximate agreement between patients and nurses in approximately half of 49 cases. Even in these studies, however, the phenomenon of underestimation has occurred among significant numbers of participants. In the study by Choinière et al., for example, nurses with a greater amount of clinical experience were more likely to underestimate the pain of burn victims, while nurses with less experience were more likely to overestimate it. Puntillo,

Neighbor, O'Neill, and Nixon (2003) compared the pain ratings of patients and nurses in an emergency department setting. Nurses rated pain on the standard 0–10 intensity scale used by patients. The nurses underestimated patients' pain, with ratings between 54 and 68% as high as those of the patients. Although, on average, the intensity of all types of pain was underestimated, the degree of underestimation varied according to the type of pain being presented. Underestimation was greatest for pain associated with musculoskeletal injuries, abdominal problems, and cellulitis/abscesses but minimal (by Iafrafi's criterion) for headaches, fractures, and radiculopathies.

In most studies, judges have evaluated patients' pain on the basis of holistic evidence, such as their observations in clinical settings. Consequently, the bases on which judgements have been made are not entirely clear. In other studies, it has been possible to be more precise about the bases on which judgements were made. For example, Prkachin, Berzins, and Mercer (1994) showed observers videotapes of the facial expressions of patients with shoulder pain going through exercises that produced pain in the affected shoulder. The patients had rated the intensity of their pain on each test using validated verbal descriptor scales (Heft, Gracely, Dubner, & McGrath, 1980). Observers used the same scales as the patients to rate the amount of pain they thought each was experiencing, basing their judgements on the patients' facial expressions. The results show that observers' judgements of patients' pain were substantially lower — by 50 to 80% — than those of the patients themselves. To the extent that we can consider patients' characterization of their pain as “ground truth,”<sup>1</sup> this finding also suggests that, in general, observers display what we have called an “underestimation bias.”

### ***Determinants of Underestimation***

Although underestimation appears to be a common finding, there are variations in its degree, apparently resulting from differential experience, social-cognitive factors, and personality characteristics. What are the potential sources of underestimation?

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<sup>1</sup>The question of whether patients' verbal characterization of their pain should enjoy such privileged status as the “gold standard” (Wheeler, 2006) does not, however, have a consensual answer (Hadjistavropoulos & Craig, 2004). Therefore, is not clear from any study of this nature whether it is appropriate to characterize observers as underestimating. Other techniques, however, provide some basis for evaluating the question of whether judgements of suffering in others can be characterized as “biased” and provide further insight into the processes involved when one person draws inferences about the suffering of another. We will continue to use the terms “underestimation” or “underestimation bias” to refer to situations in which judges' ratings of patients' pain turn out to be numerically lower than those of patients, recognizing the conceptual difficulties associated with this way of characterizing the phenomena.

A first answer to this question harkens back to the dipstick problem. Because observers do not have direct access to sufferers' internal experiences, their judgements are reliant on sources of evidence in the sufferer's behaviour or context. In the setting of most empirical studies, access to that evidence is limited. For example, in a clinical study the judge must evaluate the patient's pain-related behaviour holistically but without access to the complete medical history, and in an experimental study the judge must evaluate a record of the patient's behaviour and attention is deliberately restricted to some discrete indicator of pain. Not only are these sources of information incomplete, but some, such as facial expressions, are subtle and difficult to detect without training. For these reasons, limited information is a source of suboptimal judgements.

There are other potential sources of variations in pain judgements, however. One that is of traditional interest is experience; in this case, a history of exposure to evidence of pain in others. In her review of the accuracy of pain judgements, Solomon (2001) noted a trend in studies of the judgements of health professionals towards a paradoxical increase in underestimation with experience. As noted above, Choinière et al. (1990) found that greater clinical experience was associated with underestimation, rather than overestimation, of burn patients' pain. Von Baeyer, Johnson, and McMillan (1984) observed a similar effect with nursing students. In that study, observers' judgements were not compared with those of patients. Instead, observers rated videotaped simulations of interviews with patients. Participants with more experience showed less sympathy and concern than those with less experience. Although these findings do not reflect directly on judgements of pain, they do suggest differences in the emotional impact of pain behaviour as nursing students acquire more experience. Other investigators have provided evidence of an effect of increasing clinical experience on pain underestimation (Lenberg, Glass, & Davitz, 1970; Perry & Heidrich, 1982), although there have also been failures to observe such an effect (Dudley & Holm, 1984; Everett et al., 1994; Hamers, van den Hour, Halfens, Huijjer Abu-Saad, & Heijltjes, 1997; Oberst, 1978).

Experience with others' pain is not a unidimensional phenomenon, however, and the nature or quality of experience appears to play some role as a determinant of observers' judgements. Prkachin, Solomon, Hwang, and Mercer (2001), for example, studied the impact of different kinds of experience on pain judgements. Judges observed the videotapes of patients with shoulder pain described in the study by Prkachin et al. (1994) and rated the amount of pain experienced by the patients using the same scale that the patients used. Three observer groups, differing in the nature of their experience with pain sufferers, were studied. One group consisted of clinicians — physical and occupational therapists —

who had experience working with pain patients. A second group consisted of judges with experience of a different kind. These were people who had lived with a chronic pain sufferer. Judges in the third group had had little or no experience with pain sufferers. The ratings of all three observer groups were significantly lower than those of the patients, confirming that all three observer types underestimated pain. Interestingly, however, the three groups did not show the same degree of underestimation. Relative to controls, the clinicians showed greater underestimation. By contrast, those who had lived with a pain sufferer underestimated pain to a lesser degree.

A study by Kappesser, Williams, and Prkachin (2006) identified further potential sources of underestimation. In this study, physicians and nurses from a large city hospital viewed video records of the facial expressions of patients with shoulder pain. Stimuli were selected to display a range of pain expressions. Judges used the same verbal descriptor scales as the participants to rate the amount of pain they appeared to be experiencing. Judges participated in one of three conditions. One group was simply shown the facial expressions and asked to make their judgments. A second viewed the facial expressions but were also given access to the patient's rating of the pain. A third had both facial and verbal report information; in addition, this group was informed that some of the people they viewed were actually faking pain in order to gain access to opioid drugs.

Participants in the face-only condition showed substantial underestimation of patients' pain (approximately 4 points on a 15-point rating scale). Provision of information about the patient's pain rating substantially reduced but did not eliminate underestimation — in this condition judges' ratings were lower than those of the patients by only 2.5 rating-scale points on average. The addition of information about motivated faking largely reversed the reduction of underestimation associated with provision of the patient's verbal rating. In this condition, judges' ratings were approximately 3.5 points lower than those of the patients.

These data implicate two further processes in understanding pain underestimation. The fact that inclusion of the patients' actual verbal description of their pain reduced underestimation suggests that the provision of multiple sources of evidence (in this case, behavioural and verbal) may yield a more accurate approximation of sufferers' internal states. Indeed, the findings may be comforting since it is undoubtedly true that in clinical settings multiple sources of information about patients' suffering are likely to be available and used by care providers. Nevertheless, the findings may not be thoroughly comforting because, even with the evidence of the patients' characterization of their pain available, the judges (who were health professionals) still underestimated.

This is also consistent with the findings of Solomon, Prkachin, and Farewell (1997), who attempted to improve health professionals' ability to judge pain by training them in the recognition of facial expressions of pain. In that study, although training did reduce the discrepancy between patients' and professionals' ratings of the patients' pain, the reduction was not sufficient to eliminate underestimation.

The second issue implicated in the study by Kappesser et al. (2006) is the role of suspicion in influencing perceptions of the suffering of others. Information that *some* participants were faking their pain led to a general discounting of the pain of all. Poole and Craig (1992) made a similar observation. Williams (2002) offers an interpretation of pain expression in which she argues, consistent with concepts from evolutionary psychology (Cosmides & Tooby, 1992), that humans have evolved a "cheating detection" mechanism for circumstances that activate representations of exploitation or deceit. The fact that information evoking suspicion about patients' motives virtually eliminated the "benefit" resulting from additional information pertinent to the pain state is consistent with the idea that such a mechanism can affect perceptions of pain in others.

How does personal experience with pain influence the judgement of pain in others? Danziger, Prkachin, and Willer (2006) recently collected evidence pertinent to this question in a unique population. The participants were 12 individuals with congenital insensitivity to pain, a rare neurological condition characterized by a profound diminution in pain sensitivity, usually the result of a hereditary sensory and autonomic neuropathy. Patients and healthy controls underwent a variety of tests of perception of pain in others. One test involved facial expressions of shoulder-pain patients such as those described above. Another involved videos of a variety of people experiencing an injury. Notably, the videos of people experiencing injury were selected such that they depicted purely the event of the injury — no pain-related behaviour was displayed. Compared with healthy controls, patients with congenital insensitivity to pain did not differ in their judgements of the pain evident in the facial expressions of shoulder-pain patients. They did, however, tend to underrate the pain associated with injuries. Additional analyses revealed that, among patients with congenital insensitivity, the tendency to impute pain to others was correlated with independent measures of their empathy. This finding suggests that, at least in people with diminished appreciation of pain, personal characteristics involving the tendency to be affected emotionally by others' distress may affect perception of pain in others.

The foregoing studies document differences among various groups of people in terms of perception of pain in others. Most of the findings are

consistent with the suggestion that people in general show an underestimation bias, some identifying differences that appear to be experience-based and some implying that certain kinds of experience can promote underestimation. None of the studies, however, present experimental evidence that might illuminate the sources of underestimation. Studies of the influence of experience on increasing underestimation have been interpreted as implicating a kind of habituation in which repeated experience with suffering is thought to diminish sensitivity to pain in others. Prkachin et al. (2004) provide experimental evidence that is relevant to this issue. Four groups of observers were shown brief video clips of the facial expressions of patients with shoulder pain. The clips occurred in two categories: no pain and moderate pain. Expressions were sampled from these categories based on measurements of pain-related facial movements. The judges' task was to view each clip and indicate whether it displayed pain. The four groups differed according to their exposure to other clips of pain expression. Controls were simply shown the test clips without viewing other pain expressions. Participants in the low-exposure category viewed one example of strong pain expression before judging each test clip, those in the moderate-exposure category viewed five strong pain expressions before judging each clip, and those in the high-exposure category viewed 10 pain expressions before making their judgements. Analyses of observers' judgements by signal-detection techniques indicated that the degree of prior exposure to pain expression left the ability to detect pain expression unaffected. Increasing experience did, however, influence judges' decision criteria. Observers exposed to greater amounts of pain expression became increasingly unwilling to impute pain to others. These findings provide direct experimental support for the hypothesis that simple exposure to high amounts of pain serves to bias judges against reporting pain in others and may go a considerable way towards explaining observations of increased underestimation among health professionals with increased experience.

### **Is Pain Underestimation a Bad Thing?**

Our review suggests that pain underestimation, though not universal, is a common phenomenon among health-care practitioners. The question arises: Is underestimation simply an interesting but benign natural phenomenon, or does it have important implications, beneficial or detrimental, for health care? Theoretical arguments can be made on either side. The idea that pain underestimation may be beneficial can be viewed from the perspective of either the patient or the provider. From the perspective of the patient, it may be that health-care practitioners whose



estimate of the patient's suffering is lower than that of the patient also provide a kind of care that motivates recovery. Like concepts from the operant theory of pain behaviour (Fordyce, 1976), this notion evolves from the idea that a focus on pain, such as one might expect when a health-care provider estimates the sufferer's pain to be of high intensity, may strengthen pain-related behaviour or place a priority on pain suppression as opposed to active rehabilitation. To the extent that such efforts motivate behaviour that is focused on recovery, one would expect pain underestimation to be associated with better health outcomes.

From the perspective of the provider, pain underestimation might be seen as an adaptive coping mechanism, allowing caregivers to deploy their skills despite the empathic distress commonly engendered by exposure to suffering in others. Health-care providers commonly describe a process of becoming "numb" to suffering as they craft their skills. Pain underestimation may be a part of this process, enabling health professionals to administer skilled care under the emotionally provocative conditions under which human suffering takes place.

The argument that pain underestimation may be harmful can also be viewed from patient and provider perspectives. It is an article of faith among many health professions that empathy to the plight of others is a cornerstone of effective practice. Such empathy is largely thought to be helpful because it facilitates an effective therapeutic relationship with patients, out of which flows the kind of shared communication that is necessary for effective diagnosis, monitoring, and cooperation. Pain underestimation may reflect a "disconnection" between the patient and the provider that is associated with a sense of being misunderstood on the part of the patient. Such a sense may well be accompanied by feelings of anger and alienation, which complicate the emotional reaction to suffering and undercut the trust and cooperation that are necessary for therapeutic improvement.

From the perspective of the provider, pain underestimation may contribute to detrimental health outcomes by undermining a sense of therapeutic urgency. Arguably, a health-care provider's decision to intervene to reduce suffering is dependent on her or his estimation of the need for intervention, an estimation that is itself a partial function of the patient's pain. It seems likely that individual clinicians have thresholds of estimated suffering above which intervention may be pursued, and pursued aggressively, but below which it will not be pursued. If one's threshold is substantially reduced, the clinician may be at risk for not taking appropriate action to relieve suffering or to prevent future deterioration. In such a case, then, pain underestimation may lead to substandard care and poorer health outcomes.

It must be recognized that, certainly in principle and likely in practice, issues of pain estimation play out in circumstances that are asymmetrical. Health-care providers are gatekeepers for interventions with the potential to relieve pain. To the extent that, in such circumstances, their evaluations of the amount of suffering in others are critical determinants of the dispensation of pain relief, it is their judgements that hold the ultimate sway, for better or for worse.

The aforementioned mechanisms are but a few ways in which pain underestimation may affect health outcomes. Currently, there is little empirical basis for choosing among them, because few studies have examined the possible link between vicarious pain estimates and health outcomes. Cleeland et al. (1994) found that physician-patient discrepancies in cancer patients' pain were associated with substantially poorer pain management, suggesting that pain underestimation may contribute to poorer health outcomes. Similarly, there is a broader literature on patient-provider concordance that suggests that differences between the evaluations of health-care providers and those of patients with respect to various aspects of patients' experiences are associated with a variety of poorer health outcomes (DiMatteo & Martin, 2002). By contrast, Creamans-Smith et al. (2003) compared the pain ratings of older female osteoarthritis patients (*M* age = 69 years), their spouses, and rheumatologists. On average, the spouses' ratings tended to be higher than those of the patients, while the rheumatologists' ratings were lower. Spouse-patient and rheumatologist-patient dyads were categorized as in agreement, overestimating and underestimating. Patient-spouse underestimation was associated with diminished patient self-efficacy, positive affect, and increased depression, while underestimation in rheumatologist-patient dyads was associated with greater patient self-efficacy and positive affect. Perreault and Dionne (2006) had patients with acute and sub-acute low-back pain and their physiotherapists estimate the patients' pain on the same 11-point numerical rating scale at the beginning of a course of physiotherapy. Four weeks later, after physiotherapy, the patients' pain and functional limitations were measured using the same numerical rating scale and measures of functional limitations. Pain underestimation on the part of the treating physiotherapist was associated with improved pain ratings and function at follow-up. These findings show that underestimation may be associated with improved health outcomes.

The available evidence, therefore, is extremely limited and inconsistent. It provides no clear answer to the question of whether pain underestimation is beneficial, detrimental, or benign. This is a critical question that should be the focus of substantial empirical inquiry.

### A Model of Pain Inference

In addition to providing a framework for conceiving the pain-communication process, Figure 1 represents an attempt to summarize and synthesize the literature outlined in this article. It indicates that, of the components of evaluations of pain in others, considerably more is known about variables that affect underestimation bias than about variables that affect sensitivity. Empirical research has identified a number of categories of variables that appear to affect the extent of underestimation bias. These include the nature of the relationship between the patient and the judge (Prkachin et al., 2001), the amount of exposure of the judge to evidence of suffering (e.g., Prkachin et al., 2004), suspicion and other factors that may lead the judge to question the authenticity of pain complaints (Kappesser et al., 2006), and features of the judge's proclivity to empathize with others (Danziger et al., 2006). As also indicated in Figure 1, the influence of these variables on underestimation represents the first step in a process that affects the decisions that individuals make and the behaviours in which they engage when faced with evidence of suffering in others. These decisions and behaviours can range from vigorous and aggressive care to no care at all, and even, in principle, actions that are likely to intensify the suffering. Research into the linkage between the pain judgements and subsequent actions of observers is very limited and needs to be the focus of intensive research.

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### Authors' Note

Some of Kenneth Prkachin's and Patricia Solomon's research described herein has been supported by a grant from the Canadian Institutes for Health Research.

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## Happenings

### **Taking Pain Information to the Public**

**Celeste Johnston and Shirley Musclow**

On November 4, 2006, the Saturday leading into National Pain Awareness Week, 42 volunteers — almost all nurses — ran 4-hour Pain Information Clinics in 30 Loblaw's pharmacies from Nova Scotia to British Columbia. This was a collaborative initiative of the Canadian Pain Coalition, a partnership of patient pain groups; the Canadian Pain Society (CPS), whose focus is public education about pain; and the CPS Special Interest Group – Nursing Issues (CPS SIG-NI), which represents nurses interested in improving pain practices across Canada.

Loblaw's customers came to their local store for information about steps they could take to manage their pain. The nurses were provided with an interview guide to help customers determine what they could do to help themselves. The aim was to provide free information to the public in order to highlight pain awareness.

A Pain Survival Kit was distributed throughout the 4-hour period. The main item in the kit was an eight-module booklet on pain relief. The modules included answers to the following frequently asked questions: "What is pain? Are there different types of pain? What are the effects of pain on my body? How can I have good sleep hygiene? Is there a connection between stress and pain and depression? What can I do to lower stress? How should I talk to health care professionals about my pain? Are there things I can do besides taking medication to help my pain? What about pain medications? Where can I find more information?"

Information for the booklet was compiled by two McGill University final-year undergraduate nursing students, Kate McNaughton and Anna Kabal, under the supervision of nursing professor Celeste Johnston, who is also Director of the Canadian Pain Coalition and a member of the CPS SIG-NI. The nursing volunteers were solicited by Shirley Musclow, Chair of the CPS SIG-NI.

Feedback was generally very positive. One Loblaw's pharmacist wrote:

The clinic [was] very successful. We had a line up waiting for counselling. ...the next day people came to see us because they heard from their friends how informative it was... I am still getting phone calls from patients asking if the week is still running. Our patients are really appreciating the valued service.

Plans are being made to expand the initiative next year.

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## Book Review

### ***Postoperative Pain Management: An Evidence-Based Guide to Practice***

**George Shorten, Daniel Carr, Dominic Harmon,  
Margarita Puig, and John Browne**  
Philadelphia: Elsevier, 2006. 304 pp.  
ISBN 13-978-1-4160-2454-5

**Reviewed by Céline Gélinas**

This book addresses postoperative pain management from an evidence-based medicine perspective. It has four sections: description of evidence-based practice and medicine, scientific basis of postoperative pain and analgesia, management of postoperative pain, and specific populations and clinical settings. The book seems to be intended primarily for physicians, as it is medically based and really focused on pain-management treatments.

I really enjoyed reading this well-written evidence-based book. It is an interesting reference for those who wish to know more about medical treatments in postoperative pain management and to be updated about evidence-based practice. However, I wish I could have learned more about pain assessment, monitoring of analgesic therapy and its side effects (e.g., respiratory depression), and non-pharmacological pain-management interventions. I would have also appreciated the inclusion of a chapter on the critically ill. Many critically ill patients undergo surgery and are intubated and/or unconscious (e.g., trauma patients). These patients are unable to communicate their pain and receive many different drugs (e.g., sedatives, opioids, cardiac medications). Drug interactions would have been another interesting topic to be discussed with regard to this particular situation.

Levels of evidence used in the book vary from one chapter to another, which makes the task of the reader difficult. The structure of the chapters would have benefited from standardization in terms of levels of evidence discussed as well as study results reported to support levels of evidence. Evidence-based practice could have been summarized in tables or boxes in all of the relevant chapters. This would have been an interesting way of attracting the attention of readers and leading them to the important information as a guide for practice.

The main strength of *Postoperative Pain Management* is its evidence base, which is very relevant for clinicians. Other strengths are the fact that a wide variety of medical treatments for postoperative pain are discussed; pre-emptive and preventive approaches to pain management are outlined, with a view to achieving better pain relief and decreasing the risk of postoperative complications; and the sometimes neglected areas of postoperative pain management in children and in the elderly are included.

The book has four major weaknesses. First, little information about pain assessment is provided and some of the information that is provided is inaccurate. For instance, the Wong and Baker Faces Pain Scale is not the best picture scale to recommend, since it has been criticized as assessing emotions (being happy or sad) rather than pain intensity (Chambers & Craig, 1998). Also, the authors state that pain in non-verbal patients can be evaluated on the basis of physiological responses. Except for infants undergoing procedural pain, physiological indicators are not considered valid cues for the assessment of pain (Herr et al., 2006). Second, there is little information on pain assessment in non-verbal populations. Recommendations about valid pain-assessment tools for clinical practice could have been discussed in the text. Third, the book includes little information on the monitoring of patients who are receiving pain treatments. For example, clinicians need solid recommendations on the monitoring of respiratory depression as a side effect of opioids. Also, evidence-based protocols on the monitoring of patients with PCA (patient-controlled analgesia) or epidural analgesia would have been useful as a guide for practice. Fourth, non-pharmacological pain-management interventions are presented only briefly, with little evidence supporting their use in practice. Finally, given the many abbreviations and scientific terms used in the text, a list of abbreviations and a glossary could have been included at the back of the book.

*Postoperative Pain Management* is an interesting evidence-based reference for clinicians, especially physicians, wishing to know more about treatments for postoperative pain. A compact disc included with the book provides many case studies and useful self-assessment questions. However, the reader seeking a complete reference, including pain assessment, monitoring of analgesic therapy and its side effects, and non-pharmacological pain-management interventions, will be disappointed, as this book offers little information on these topics.

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## **L'utilisation de la théorie du comportement axé sur un objectif pour prédire l'intention d'exercice chez les adultes obèses**

**François Boudreau et Gaston Godin**

Cette étude transversale a pour objectif d'utiliser la théorie du comportement axé sur un objectif (TCAO) d'Ajzen comme cadre théorique pour comprendre l'intention d'activité physique chez un groupe d'individus obèses. Des individus ( $n = 96$ ) identifiés comme obèses ( $\text{IMC} \geq 30 \text{ kg/m}^2$ ) ont rempli un questionnaire autoadministré évaluant l'intention d'être physiquement actif et ses variables théoriquement afférentes. L'utilisation de la TCAO a expliqué 66 % de la variance liée aux intentions d'exercice physique. Le contrôle comportemental perçu ( $\beta = 0,40$ ) et l'attitude ( $\beta = 0,36$ ) constituaient d'importants prédicteurs de comportement indépendants. La prise en compte de comportements antérieurs ( $\beta = 0,32$ ) a permis d'expliquer 7 % des variances. Ces conclusions ont appuyé l'idée selon laquelle les infirmières doivent, à l'étape de la conception d'interventions pour individus obèses, mettre l'accent sur l'acquisition d'habiletés qui permettront de surmonter les obstacles à l'activité physique, ainsi que sur le renforcement de ce comportement.

Mots clés : activité physique, intention, théorie du comportement axé sur un objectif

# **Using the Theory of Planned Behaviour to Predict Exercise Intention in Obese Adults**

**François Boudreau and Gaston Godin**

The purpose of this cross-sectional study was to use Ajzen's Theory of Planned Behaviour (TPB) as a theoretical framework for understanding the intention to be physically active among a group of obese individuals. Individuals ( $n = 96$ ) classified as obese ( $\text{BMI} \geq 30 \text{ kg/m}^2$ ) completed a self-administered questionnaire assessing intention to be physically active and its theoretically related variables. The TPB explained 66% of the variance in physical activity intentions. Significant independent predictors of intention were perceived behavioural control ( $\beta = .40$ ) and attitude ( $\beta = .36$ ). The consideration of past behaviour ( $\beta = .32$ ) explained an additional 7% of the variance. These findings support the idea that, in designing interventions for obese individuals, nurses should focus on developing skills to overcome barriers to physical activity and on developing a positive attitude towards this behaviour.

**Keywords:** Obesity, physical activity, intention, Theory of Planned Behaviour

Today, regular physical activity must be considered a critical part of the treatment for obesity. In primary care settings, nurses are in a position to assess and manage obesity in patients (Banning, 2005). However, one study found that only 32% of nurses believed they were effective in counselling to promote a change in lifestyle in order to reduce obesity (Steptoe, Doherty, Kendrick, Rink, & Hilton, 1999). According to Hardeman, Griffin, Johnston, Kinmonth, and Wareham (2000), health education interventions addressing the problem of obesity would be more effective if explicitly based on methods of behaviour modification that have shown to be effective in other contexts. For instance, in order to develop theory-based health education interventions to promote leisure-time physical activity in obese individuals, nurses should first identify the key correlates of the behaviour under study in the target population. This would enable nurses to identify the content of the intervention messages, select appropriate methods, and develop material specifically adapted to the characteristics of the target population. Such interventions would have greater likelihood of success.

It is reported in the literature that the Theory of Planned Behaviour (TPB) (Ajzen, 1991) "may have a valuable contribution to make to developing effective interventions aimed at behavior change, especially

among individuals where motivation to act cannot be taken for granted” (Hardeman et al., 2002, p. 151). According to the TPB, the proximal determinant of behaviour is the intention to adopt or not to adopt that behaviour, while the proximate determinants of the intention to adopt a behaviour are the individual’s attitude, subjective norm, and perceived behavioural control with respect to adopting the behaviour. Attitude represents one’s evaluation of the perceived benefits and drawbacks of adopting a given behaviour (e.g., “My doing physical activities in my free time during the next month would be good/bad”). Subjective norm reflects the perceived expectations of specific individuals or groups regarding one’s adoption of a given behaviour (e.g., “In your opinion, are the people who are most important to you in favour or not in favour of your regular participation in one or more physical activities in your free time during the next month?”). Lastly, perceived behavioural control is determined by the individual’s perception of the presence or absence of resources and opportunities as well as perceived obstacles and impediments regarding adoption of the target behaviour (e.g., “To me, participating in one or more physical activities in my free time during the next year appears difficult/easy”). Perceived behavioural control can also influence behaviour directly, when it closely approximates actual control.

In short, the TPB could prove useful for identifying the determinants of regular leisure-time physical activity among obese individuals. Identification of these determinants would, in turn, be useful in nursing practice for developing health education interventions aimed at promoting physical activity in these individuals. To the best of our knowledge, the TPB has not been applied in the study of exercise among obese individuals. Thus, the aim of this study was to use the TPB to examine intention to engage in regular physical activity among a group of obese individuals. The main research question was: *Can attitude, subjective norm, and perceived behavioural control explain physical activity intentions?* To address this question, the following hypotheses were formulated: 1. *A significant portion of variance will be explained by a combination of attitude, subjective norm, and perceived behavioural control.* 2. *The relative importance of attitude, subjective norm, and perceived behavioural control will vary.*

## Method

### *Participants and Procedure*

This study consisted of the secondary analysis of data from a cross-sectional survey on cardiovascular risk factors among a sample of the population served by a Local Community Health Service Centre in the province of Quebec, Canada. The goal of the survey was to determine the overall prevalence and distribution of cardiovascular risk factors.

Briefly, a sample of 900 randomly selected individuals between the ages of 35 and 64 was identified. These individuals were mailed a package containing a self-administered questionnaire, a return envelope, and a covering letter — signed by the principal investigator and the health coordinator of the Local Community Health Service Centre — describing the purpose of the survey and soliciting the individual's cooperation. The recipients were advised that their responses would be confidential and that no name would appear on the questionnaire. All of the study procedures were approved by an ethics review board. Two follow-up reminders were sent, one after the first week and one after the fourth week. Overall, 558 completed questionnaires were returned, for a participation rate of 63%. Among the 558 respondents, 96 were classified as obese according to their BMI ( $\geq 30$  kg/m<sup>2</sup>).

### **Measures**

The psychosocial variables assessed were intention, attitude, subjective norm, and perceived behavioural control. The chosen time frame of 1 year for measuring the psychosocial variables was the same as that used in a province-wide survey conducted by a Quebec government agency (Daveluy, Pica, Audet, Courtemanche, & Lapointe, 2000). That survey was adapted to make the results comparable to those of the present population survey. In order to standardize the definition of physical activity for all participants, the following two statements were included at the top of each page of the questionnaire: "Physical activity includes all activities, such as sports, outdoor activities, physical fitness, and brisk walking," and "Participation in physical activity is considered regular when done for 20 to 30 minutes per session at least three times a week." Although the determinants of physical activity could vary according to the three components of physical activity (frequency, intensity, and duration) (Courneya & McAuley, 1994), the wording of the questions in this study was oriented towards frequency, as this dimension reflects the behavioural aspect.

**Intention.** Two items were used to assess intention. The first asked, "Do you intend to participate regularly in one or more physical activities for 20 to 30 minutes per session in your free time during the next year?" The response was recorded on a five-point scale (1 = definitely not, 5 = definitely). The second stated, "I intend to participate regularly in one or more physical activities for 20 to 30 minutes per session in my free time during the next year" (1 = strongly disagree, 5 = strongly agree). The two items correlated at .75 ( $p < .01$ ) and the mean of the sum was taken as the intention score. Test-retest reliability for this question has been verified several times, with the values varying between

.65 (Godin, Valois, Shephard, & Desharnais, 1987) and .77 (Valois, Godin, & Bertrand, 1992).

**Attitude.** Attitude towards adoption of the behaviour was measured on six five-point items on a semantic differential scale. Each of the six scales appeared following the statement "I think that participating regularly in one or more physical activities in my free time during the next year would be..." The bipolar adjectives used were *unpleasant/pleasant*, *boring/interesting*, *useless/useful*, *tiresome/stimulating*, *disadvantageous/advantageous*, and *unreasonable/reasonable*. The score for attitude was expressed as the average of the sum of the six pairs of adjectives. Internal consistency was verified using Cronbach's alpha coefficient; an appropriate value of .82 was found. Test-retest reliability for this measure has been reported as .81 (Valois et al., 1992).

**Subjective norm.** The participants were asked the following question: "In your opinion, are the people who are most important to you in favour or not in favour of your participating regularly in one or more physical activities in your free time during the next year?" This item was measured on a five-point scale (1 = strongly not in favour, 5 = strongly in favour). Test-retest reliability for a measure similar to that used in this study produced a value of .66 (Courneya & McAuley, 1995).

**Perceived behavioural control.** Three items adapted from Nguyen, Potvin, and Otis (1997) were used to assess perceived behavioural control in the following format: "To me, participating in one or more physical activities in my free time during the next year appears..." *very difficult/very easy*, *complicated/straightforward*, *unachievable/achievable*; five-point scales were used. The mean of the three scales was taken as a composite score for PBC. Cronbach's alpha coefficient indicated an appropriate value of .92. Test-retest reliability of such a measure of perceived behavioural control is reported as .63 (Valois et al., 1992).

**Past behaviour.** The role of past behaviour in the TPB as discussed by Conner and Armitage (1998) was retained on the basis of a meta-analytic review indicating that it may play an important role in predicting intention to be physically active (Hagger, Chatzisarantis, & Biddle, 2002). Past behaviour was assessed using a simple self-report question: "How often have you participated in one or more physical activities for 20 to 30 minutes per session during your free time in the last 3 months?" (1 = never, 2 = less than once a month, 3 = two or three times a month, 4 = once a week, 5 = twice a week, 6 = three times a week, 7 = four times a week). This method of assessing behaviour is based on previous validated studies (Gionet & Godin, 1989; Godin, Jobin, & Bouillon, 1986). Test-retest reliability for this scale was .64 (Godin et al., 1986). In the previous studies, concurrent validity was established against measures



of maximum oxygen intake (VO<sub>2</sub> max), body fat, and muscular endurance.

Age, gender, and BMI were also assessed. Based on respondents' self-reported weight (kg) and height (m),<sup>2</sup> BMI was calculated as weight (kg)/height (m).<sup>2</sup> The weight classification recommended by the WHO Expert Consultation on Obesity was used; thus, BMI between 25.0 kg/m<sup>2</sup> and 29.9 kg/m<sup>2</sup> denoted "overweight" and BMI of 30.0 kg/m<sup>2</sup> or greater represented "obesity" (World Health Organization, 2000).

### **Statistical Analysis**

The data were analyzed using the SPSS statistical package (Version 10.0). The hypotheses concerning TPB were tested according to Ajzen's (1991) recommendations. First, Pearson product-moment correlations were calculated to examine the interrelationships between the TPB variables and additional variables. Then, a hierarchical regression analysis was conducted to predict intention to be physically active based on the TPB variables and additional variables.

## **Results**

A total of 96 individuals were classified as obese based on their BMI ( $\geq 30$ ). Four questionnaires were excluded because of missing data on the TPB variables. Thus, data analysis was based on the responses of 92 participants (49% female). The average age of the participants was 47.7 years ( $SD = 7$ ); 29% of participants had completed postsecondary education, 58% had completed high school, and 13% had not completed high school. The measure of past behaviour indicated that 47.8% of respondents had not participated in any leisure-time physical activity during the previous 3 months, whereas 21.8% had been physically active three or more times per week.

Intercorrelations, mean scores, and standard deviations of the variables are presented in Table 1. The correlation matrix of the variables revealed positive correlations between intention and attitude ( $r = .65, p < .01$ ), perceived behavioural control ( $r = .72, p < .01$ ), and past behaviour ( $r = .62, p < .01$ ). Subjective norm was weakly positively correlated with intention ( $r = .25, p < .05$ ). No correlation was observed between intention and age ( $r = .11, p > .05$ ), gender ( $r = -.18, p > .05$ ), or BMI ( $r = .14, p > .05$ ).

The results of the hierarchical regression analysis are presented in Table 2. In the first step, attitude and perceived behavioural control accounted for 66% of the variance in intention ( $F(3,88) = 56.01, p < .0001$ ). In the second step, the addition of past behaviour added 7% of the explained variance in intention ( $F(1,87) = 25.55, p < .0001$ ). In order

Table 1 Intercorrelations, Mean Scores, and Standard Deviations of the Theoretical Model and Additional Variables										
	1	2	3	4	5	6	7	8	M	SD
1. Intention <sup>a</sup>	–	.65**	.25*	.72**	.62**	.11	-.18	.14	3.94	0.86
2. Attitude <sup>a</sup>		–	.33**	.44**	.31**	.04	-.11	.12	4.19	0.58
3. Subjective norm <sup>a</sup>			–	.19	.02	.01	.11	.02	4.25	0.82
4. Perceived behavioural control <sup>a</sup>				–	.46**	.06	-.16	.17	3.58	0.87
5. Past behaviour <sup>b</sup>					–	.18	-.14	.12	3.22	2.22
6. Age						–	-.24*	.07	47.74	6.97
7. Gender <sup>c</sup>							–	-.20	.51	0.50
8. BMI								–	33.89	4.33

<sup>a</sup> Mean score varying from 1 to 5.

<sup>b</sup> Mean score varying from 0 to 16 times per month.

<sup>c</sup> 0 = female; 1 = male.

\* $p < .05$ ; \*\* $p < .01$ .

**Table 2** *Hierarchical Regression Analysis of Intention from Theoretical Model and Additional Variable*

Predictor	R	R <sup>2</sup>	ΔR <sup>2</sup>	F for Change	β <sup>1</sup>	β <sup>2</sup>
<b>Step 1</b>	.81	.66	.66	56.01*		
Attitude					.42*	.36*
Subjective norm					.01	.04
Perceived behavioural control					.53*	.40*
<b>Step 2</b>	.86	.73	.07	25.55*		
Past behaviour						.32*

R<sup>2</sup> = .73; \* p < .0001.  
 β<sup>1</sup>: standardized regression coefficients for first step.  
 β<sup>2</sup>: final standardized regression coefficient.

of relative importance, the standardized regression coefficients indicated that perceived behavioural control ( $\beta = .40, p < .0001$ ), attitude ( $\beta = .36, p < .0001$ ), and past behaviour ( $\beta = .32, p < .0001$ ) were the most important variables in predicting intention to be physically active.

### Discussion

The goal of this study was to verify the utility of the Theory of Planned Behaviour to predict the intention of obese people to participate in free-time physical activity on a regular basis. The results indicate that intention is associated firstly with perceived behavioural control and secondly with having a favourable attitude towards this behaviour. A third determinant, past behaviour (which is not part of the TPB), also helped to explain intention. Thus, the results of this study suggest that the TPB is an appropriate theoretical framework for understanding the determinants of motivation to be physically active with respect to obese individuals. Also, though secondary to the main goal of the study, self-reports of recent physical activity indicate that nearly half of the respondents had a sedentary lifestyle. Only one person out of five reported participating in physical exercise on a regular basis.

Regarding the first hypothesis, a significant portion of the variance in intention ( $R^2 = 66\%$ ) was explained by the TPB variables. This was higher than the average reported by Godin and Kok (1996) for prediction of exercise among different segments of the population; indeed, a value of 42% was derived from 21 applications regarding prediction of

exercise intention. However, the regression values from individual studies varied from 13% to 66%. For instance, Biddle, Goudas, and Page (1994) ( $R^2$  of .62), Ajzen and Driver (1992) ( $R^2$  of .66), and Kimiecik (1994) ( $R^2$  of .66) report values in the same range as that found in the present study. Therefore, the present observed value in terms of explained variance is not unusual.

Concerning the second hypothesis, it was observed that attitude ( $\beta = .36$ ) and perceived behaviour ( $\beta = .40$ ) had similar standardized regression coefficients. These results are consistent with those observed by Godin and Kok (1996) and Hagger et al. (2002) for application of the TPB in the context of physical activity. Subjective norm was not a significant determinant of intention to engage in leisure-time physical activity on a regular basis. Therefore, perceived social norm can be considered of little importance to obese individuals regarding intention to exercise. This observation is congruent with several reviews of the scientific literature showing a weak correlation between subjective norm and intention to adopt various behaviours (Armitage & Conner, 2001; Godin & Kok), including participation in physical activity (Hausenblas, Carron, & Mack, 1997).

Perceived behavioural control can be viewed as the combined influence of two components: self-efficacy (ease or difficulty of adopting a behaviour), and controllability (the extent to which engagement is up to the person) (see Ajzen, 2002, for a review). Therefore, the perception of ease or difficulty of adopting a behaviour depends on the individual's evaluation of (1) available opportunities, and (2) the presence or absence of the necessary time, money, or ability. For the obese person, there is true difficulty in moving, because of body weight. Thus, nurses working with obese clients should have them begin slowly, with light exercise, and to slowly add frequency, intensity, and duration as the person's physical abilities improve.

The intention of obese individuals to engage in regular physical activity was also explained by attitude. This suggests that respondents who expressed an intention to be physically active perceived more advantages than disadvantages to engaging in regular physical exercise. This finding is congruent with that of Sarkin, Johnson, Prochaska, and Prochaska (2001), who also found that for individuals with excess weight ( $BMI \geq 25 \text{ kg/m}^2$ ), intention to engage in moderate physical activity was associated with the perceived advantages of exercising. Thus, in designing health education interventions, nurses should provide exercise-related information stressing the benefits of participating in some form of physical activity (Jones, Sinclair, & Courneya, 2003).

The additional contribution of past behaviour was in the same range as the values reported by Conner and Armitage (1998) following their

TPB meta-analysis. These authors found that, after taking into account the TPB determinants, past behaviour explained a further 7.2%, on average, of the variance in intention. The role of past behaviour as a predictor of exercise intention has also been documented for various population subgroups (Blanchard, Courneya, Rodgers, Daub, & Knapik, 2002; Godin, Vezina, & Leclerc, 1989). The results of the present study with a group of obese individuals are in line with these observations. Although past exercise behaviour does not provide any insights into intervention strategies, as discussed by Ajzen (1991), it does suggest that it is important for nurses to find ways of increasing obese individuals' number of active days so that these persons may strengthen their intention to adopt an active lifestyle. Indeed, in the present study the respondents who were physically active during the previous few months exhibited the strongest intention to exercise during the next year.

### ***Limitations***

This study has a number of limitations. Firstly, the classification of obese was based on self-reported height and weight. This may have underestimated the actual number of obese people. Indeed, it has been documented that height and weight are often overestimated and underestimated by respondents (Newell, Girgis, Sanson-Fisher, & Savolainen, 1999; Niedhammer, Bugel, Bonenfant, Goldberg, & Leclerc, 2000). Secondly, the assessment of physical activity was based on self-reported leisure-time physical activity. Even though the questionnaire that was used has been validated in several studies (e.g., Godin et al., 1986), an objective measure may be more appropriate for use with obese individuals (Westerterp, 1999). Thirdly, according to the TPB (Ajzen, 1991) the main constructs of attitude, subjective norm, and perceived behavioural control are determined by underlying beliefs (i.e., behavioural, normative, and control). Ultimately, these are the beliefs that guide the development of educational interventions. However, they were not elicited in this study, thus limiting the identification of the content of an intervention. Future studies should provide this important information. A final limitation was the cross-sectional design of the study and reliance on intention measure as the dependent variable. The scientific literature recognizes, however, that intention is a reliable predictor of future exercise behaviour. In fact, based on several applications of Ajzen's theory in the field of exercise behaviour, the explained variance of exercise by intention only was 27% (Godin & Kok, 1996). Consequently, an intention measure is an acceptable proxy for exercise behaviour.

### **Implications for Nursing Practice**

Overall, the results of this study suggest that, in designing effective health education interventions to promote regular leisure-time physical activity in obese individuals, nurses should favour the development of a sense of control over behaviour. In other words, nurses should help obese individuals to develop the skills needed to overcome barriers. Nurses should also support the development of a positive attitude towards exercise. In this regard, a health education intervention that highlights positive outcomes and minimizes negative outcomes could be an appropriate approach. Also, from a public health perspective, nurses should endeavour not to place the overall responsibility exclusively on the obese person but to take his or her environment and social context into account.

Finally, in order to motivate obese individuals to initiate regular leisure-time physical activity, nurses should use innovative strategies for delivering health education messages. Telecommunication and computer technologies can be an ideal medium for promoting leisure-time physical activity (Marcus, Nigg, Riebe, & Forsyth, 2000). In this regard, a promising and relatively new approach in health education is computerized tailoring. According to Kreuter and Skinner (2000), tailoring can be defined as “any combination of information or change strategies intended to reach one specific person, based on characteristics that are unique to that person, related to outcome of interest, and have been derived from an individual assessment” (p. 1). It is interesting to note that this definition is congruent with the nursing process — that is, individualization of interventions based on the client’s needs (Bakken, 2001). The results of a recent systematic review confirm the conclusions drawn in earlier reviews and position papers: tailoring is a promising means of promoting a healthy diet and possibly physical activity as well (Kroeze, Werkman, & Brug, 2006).

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Résumé

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## **Le rôle de l’infirmière d’essai clinique dans le processus d’obtention du consentement éclairé**

**Franca Cantini et Carolyn Ells**

Cette étude descriptive visait à recueillir de l’information sur le rôle que jouent les infirmières d’essai clinique dans le processus d’obtention du consentement éclairé. On a fait remplir un questionnaire auto-administré de 50 éléments à 95 infirmières employées dans des hôpitaux affiliés à l’Université McGill à Montréal, Québec, Canada, qui participaient à un projet de recherche clinique dont le chercheur principal était un médecin et les sujets des adultes compétents. Les infirmières étaient toutes membres de l’association provinciale des infirmières. L’analyse révèle que les infirmières d’essai clinique jouent un rôle important dans l’obtention du consentement éclairé et qu’elles vivent des conflits d’intérêts et des dilemmes d’ordre éthique dans l’exercice de ce rôle. L’étude confirme la nécessité d’élaborer des lignes directrices précises en matière de pratique et d’éthique pour guider les infirmières en recherche clinique, ainsi que des programmes de formation.

Mots clés : consentement éclairé, essai clinique, infirmière, éthique

# **The Role of the Clinical Trial Nurse in the Informed Consent Process**

**Franca Cantini and Carolyn Ells**

The purpose of this descriptive study was to elicit information about the current practice of clinical trial nurses in the informed consent process. A 50-item self-administered anonymous questionnaire was completed by a sample of 95 nurses from hospitals affiliated with McGill University in Montreal, Quebec, Canada, who were members of a clinical trial research team whose principal investigator was a physician and whose research participants were competent adults. The nurses were all members of the provincial nurses' association. Clinical trial nurses were found to have an important role in the informed consent process and to experience conflict of interest and other ethical dilemmas as members of clinical trial research teams. There is a need to develop specific practical and ethical guidelines for nurses involved with clinical trial research and to develop educational programs for nurses working in clinical research.

Keywords: Informed consent, clinical trial, nurse, ethics, research ethics

## **Introduction**

The extent of today's involvement of nurses in the informed consent (IC) process in research is unclear. In the Canadian province of Quebec, as documented by Deschamps et al. (1995), nurses are the professional group most commonly called upon to collaborate with a principal investigator (PI), usually a physician, in clinical trial research. But not only is there no official, standard title for these nurses — among the many variations are research assistant, research nurse, study coordinator, study nurse, nurse coordinator, and clinical trial nurse (CTN) — there is also a lack of practical guidelines issued by professional nursing organizations such as the *Ordre des Infirmières et Infirmiers du Québec* (OIIQ) for defining the role and responsibilities of these nurses.

The literature reveals that nurses are actively participating as members of research teams in the clinical setting (Arrigo, Gall, Delogne, & Molin, 1994; Barrett, 2002; Berry, Dodd, Hinds, & Ferrell, 1996; Davis, Chandros Hull, Grady, Wilfond, & Henderson, 2002; Di Giulio et al., 1996; Ehrenberger & Aikin, 2003; Ehrenberger & Lillington, 2004; Lynch, 1988; McLean, 1996; Mueller, 2001; Papakonstantinou et al., 1997; Sadler, Lantz, Fullerton, & Dault, 1999). However, the lack of guidelines, policies, and job descriptions for CTNs (Davis, 1989; Davis et al.; Johnson, 1986), and the participation of CTNs in clinical trials for which they are not the PI

of the study (Berry et al.; Mueller), has wrought confusion as to the functions and ethical obligations of these nurses. For instance, CTNs experience conflict between their loyalty to the investigator, their responsibilities to the sponsoring for-profit companies, and their primary responsibility to serve the interests of the study participants. This has caused CTNs to question their duty and their moral obligations. It has been suggested that ethical dilemmas and conflicts of interest experienced by CTNs are sometimes related to the fact that the PI is a physician (Davis, 1989; Johnson).

The literature contains sparse empirical data on the number of nurses participating in the IC process and the level of their participation. Nevertheless, the activities of CTNs as described by several authors reveal that it is common practice for PIs to delegate responsibility for obtaining IC partially or totally to CTNs (Arrigo et al., 1994; Berry et al., 1996; Davis, 1989; Davis, 1988; Deschamps et al., 1995; Lynch, 1988; McLean, 1996; Ocker & Pawlik Plank, 2000; Sadler et al., 1999). But the real nature of CTNs' role in the IC process remains unclear, as do the conflicts of interest and ethical dilemmas that attend the nurses' participation in the IC process.

In reporting on their 1994 quantitative study, Arrigo and colleagues describe CTNs' involvement in the IC process as providing information to the patient (73%) and participating in obtaining IC (56%). However, these investigators do not provide much information regarding the nature of the nurses' participation in the IC process, nor do they identify the point at which the nurses become involved in the IC process. Further, they do not address or identify ethical dilemmas or conflicts of interest encountered by CTNs related to the IC process.

More recent studies have begun to provide specific details about the roles of CTNs in the IC process. Ocker and Pawlik Plank (2000) evaluate the role of CTNs through literature review, analyses of job description, and discussions with CTNs. Their research reveals that CTNs may assess the knowledge and concerns of potential participants and their families about clinical trials at the beginning of and during the IC process. In addition, CTNs assess the potential participants' and families' understanding of information given about the research as well as education (mainly disclosure of information) associated with the IC process. This can include assessing potential participants' ability to read and comprehend the information given and helping them to understand "the randomization and registration process, the treatment goals of the study, the study requirements, the alternatives to the research study, and the potential benefits, side effects, or complications of the treatment protocol." For the health professionals involved in the study, job descriptions were drawn up and these distinguished the roles of CTNs in a

combined oncology research and clinical setting from the roles of the other team members. The authors report that CTNs were more satisfied with their jobs after receiving a job description (which included their role in the IC process) because of the clarity about role accountability and responsibility and the legitimacy that the job description lent to their role.

In 2004, Ehrenberger and Lillington published a study on the development of a reliable and valid measurement tool to delineate the role of CTNs (Ehrenberger & Lillington, 2004). They include the IC process as one of eight distinct CTN roles. According to the authors, CTNs “explain the study to the potential subject using the basic elements of informed consent (e.g., purpose, benefits, risks)” and “assess the potential subject’s understanding of the consent form information.” Note that for this measurement tool disclosing information about the research is not called “education” or “reinforcement” but is squarely classified as a CTN responsibility integral to the IC process. The authors also specify a role for CTNs in identifying and supporting discussion of ethical issues related to research.

Some agencies (Canadian Nurses Association, 2002; International Council of Nurses, 2000; Ordre des Infirmières et Infirmiers du Québec [OIIQ], 2005) have developed and published codes of ethics as well as ethical guidelines regarding nurses’ behaviours in their various roles. However, these codes and guidelines do not address important areas of ethical concern for CTNs participating in the IC process. (We will return to this topic in the Discussion.) More information is needed if clear boundaries are to be drawn and if practical and ethical guidelines are to be developed.

A descriptive study was designed in order to gather information about current practices in Canadian settings, with a view to developing ethical guidelines for nursing practice and eventually developing standard educational programs for nurses working in clinical research.

### **Ethical Framework and Concepts**

Professional nursing codes of ethics were used as frameworks guiding this study, since they express the profession’s ethical ideals regarding the moral behaviour of its members (Yeo & Moorhouse, 1996). For example, the *Code of Ethics for Registered Nurses* (Canadian Nurses Association, 2002) sets out the ethical behaviours expected of nurses and addresses nurses’ obligation to use their knowledge and skills for the benefit of others, to minimize harm, to respect client autonomy, and to provide fair and just care for their clients.

These codes of ethics reflect major nursing goals (e.g., health and well-being, health promotion and protection, relief of suffering) and do not deem them subservient to the goals of other professions or parties. Similarly, they reflect the eight principles/values that are central to ethical nursing practice in Canada: safe, competent, and ethical care; health and well-being; choice; dignity; confidentiality; justice; accountability; and quality practice environments (Canadian Nursing Association, 2002). At the foundation of several of these values are more general ethical principles described in the work of Beauchamp and Childress (2001) — respect for autonomy, non-maleficence, beneficence, and distributive justice — which are common to most if not all health professions.

Although the dominance of the principle/value of respect for autonomy, along with a conception of autonomy that is strongly individualistic, has received scholarly criticism, the health professions continue to support and give considerable importance to respect for patient/participant autonomy in health care and research, particularly as a moral foundation for IC. Health professionals, including nurses, tend to interpret “respect for autonomy” as the obligation of professionals to communicate information, to assess and ensure comprehension of that information, to assess and ensure the voluntary choice/participation of the patient/participant, and to provide adequate time for decision-making (Beauchamp & Childress, 2001).

### **Key Concepts**

With a study questionnaire designed to measure five key concepts, we sought both to determine the role of the CTN in the IC process and to probe for ethical issues that might arise. The first three concepts correspond to key elements of IC that are reflected in nursing codes of ethics and thus potentially come under the purview of the role of CTNs in the IC process. The first concept, *disclosure of information*, refers to information relevant to the decision whether to participate in the research (e.g., purpose of the research, the risks and benefits of participation, alternatives to participation). The second, *comprehension of information*, refers to the (potential) participant’s understanding of the information disclosed during the IC process. The third concept, *voluntary participation*, refers to the freedom to decide whether to take part in the research unimpeded by coercion or manipulation, as well as the freedom to withdraw from participation at any time during the research process without prejudice.

The latter concepts seek to identify ethical challenges for CTNs related to their role in the IC process. Following Jameton (1984), the fourth concept, *ethical dilemma*, is typically divided into three categories: ethical/moral uncertainty (about what principles/values apply or what

they mean), ethical/moral conflict (when an applicable principle/value leads to conflicting courses of action), and ethical/moral distress (when a law, policy, or power relationship prevents one from taking a course of action that is warranted). For CTNs involved in the IC process, ethical dilemmas can arise from factors that negatively affect disclosure of information, (potential) participants' comprehension of information, or voluntary participation. They can arise from the lack of a clear job description, lack of clear policies and guidelines about their role, lack of adequate information about the study, or lack of sufficient information or education about the IC process. They can also arise from conflict of interest. This can be considered a subcategory of ethical dilemma, but for the purpose of our research we highlight it as a distinct concept. *Conflict of interest* refers to a situation in which two or more interests are at stake and suggest conflicting courses of action. It has the potential to compromise objectivity in the execution of one's responsibilities. Such interests can be financial, professional, personal, educational, or a combination of these and other interests. For example, CTNs may have interests in ensuring the well-being of research participants, in serving the aims of the research, and in meeting the expectations of their employers, with each interest calling for a different course of action.

### **Study Objectives**

The study had two objectives: to describe the role of Quebec CTNs in an IC process in which the PI is a physician, and to explore conflicts of interest and ethical dilemmas encountered by nurses in fulfilling that role. The study population was limited to nurses working in collaboration with a physician as the PI, the purpose being to validate the results of earlier studies (Davis, 1989; Johnson, 1986) suggesting that dilemmas and conflicts experienced by CTNs are related to the fact that the PI is a physician.

The research questions were the following. 1. *What is the role of the CTN in the IC process vis-à-vis three distinct aspects: disclosing information, assessing the participant's comprehension of the process, and ensuring the patient's voluntary participation in the clinical trial?* 2. *What are the types and frequency of conflicts of interest and ethical dilemmas encountered by CTNs participating in the IC process?*

### **Methodology**

Because of the limited data available regarding the role of the CTNs in the IC process, we chose a descriptive study design. Feasibility served to limit the target population and the sampling procedure.

### **Sample**

The target population consisted of all registered nurses working in clinical trial settings, with a physician as PI, at four McGill University-affiliated hospitals: the Sir Mortimer B. Davis Jewish General Hospital, the Montreal General Hospital, the Royal Victoria Hospital, and St. Mary's Hospital. To be included in the study, the participant had to be a practising nurse (validated by membership in the OIIQ) and be a member of a clinical trial research team for which the PI was a physician and whose research participants were competent adults able to read and understand English.

### **Sampling Procedure**

Because no registries or records identifying CTNs' names or workplaces were available, we used a convenience-type networking procedure to identify potential participants. We identified and contacted key nurses working in clinical trial settings through the Research Ethics Office Coordinators Network, a body familiar with the research being conducted in the relevant hospitals and the nurses working in clinical trial settings. These nurses in turn suggested other nurses, and the networking snowballed until no additional CTNs were identified. All identified CTNs were invited to take part in the research. They were told about the study aims, what participation would entail, possible risks and benefits, their rights and freedoms regarding the decision whether to participate, and how their anonymity would be protected. Interested parties were given a questionnaire, an accompanying explanatory letter, and a self-addressed envelope. They were instructed to complete the questionnaire and return it via internal mail using the self-addressed envelope. Four weeks after the initial contact, thank you/reminder letters were sent to all potential participants along with a second information sheet, questionnaire, and self-addressed envelope.

### **Questionnaire<sup>1</sup>**

We developed our 50-item self-administered questionnaire based on the available literature (Medical Research Council, Natural Sciences and Engineering Research Council, & Social Sciences and Humanities Research Council [MRC, NSERC, & SSHRC], 1998; World Medical Association, 2004). Two questions were taken from the validated questionnaire used by Arrigo and colleagues (1994). Two thirds of the questions were close-ended, mainly Likert-type (1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = always) or Likert-scale (1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree). We included some

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<sup>1</sup>For a copy of the questionnaire, contact Franca Cantini: [fcantini@lab.jgh.mcgill.ca](mailto:fcantini@lab.jgh.mcgill.ca).



yes/no questions and some items asking participants to select a response from among alternatives. A third of the questions were open-ended, whereby participants could elaborate on their responses. The questionnaire was piloted to three experts in the field in order to test its reliability and face validity. Once comments from this initial pilot were incorporated into the questionnaire, the revised version was piloted to four CTNs working in various institutions and varying in age and in years of experience. As determined by the second pilot, the questionnaire required approximately 15 minutes to complete and met the objectives in terms of information sought.

### ***Variables and Measures***

Five concepts (disclosure of information, comprehension, voluntariness, conflict of interest, and ethical dilemmas) were studied. Specific questionnaire items were used to measure these study variables.

### ***Analysis***

We used SPSS and Van Kaam's (1966) method to analyze data from descriptions of respondents' "lived experiences."

### ***Ethical Considerations***

The aims, risks, and benefits of the research were disclosed to potential participants, as were the voluntary nature of participation and the means used to ensure confidentiality. In terms of ensuring anonymity, the questionnaires were unlinkable and untraceable to specific participants. The project was approved by the research ethics committees at the Université de Montréal, McGill University, and each of the four hospitals.

## **Results**

### ***Demographics***

A total of 95 nurses met the inclusion criteria and were invited to participate in the study. Of the 95 questionnaires distributed, 60 were returned (63.2% response rate); the second mailing netted five more questionnaires, for a total of 65 respondents (68.5% response rate). The respondents, who ranged in age from 25 to 60 years (*mean* = 39.5 years; *SD* = 7.9), had an average of 5.1 years' experience in the clinical trial setting (*SD* = 4.7). For the majority of respondents, the highest level of nursing education was a bachelor's degree (44.6%), followed by a college diploma (35.4%), an undergraduate certificate in nursing (13.8%), and a master's degree (6.2%). Twenty-three of the 65 respondents (35%) indicated that their highest level of education was in a field other than nursing:

community health (19%), business administration/management (14.2%), health sciences (14.2%).

The results show that the majority of respondents (66.2%) received some education in research ethics, whether during nursing studies (26.2%), during on-the-job training (20%), or after completing nursing studies but before assuming their current position (6.2%). Of the nine respondents who received training under more than one of the above categories, six received training both during their nursing studies and on the job, one received training during nursing studies and also prior to assuming the position, and one received training prior to assuming the position as well as on the job. Only one participant received training at all three points: during nursing studies, after completion of studies, and on the job.

In terms of amount of training received during their nursing studies, seven respondents reported receiving 45 hours or more, seven reported levels between 12 and 30 hours, and six reported levels between 2 and 6 hours. All those who received training before assuming their position but after completing nursing studies did so via a 45-hour undergraduate course. Lastly, for those trained on the job, 40% reported training of between 6 and 24 hours. On-the-job training was provided by the nurse being replaced (42.9%), the PI (28.5%), or the sponsoring company (28.5%). Of the respondents, 33.8% had not received any form of research ethics education at the start of their job in the clinical research setting. Although eight respondents (12.3%) had since received some research ethics education, 14 (21.5%) were practising in the field with little if any formal training or education in research ethics.

Less than half of the respondents (27, or 41.5%) reported having a job description. Of these, only 12 knew who had drawn it up. Seven nurses said they had written their own job description, while three specified that the PI had written it. One participant named both the sponsoring company and the institution as authors of his/her job description. With regard to their current title, 32.3% of respondents used the title "research coordinator," 32.3% "research nurse" and 30.8% "study coordinator." Less frequently employed were the titles "clinical trial nurse" (13.8%), "study nurse" (6.2%), and "research study coordinator" (4.6%); 15.4% of respondents reported using two or more titles interchangeably.

### ***Role of the CTN in the Informed Consent Process***

***Point of involvement in IC process.*** A large percentage of respondents (75%) described being involved in the IC process before, during, and after the securing of IC. However, eight respondents reported being involved only before the securing of IC, four only before and during the securing of IC, and three only after the securing of IC; 97% of respon-

dents indicated that they did not perceive IC as simply the formality of a signature.

**Disclosure of information.** Almost all respondents (96.9%) reported that they participated in securing IC. All respondents indicated that they participated in providing information about the research to the participant; 98.5% provided participant and family education. In supplying greater detail about providing information to research participants, 56 respondents (86.2%) claimed that they did so often, six (9.2%) sometimes, two (3%) rarely, and one (1.5%) always. The majority of respondents indicated that the provision of information to research participants was a collaborative effort shared by the nurse and the PI. Shared explanations included: the purpose of the study (74.5%), the risks involved (67.3%), the potential benefits (69.1%), and the alternatives available (65.5%).

**Comprehension of information.** Just over half of the respondents (56%) said it was the responsibility of both the PI and the CTN to assess the participants' comprehension of the study and the information provided prior to the securing of consent. Twenty-two respondents (40%) said that this task was solely the responsibility of the CTN and one that it was solely the responsibility of the PI. Only one respondent said that no one assessed the participants' comprehension. Almost all respondents (95.4%) reported that their responsibility included answering participants' questions. In addition, respondents indicated that they were involved always (48.2%), often (30.4%), or sometimes (16.1%) in assessing the participants' comprehension of the options available.

**Voluntary participation.** The majority of CTNs (92.3%) reported assessing whether the participants took part in the research voluntarily (without undue pressure). Of these, 72.3% responded that they always, 12.3% often, and 7.7% sometimes assessed voluntary participation. Only a small percentage reported never (2.4%) or rarely (5.3%) assessing whether the participants truly volunteered (without undue pressure) to take part.

Almost all the respondents (93.8%) reported verifying the participants' willingness to continue taking part throughout the study (even after having signed the consent form). Forty-five indicated verifying always (69.2%), nine often (13.8%), and seven sometimes (10.8%).

### ***Conflicts of Interest and Ethical Dilemmas***

**Conflicts of interest.** Twenty-eight respondents (43%) reported never experiencing conflict of interest related to their role in the IC process. Of the 37 nurses who reported experiencing conflict of interest between their obligations to the participants and to the research project (56%), the frequency of occurrence varied (rarely = 29.2%, sometimes = 26.2%,

often = 1.5%), as did the conflict type. Only 21 respondents went on to describe the conflict.

After using Van Kaam's (1966) method for analyzing data from descriptions of the respondents' "lived experiences," we ranked the reported conflicts of interest in descending order according to frequency of occurrence: participants lacking full comprehension of the implications or purposes of the study (10 respondents); alternatives not offered to patients (4 respondents); respondents asked to approach potential participants at inappropriate times (when patients were vulnerable or seriously ill) (3 respondents); patients refused to read consent form because they trusted the physician investigator (2 respondents); patients unaware of voluntary nature of participation (1 respondent); and PI insistence on enrolling patients in the study even though they did not meet eligibility criteria (1 respondent). In effect, professional conflict of interest was the most frequently reported type of conflict, inasmuch as 38 nurses had experienced a situation in which patients appeared not to understand the implications of their participation but still signed the consent form (occurring rarely = 30.8%, sometimes = 24.6%, often = 3.1%).

**Ethical dilemmas.** Approximately two thirds of respondents (42) reported experiencing ethical dilemmas as a result of their role in the IC process. According to these respondents, ethical dilemmas were usually caused by a lack of clear policies and guidelines regarding nurses' role in the IC process (27%), the fact that their employer was also the PI of the study (23.8%), or the lack of a job description (22.3%). Insufficient information and education were the least identified causes of ethical dilemmas.

Respondents indicated that they always (92.3%) or often (6.2%) had access to the research protocol, and 95.4% reported reading the protocol. As well, the majority of respondents (67.7%) had their questions about protocol answered by the PI (often = 18.5%, sometimes = 11.7%); only one respondent reported never receiving answers from the PI. With regard to education, 35.4% of the respondents rated their knowledge of the IC process as excellent, 38.5% as very good, 21.7% as good, and 4.6% as poor. Nevertheless, half of the respondents (50.8%) reported needing more education to properly fulfil their role in the IC process. More specifically, 30.8% said they needed education in legal obligations and implications with regard to obtaining consent as well as liability issues regarding the CTN's role in the IC process, while 20% said they needed more education in the IC process generally.

### **Correlational Analyses**

Correlational analyses were performed to determine the existence of a relationship between the key concepts (conflicts of interest, ethical

dilemmas) and continuous variables (age, years of experience, amount of research ethics training received). In addition, a *t* test was used to compare the mean score of two groups (Table 1) — those with and without a job description — in order to determine whether this variable influenced the experience of conflicts and ethical dilemmas.

As evidenced in Table 2 by Pearson’s correlation tests, years of experience and number of hours of research ethics training had a significant effect on the perceived experience of conflict of interest. This finding suggests that those with more research ethics education and more years of experience in the field have an increased tendency to report conflict. This may be the very reason for the low prevalence of conflict among the study population. Most respondents had little if any research ethics education and little CTN experience. One can therefore postulate that research ethics education and years of experience sensitize the CTN to potential conflicts and dilemmas and render them better able to identify and report any such instances. With regard to the other variables, such as job description, the tests revealed no significant relationships (Table 2).

**Table 1 Mean Score of Two Groups, Those With and Without a Job Description**

	Conflict of Interest			<i>p</i>	Ethical Dilemma			<i>p</i>
Job description	<i>n</i>	Mean	SD	0.278	<i>n</i>	Mean	SD	0.320
Yes	26	7.5	2.5		27	11.4	3.8	
No	37	6.8	2.6		35	10.4	3.7	

**Table 2 Pearson’s Correlation Between Key Concepts and Age, Years of Experience, and Research Ethics Training**

	Conflict of Interest	Ethical Dilemma
Age	0.16	-0.08
Years of experience Mean = 5.1 SD = 4.7	0.32*	-0.21
Hours of training in research ethics	0.262*	0.177

\*Significant at 0.05 (2-tailed).

## Discussion

### *Role of the CTN in the IC Process*

The results of this descriptive study demonstrate that a large majority of CTNs in the study population are actively involved in ensuring disclosure of information, comprehension, and voluntariness in the informed consent process, and that they are meeting their professional obligations in this regard. The analyses indicate that the role of the CTN in the IC process is that of resource person (providing information as required, assessing participants' comprehension), watchdog (ensuring that coercion and manipulation tactics are not employed), and advocate (ensuring that participants' rights are respected). Finally, the results indicate that it is common practice for CTNs to fulfil their role in the IC process in collaboration with the principal investigator. Nevertheless, one third of the respondents were delegated complete responsibility for disclosing information, two thirds had responsibility for assessing participants' comprehension, and almost all had responsibility for assessing voluntary participation. Thus CTNs perceive themselves as playing a central role in the IC process — and this with little or no educational preparation. They are therefore placed in a position where they must engage in self-learning and implement national and international guidelines (e.g., Gouvernement du Québec, 1998; Health Canada, 1997; MRC, NSERC, & SSHRC, 1998) governing the practice of research. In other words, the lack of educational preparation and lack of specific nursing guidelines create a situation in which CTNs are expected to take a proactive stance and familiarize themselves with regulations and guidelines governing research in order to fulfil their professional role. The guidelines available to them are of limited help when it comes to defining the role of CTNs in the IC process. These CTNs are pioneering the role of the nurse in the IC process, but in so doing find themselves in vulnerable situations, confronted with conflicts of interest and ethical dilemmas. Given this situation, should CTNs exercise caution, or should they simply decline to take part in the IC process?

The role of the nurse in the IC process has long been a controversial one (Davis, 1989). There are two existing paradigms. One argues that the PI is responsible for obtaining the IC and that this is a personal duty that cannot be delegated (Smith, 2000; World Medical Association, 2004). The other asserts that while IC is indeed the PI's responsibility, the nurse has an ethical duty and/or moral responsibility to ensure that the participant understands the IC process (Berry et al., 1996; Canadian Nurses Association, 2002; Cassidy & Macfarlane, 1991; Davis, 1989; Johnson, 1986; Lynch, 1988; McLean, 1996; Sadler et al., 1999). Some go so far as to declare that the nurse, whether or not entrusted with this responsi-

bility, is at least as responsible as the physician for obtaining IC and has an obligation to provide information to the potential participant, in collaboration with the physician (Berry et al.; Cisar & Bell, 1995; Sadler et al.).

As prescribed by the values enshrined in the *Code of Ethics for Nurses* (Canadian Nurses Association, 2002), the obligations of the professional nurse include truthful disclosure of information, assessment of clients' understanding with regard to their care — providing information as required — and, finally, ensuring that coercion and manipulative tactics are not employed in the securing of consent. As well, the International Council of Nurses (1996) *Ethical Guidelines for Nursing Research* state that all nurses have an ethical responsibility and duty to protect their patients, whether research participants or not. Finally, in order to minimize undue influence, when the research participant is also in a relationship of dependency with the investigator, such as a patient/physician relationship, caution is warranted (Smith, 2000). The Medical Research Council of Canada (1987) suggests that in order to minimize the potential for conflict of interest, it is prudent for PIs to delegate the securing of IC to other health professionals, especially if the PI is also the treating physician. Given the above, one could argue that nurses do indeed have a professional and moral duty to ensure that research participants have provided IC, regardless of whether the responsibility for obtaining it is delegated to the CTN. So, given the controversy and our results, should the responsibility for obtaining IC be delegated to the CTN?

According to Lynch (1988), because nurses receive education in the principles of client teaching, communication, and interpersonal relationships, coupled with the fact that they are the professional group with the closest and most frequent contact with research participants, they are ideally positioned to be delegated responsibility for the IC process. Conversely, McLean (1996) offers a word of caution to nurses who take on the role of obtaining consent for research purposes. McLean asserts that prudence is called for and that responsibility for securing IC should not be assumed unless the nurse is at the very least knowledgeable about and familiar with the research protocol, the condition being investigated, the screening criteria and process, any risks and potential benefits, and relevant legal and ethical issues. Furthermore, McLean recommends that nurses become familiar with the proper procedures for delegating medical functions to nurses and with institutional policies and procedures governing the IC process. Analysts such as Lynch and McLean underline the importance of research ethics education, for CTNs cannot become sensitized to the legal and ethical implications of such a role without being properly educated.

With regard to lack of education, 35.4% of respondents rated their knowledge of the IC process as excellent, while only 4.6% rated it as poor. Nevertheless, half of the respondents cited a need for more education in the IC process, identifying legal obligations and implications for CTNs regarding IC and the IC process as areas of weakness. The desire for education among CTNs about their role is also supported in the recent literature (Davis et al., 2002; Ehrenberger & Aikin, 2003).

### ***Education and Policy***

It would seem appropriate for the nursing curricula to include research ethics courses. Also critical is the need for standardized, perhaps even mandatory, minimal training for CTNs. Such training should include education in ethical issues common to their role. Only one third of respondents had received training in research ethics, provided by either the PI, the nurse leaving the position, or the sponsoring company. It is unacceptable for nursing to leave it up to other disciplines to define the role and standards of the CTN through education and job description.

Furthermore, it is essential that guidelines be developed in order to provide a framework on which CTNs can base their practice and clear boundaries regarding their role in the IC process. This would serve to address the conflict and dilemmas described by the respondents. It is also essential for the proper conduct of research, adhering to the highest level of ethical and professional standards. The lack of guidelines and clear policies was the most common cause of ethical dilemmas described by the respondents. Other causes of ethical dilemmas included the PI of a study also being the employer of the CTN (23.8%) and the lack of a job description (22.3%), both of which situations could be addressed in guidelines or policies in order to minimize the ethical difficulties confronting CTNs.

With regard to conflict of interest, more than half of the respondents reported experiencing conflict between their obligations to the participants and their duty to ensure the successful completion of the study. The cause of such conflict was most commonly reported as organizational, with the PI being the employer of the CTN. This situation results in other professions and for-profit companies defining and guiding nursing practice with regard to CTNs. In the absence of guidelines and policies on the role of CTNs, either the employer (usually the PI) draws up (or has the sponsor draw up) a job description governing the practice of the employee (CTN) or no job description is drawn up at all. All of these scenarios are unacceptable. The nursing profession should intervene and develop educational programs as well as policies and guidelines in order to address the vulnerable situations described in this study.



### ***Revised Professional Code of Ethics in Quebec***

In Quebec, the *Code of Ethics of Nurses* was amended by the OIIQ and adopted by the government in June 2005 (OIIQ, 2005). The amended code addresses some of the issues identified in this study, namely consent issues (i.e., nurses must ensure disclosure of information, comprehension of information, and voluntary participation) and conflict-of-interest issues (i.e., nurses must advise an appropriate authority, such as a research ethics committee, of any conduct that appears to run counter to scientific and ethical norms). The amended code is a step in the right direction, as it provides practical guidelines with regard to the role of the CTN in the IC process.

### ***Methodological Limitations***

The convenience non-random sample, which included only practising nurses working with a physician PI at a McGill-affiliated hospital, affects the external validity of the study and limits the generalizability of the results. This limitation resulted from a lack of financial and human resources.

With regard to the questionnaire, it was noted that the results obtained in certain areas were not well dispersed. This limitation could not have been anticipated, as no empirical data giving an idea of the prevalence of the concepts being studied were available at the time. In addition, the questionnaire falls short with respect to exploring the collaborative role described by the sample regarding disclosure of information and comprehension. Also unexplored was the means by which the nurse assesses the participants' comprehension and voluntary participation. These shortcomings are related to the fact that the level of participation and involvement of the CTN in the IC process was unclear at the time when the questionnaire was developed.

### ***Conclusion***

The results of this study point to the need for standard ethical and practical guidelines with respect to the role of the CTN in the IC process. This void is responsible for these nurses' experience of conflicts of interest and ethical dilemmas. Furthermore, the results of this study suggest the need for standardization of educational preparation and training in this setting.

One can argue that CTNs who collaborate as members of research teams in clinical trials are not participating in research that serves to advance nursing knowledge and that this could be the reason for the lack of guidelines and recognition by the nursing profession. However, we believe that this thinking must change and that it is indeed beginning to

change. The recent revision of the nursing code of ethics in Quebec is a step in the right direction.

The empirical data collected in this study confirm what has been reported elsewhere: CTNs play a critical role in the IC process in Quebec and are experiencing conflicts of interest and ethical dilemmas. In order to serve the interests of the public as well as of nurses themselves, nursing educators and the nursing profession must recognize this fact and continue to develop educational programs for nurses who are involved in research as well as guidelines governing the practice of CTNs.

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### Authors' Note

The authors wish to acknowledge the guidance and assistance of Drs. Jocelyn St. Arnaud and Jack Mendelson in planning and conducting the research. In addition, they would like to thank Dr. Margaret Purden for her support. The research of Dr. Ells was supported by a grant from the Social Sciences and Humanities Research Council of Canada. The authors are accountable for any shortcomings in the research.

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## **Le mesurage de l'apport alimentaire en recherche infirmière**

**Eileen R. Fowles, Bobbie Sue Sterling  
et Lorraine O. Walker**

L'évaluation précise de l'apport alimentaire est une composante essentielle qui doit être intégrée à la recherche internationale en santé afin d'identifier les déviations nutritionnelles pouvant entraîner des risques de maladies chroniques chez les individus. Une incapacité à se pencher sur les problèmes connus qu'entraîne l'utilisation d'outils de mesurage alimentaire traditionnels peut entraver la réalisation d'une évaluation précise. Cet article décrit l'application ainsi que les avantages et les désavantages de cinq méthodes d'évaluation alimentaire fréquemment utilisées. Les auteures discutent également de la gestion des erreurs de mesurage associées à chacune d'elles et recommandent l'utilisation de ces méthodes dans le cadre de recherches communautaires portant sur la santé. L'utilisation de méthodes d'évaluation complémentaires à plusieurs étapes de mesurage améliore la fiabilité des résultats. Le recours à une évaluation de la qualité générale de l'apport alimentaire correspond à une approche d'intervention holistique conçue pour améliorer la santé. C'est aussi un outil méthodologique qui s'avère intéressant pour la recherche nutritionnelle. L'utilisation d'approches novatrices pourra permettre d'identifier avec plus de précision les tendances alimentaires contribuant à l'apparition de maladies. Bien que complexe, l'étude de l'apport alimentaire en recherche sur la santé s'avère une étape essentielle à l'identification du risque de maladie chez un individu et de sa réaction au traitement.

Mots clés : évaluation alimentaire, erreur de mesurage

# **Measuring Dietary Intake in Nursing Research**

**Eileen R. Fowles, Bobbie Sue Sterling,  
and Lorraine O. Walker**

Accurately assessing dietary intake is an essential component of international health research to identify nutritional deviations that may place people at risk for developing chronic diseases. Accurate assessment may be hampered by failure to address known measurement problems with traditional dietary assessment tools. This article describes the application and advantages and disadvantages of 5 frequently used dietary assessment methods, discusses the management of measurement error common to each, and recommends use of these methods in community-based health research. Using complementary assessment methods at multiple measurement points enhances the reliability of the findings. Assessing overall dietary quality is consistent with a holistic approach to interventions designed to improve health and is a valuable methodology for nutritional research. Using innovative approaches may more accurately identify dietary patterns that contribute to disease development. Although complex, examining nutritional intake in health research is essential to determining an individual's disease risk status and response to treatment.

**Keywords:** Dietary assessment, food frequency questionnaires, measurement error, nutrition

Nutrition is an integral component of international initiatives aimed at improving health and preventing and managing chronic diseases (Muller & Krawinkel, 2005; World Health Organization, 2000a). Recent findings indicate that poor diet along with a sedentary lifestyle is second only to smoking as the leading modifiable cause of mortality (Mokdad, Marks, Stroup, & Gerberding, 2004). Diet is a key factor in the prevention and management of obesity (World Health Organization, 2000b) and related chronic illnesses, such as type 2 diabetes (Schulze & Hu, 2005). Diet may also contribute to health outcomes related to life stages, such as pregnancy and childbirth (Institute of Medicine, 2003), adolescence (Chan, Hoffman, & McMurry, 1995), and aging (Battino & Ferreiro, 2004).

Within a research context, dietary assessments are conducted to determine overall dietary quality, total energy (kilocalorie [kcal]) intake, the level of a nutrient group, such as fat intake, or a particular micronutrient, such as calcium, to assess risk status or response to treatment (Willett, 1998). Accurate measurement of overall dietary quality as well as specific macro- and micronutrients is a crucial component of health

status assessments. Nurses need to know how to effectively measure dietary intake in community-based studies designed to improve health and prevent or manage disease. However, little information regarding nutritional assessment methods is currently available in the nursing literature and nurse researchers may not be fully aware of innovations for enhancing the accuracy of dietary assessments. This article describes the advantages and disadvantages of various dietary assessment methods and discusses strategies for managing potential measurement error and enhancing the validity of selected dietary assessment tools in community-based health improvement and disease prevention research.

### **Dietary Assessment Methods**

The overarching goal in any dietary assessment is to maximize opportunity for accurate and reliable assessment while minimizing the effects of both random and systematic measurement error. Selecting the most appropriate assessment approaches for the research question and then instituting procedures to control within- and between-persons error can best meet this goal.

Direct observation of food intake conducted either alone or with weighed food records is one of the most accurate methods for quantifying dietary intake and is often used in controlled inpatient settings. However, subjects may alter usual eating behaviours when being observed, or may supplement weighed food records, which can produce an inaccurate picture of typical intake (Barrett-Connor, 1991). Although direct observations of food intake in a controlled hospital setting are possible, use of such methods may not be feasible or appropriate for large, community-based studies. Thus, the most frequently used dietary assessment approaches in community-based research are 24-hour dietary recall, food records, food frequency questionnaires, and biomarkers.

Several factors need to be considered in selecting an appropriate dietary assessment measure. These factors include the specific research question, including the exact planned use of the dietary data. For example, is the dietary variable of interest absolute energy intake (kcal), the level of a particular macronutrient (total grams of fat), change in intake over time, or a measurable physiological response to the level of dietary intake? A second consideration in selecting a dietary assessment measure includes characteristics of the targeted research population — that is, the setting for the assessment, age, literacy level, availability of assessment tools in a specific language, and cognitive abilities of the intended sample. It is also important to consider the availability of computer resources and trained personnel to gather data or to enter the data for analysis. Even though technology significantly expedites dietary

intake entry and analysis, procedures for verifying accuracy of data gathering, entry, checking, and analysis may be both time-intensive and labour-intensive (see Table 1).

Most research approaches rely on self-reported food intake that may or may not be augmented by an interviewer trained to extract more complete intake information. The results of nutritional assessments, however, may be inaccurate because of underreporting of dietary intake despite construction of a thorough food frequency scale or the efforts of a trained interviewer (Willett, 1998). Understanding the advantages and disadvantages of the various dietary assessment methods and innovations for managing measurement errors may help the researcher to report nutritional outcomes that accurately reflect disease risk status or response to nutritional interventions (see Table 2).

### ***24-Hour Dietary Recall***

Twenty-four-hour dietary recall is one of the most frequently used methods for determining usual dietary intake. (See advantages and disadvantages in Table 2.) This assessment generally requires less than 30 minutes to complete and does not require participant literacy. Twenty-four-hour dietary recall can be completed via telephone (Johnson, 2002) and does not result in undue participant burden (Biro, Hulshof, Ovesen, & Cruz, 2002). The resultant dietary data can be entered into a food analysis program. Participants may be less likely to alter eating behaviours when responding to a 24-hour dietary recall because the nutrient information is collected after the fact (Willett, 1998).

Recalling intake, however, may be difficult for children and for some cognitively impaired or elderly persons. However, the major methodological concerns with recall are the inadvertent overreporting and underreporting of consumed foods, daily or seasonal variations between foods consumed on a weekend versus a weekday, and the possibility of the participant's providing socially desirable responses (Willett, 1998). These problems can be minimized by incorporating multiple, non-consecutive 24-hour dietary recall (Willett) and by using a standardized approach, such as the calibration method employed in Europe (Slimani et al., 2000; Slimani, Valsta, & EFCOSUM Group, 2002) or the recently developed US-based "multiple pass" method to obtain more complete intake amounts (Moshfegh et al., 2001). These innovative methods have been found to enhance accuracy of food-intake assessment of young children (Johnson, Driscoll, & Goran, 1996), of men and women under controlled conditions (Conway, Ingwersen, & Moshfegh, 2004; Conway, Ingwersen, Vinyard, & Moshfegh, 2003), and in large multinational populations (Slimani et al., 2000). Using modern computer-assisted programs, such as the EPIC-SOFT program developed in Europe or the US-based



**Table 1 Sample of Products and Programs for Nutritional Assessment**

<p><b>Dietary Intake Collection Products<sup>a</sup></b></p> <p>BalanceLog (<a href="http://www.healthetech.com">http://www.healthetech.com</a>)</p> <p>DietMax for a Pocket PC, 2003 (<a href="http://www.sparklesolutions.net/index.html">http://www.sparklesolutions.net/index.html</a>)</p> <p>DietMate Pro (<a href="http://www.dietmatepro.org/">http://www.dietmatepro.org/</a>)</p> <p>EPIC-SOFT (see Slimani et al., 2000; contact N. Slimani for information: <a href="mailto:Slimani@iarc.fr">Slimani@iarc.fr</a>)</p>	<p>PDA-based software to track and analyze food intake and activity; Windows- and Mac-compatible.</p> <p>PocketPC-based software to track food intake.</p> <p>Palm-based tracking of food intake that can provide feedback to client. Client sync's intake data into a Web site for analysis that is accessible to researchers and clinicians.</p> <p>Computer-based software developed to collect interactive dietary information in 11 European countries.</p>
<p><b>Dietary Analysis Programs<sup>b</sup></b></p> <p>CAFÉ: Compositional Analyses from Frequency Estimates (see Welch, Luben, Khaw, &amp; Bingham, 2005; contact A. Welch for information: <a href="mailto:ailsa.welch@phpc.com.ac.uk">ailsa.welch@phpc.com.ac.uk</a>)</p> <p>WISP: Intake, Recipe and Menu Analysis (<a href="http://www.tinuvielsoftware.com/wisp.html">http://www.tinuvielsoftware.com/wisp.html</a>)</p>	<ul style="list-style-type: none"> <li>• Based on UK food composition tables.</li> <li>• Developed to analyze data from the EPIC study.</li> <li>• Modifies nutrient intake according to type of fats used in food preparation.</li> <li>• Updateable.</li> <li>• Over 4,500 food items.</li> <li>• Can store 100,000 recipes.</li> <li>• Uses UK or US food composition tables.</li> <li>• Analysis of 120 (UK) or 125 (US) nutrients.</li> </ul>

<p>Food Processor (<a href="http://www.esha.com">http://www.esha.com</a>)</p> <p>Diet Balancer for Windows (<a href="http://www.xkee.com/home-education/diet-balancer/">http://www.xkee.com/home-education/diet-balancer/</a>)</p> <p>FoodWorks 7.0 (<a href="http://www.nutritionco.com/">http://www.nutritionco.com/</a>)</p> <p>Minnesota Nutrition Data System (<a href="http://www.ncc.umn.edu/">http://www.ncc.umn.edu/</a>)</p> <p>Nutritionist Pro (<a href="http://www.firstdatabank.com/specialty_software/nutritionist_pro/">http://www.firstdatabank.com/specialty_software/nutritionist_pro/</a>)</p> <p>Food/Analyst Plus (<a href="http://www.hoptechno.com/faplus.htm">http://www.hoptechno.com/faplus.htm</a>)</p>	<ul style="list-style-type: none"> <li>• Over 29,000 foods in database.</li> <li>• Analysis for 133 nutrients and nutrient factors.</li> <li>• Database updates offered twice yearly.</li> <li>• 4,500 foods, including fast foods, in database.</li> <li>• Allows for the addition of foods to list.</li> <li>• Over 16,000 foods in database.</li> <li>• Unlimited database expansion — add new foods.</li> <li>• Analysis for 113 nutrients and food components.</li> <li>• Over 18,000 foods in database.</li> <li>• Analysis for 136 nutrient, nutrient ratios, and food components.</li> <li>• Interview prompts to guide data collection using multiple-pass approach for 24-hour recall.</li> <li>• Over 20,000 foods, including brand-name foods, fast foods, ethnic foods, and enteral products.</li> <li>• Analysis for 90 nutrients and nutrient factors.</li> <li>• Database updates offered twice yearly.</li> <li>• Over 23,000 foods, including fast foods and common restaurant meals.</li> <li>• Allows for the addition of foods and label information.</li> <li>• Analysis for 100 nutrients.</li> </ul>
<p><sup>a</sup> Product costs vary from US\$14 to \$179.</p> <p><sup>b</sup> See Lee, Nieman, and Rainwater (1995) for a discussion of dietary analysis programs. Costs vary from US\$200 to \$8,500.</p>	

Table 2 *Advantages and Disadvantages of Dietary Assessment Methods*

Description of Assessment Method	Advantages	Disadvantages
<p><b>Direct Observation with Weighed Food Records</b></p> <ul style="list-style-type: none"> <li>• Weigh each item of food on plate before and after meal.</li> </ul>	<ul style="list-style-type: none"> <li>• Valid measure of amount of food consumed.</li> </ul>	<ul style="list-style-type: none"> <li>• May not reflect typical intake.</li> <li>• Costly; impractical for large studies.</li> </ul>
<p><b>24-hour Dietary Recall</b></p> <ul style="list-style-type: none"> <li>• Trained interviewer elicits foods, portion size, place, and timing of meals eaten within past 24 hours.</li> </ul>	<ul style="list-style-type: none"> <li>• Easy to complete.</li> <li>• By phone or in person.</li> <li>• Some computer programs provide prompts to foster more complete dietary intake information and rapid analysis.</li> </ul>	<ul style="list-style-type: none"> <li>• Relies on short-term memory.</li> <li>• May not reflect typical intake.</li> <li>• Data entry may be time-intensive.</li> </ul>
<p><b>Food Records</b></p> <ul style="list-style-type: none"> <li>• Trained interviewer instructs person to make detailed list of foods consumed, including preparation methods and brand names.</li> </ul>	<ul style="list-style-type: none"> <li>• Does not rely on short-term memory.</li> <li>• Accurate estimate of portion sizes with use of food models.</li> <li>• Can include culture-specific foods.</li> </ul>	<ul style="list-style-type: none"> <li>• Requires motivation for prolonged period of record-keeping.</li> <li>• Person may alter typical diet.</li> <li>• Cost of carefully training participants is high.</li> </ul>

<p><b>Food Frequency Questionnaires</b></p> <ul style="list-style-type: none"> <li>• Consists of a list of foods with options to select for the amount and frequency of consumption on a weekly or monthly basis within a specified period from 3 to 12 months.</li> </ul>	<ul style="list-style-type: none"> <li>• Optically scanned into computer analysis program.</li> <li>• Does not require trained interviewer.</li> <li>• Assesses dietary patterns over an extended period.</li> </ul>	<ul style="list-style-type: none"> <li>• Needs a comprehensive list of foods that identify health risk of interest, including culturally sensitive foods.</li> <li>• Prone to response-set biases if too long.</li> <li>• Inconsistent estimates of portion sizes (small, medium, large) and frequency.</li> <li>• May be insensitive to foods in culturally diverse populations.</li> <li>• Uncertain validity.</li> <li>• High cost for some analysis programs.</li> </ul>
<p><b>Biomarkers</b></p> <ul style="list-style-type: none"> <li>• Estimates of nutrient of interest obtained from blood, urine, saliva, and hair samples.</li> </ul>	<ul style="list-style-type: none"> <li>• Estimates availability of some nutrients that are difficult to assess with questionnaire data.</li> <li>• May have less error than dietary assessments.</li> </ul>	<ul style="list-style-type: none"> <li>• Absorption rates vary among nutrients and individuals.</li> <li>• Influenced by individual metabolic differences.</li> <li>• Nutrient availability affected by food-preparation methods.</li> <li>• Logistic and cost concerns.</li> </ul>
<p>Source: Information compiled from Johnson (2002) and Willett (1998).</p>		

Minnesota Nutrition Data System, may reduce systematic bias, which often develops when interviewers obtain the information. These programs may improve the reliability of the nutrient analysis (Slimani et al., 2000) (see Table 1).

Collecting 24-hour dietary recall information across 3 to 5 non-consecutive days, one of which is a weekend day, or for multiple days over a 1- or 2-week period, maximizes the probability of capturing daily variations and provides dietary information that more closely reflects usual eating habits than assessing intake over 2 days consisting of 1 weekday and 1 weekend day (Willett, 1998). Differences in average intake within a population may be determined by a single 24-hour intake only if sample sizes are very large. The research question guides the number of required 24-hour intake records and needs a balance of weekday and weekend days (Margetts & Nelson, 1997; Willett). This assessment strategy better captures intake of cultural foods and is useful in determining average nutrient intake levels.

### ***Food Records***

Food records or food diaries, another commonly used open-ended dietary intake approach, requires the participant to complete a description of food intake either shortly after eating or at the end of the day. This approach requires consistent participant motivation to complete the record accurately. When using written food records, dietary information is typically collected for 3 to 7 days, which encompasses a variety of work and non-work and weekday and weekend days. One of the advantages of food records as well as 24-hour dietary recall is that they allow research participants to describe what they actually are eating. This is a great advantage for cultural groups that may have dietary foods not typically listed on food frequency questionnaires. Similar to 24-hour dietary recall, food records are useful in research projects to determine changes in average intake and macro- or micronutrient levels over a brief period.

Comparing the accuracy of assessments using 24-hour dietary recall and food records is revealing. One study in which dietary data were collected by 24-hour dietary recall and food records noted that unannounced 24-hour dietary recall (conducted by telephone) more accurately assessed changes in fat intake during a low-fat diet intervention than 4-day food records (Buzzard et al., 1996). In this study, several areas of measurement error were noted. First, underreporting of fat intake was noted at baseline using 24-hour recall and in multiple 4-day food records, when compared to unannounced 24-hour dietary recall. Second, a compliance bias was noted, in which participants tended to report more favourable fat intakes when recording intake for 4 days than during a

spontaneous 24-hour dietary recall (Buzzard et al.). Other researchers have noted that estimates of nutrient intake varied by 70 to 80% when compared to observed food intake (Emmons & Hayes, 1973; Krantzler et al., 1982; Schnakenberg, Hill, Kretsch, & Morris, 1981). This difference resulted primarily from omitted foods.

Underreporting of food intake and compliance bias are common sources of error when 24-hour dietary recall or food records are used. These errors occur when participants do not fully understand how to estimate portion sizes or when they provide socially desirable responses (Biro et al., 2002). To minimize such sources of measurement error, nurse researchers should use careful and consistent instructions from a trained interviewer, supplement these with printed instructions given to study participants for home use, emphasize the importance and value of the participant's actual intake, and follow up with telephone or mail reminders. In addition, use of food models during face-to-face interviews may clarify participant's perceptions of a serving size. Providing participants with a standard set of measuring devices, weighing scales, and pictures can ensure a more accurate estimate of portion size. Offering incentives and asking participants to keep food records for the minimum time necessary to obtain the nutrient information may result in a better response rate (Willett, 1998). Finally, a trained interviewer can review food records to explore any apparent omissions or overestimations.

A number of recent innovations go beyond the traditional manner of collecting food records in research. These may help to extend the reach of nutrition research and may address some of the methodological concerns related to 24-hour recall and food records. For example, mailing participants a booklet (Kolar et al., 2005) or a videotape (Timmerman & Stuijbergen, 1999) containing detailed instructions for recording food intake, questions about food-use patterns, and photographs of serving sizes, in addition to mailing measuring spoons and cups, can effectively eliminate the need for intensive in-person participant training and extensive review of records. Newer technologies, such as Web-based records or personal digital assistants (PDAs), have been used effectively to collect 24-hour dietary recall and food records (Bälter, Bälter, Fodnell, & Lagerros, 2005; Beasley, Riley, & Jean-Mary, 2005).

### ***Food Frequency Questionnaires***

Food frequency questionnaires (FFQs) are used in large epidemiological studies to assess "typical" dietary intake over a designated period. Typical FFQs consist of a detailed list of foods and a section for reporting how often each food was eaten over the selected period. The numbers and variety of foods listed in commercially available FFQs vary from only foods related to a single nutrient to more than 190 food items (Nelson

& Bingham, 1998). Examples of FFQs include the European Prospective Investigation of Cancer FFQ (EPIC FFQ; McKeown et al., 2001), the Harvard Semiquantitative FFQ (Willett FFQ; Willett et al., 1985), the NCI/Block Health Habits and History Questionnaire (Block FFQ; Block et al., 1986), and the Diet History Questionnaire (DHQ; Subar et al., 2001).

FFQs have many advantages as well as several inherent methodological drawbacks. In addition to the concerns listed in Table 2, the food items listed in FFQs must be sufficiently comprehensive to include foods containing nutrients of interest or pertinent to the disease under study and cultural or ethnic foods representative of the research population. Even with these inclusion requirements, the list must not be so long that respondents become overburdened and fail to complete the form in a thoughtful manner. Respondents must be literate in the language of the FFQ. FFQs are considered semiquantitative because perceptions of portion sizes listed (e.g., small, average, large) vary among respondents. Consumption of unlisted foods and frequency of eating seasonal foods, such as summer fruits, can lead to an inaccurate assessment of "usual" daily caloric or nutrient intake over 12 months (Willett, 1998).

FFQs developed for adult populations may not reflect typical intake during nutritionally critical periods such as childhood, adolescence, pregnancy, or chronic illness. Several instruments have been developed to assess dietary intake during childhood and adolescence (Hammond, Nelson, Chinn, & Rona, 1995; Rockett et al., 1997), during the preconception period and pregnancy (Brown et al., 1996; Forsythe & Gage, 1994; Greeley, Storbakken, & Magel, 1992; Wei et al., 1999), and in cancer patients (Ambrosini et al., 2003; Kristal, Feng, Coates, Oberman, & George, 1997). Careful validation studies must be conducted when developing a population-, disease-, or culture-specific FFQ (Margetts & Nelson, 1997; Willett, 1998). Such validation is also needed when an FFQ developed for one country is adapted for use in another.

FFQs have been used for several research purposes. Brief FFQs have been developed to screen for specific food or nutrient intake. These instruments include a limited number of items targeting different food groups such as fruits and vegetables (Jansen et al., 2004; Ling & Horwath, 1999), fat intake (Howell, McNamara, Tosca, Smith, & Gaines, 1998), or individual nutrients such as calcium (Angus, Sambrook, Pocock, & Eisman, 1989). FFQs have also been used to track usual dietary intake over a prolonged period, but these may not be useful for determining changes in dietary patterns before or after a nutritional intervention.

The uncertain validity of FFQs is perhaps the most pressing problem with this dietary assessment method. FFQs are reported to overestimate energy and nutrient intake when compared to directed and undirected

24-hour dietary recall (Castor, 1985; Sorenson, Calkins, Connolly, & Diamond, 1985), 2-day weighed food records (Sorenson et al.), 16-day weighed food records (Bingham et al., 1994), interviewer-conducted diet histories (Jain, Howe, & Rohan, 1996; Sorenson et al.), and 7-day food records (Jain et al.).

More recently, nutrient analysis using FFQs has been compared to quantitative biochemical markers. Seven-day (McKeown et al., 2001) and 4-day (Rothenberg, 1994) food records are more closely associated with urinary nitrogen levels than FFQs. In a recent epidemiological study, FFQs performed less accurately than 24-hour dietary recall in assessing energy expenditure when compared to doubly labelled water measures and to nutrient intake measured by biochemical markers (Subar et al., 2003).

In an effort to overcome underreporting and overreporting energy intake assessed with FFQs, adjustments can be applied by using the cut-off values established by Goldberg and colleagues (1991). These values are based on a ratio between the observed energy intake and estimated basal metabolic rate (EI/BMR) for a known activity level that reflects a “reasonable intake” for the individual (Becker & Welten, 2001). Data for persons reporting low levels of energy intake based on EI/BMR or “unreasonably low intake” should be excluded from analysis. Employing cut-off values may not be useful to adjust for measurement errors for within-person variations on individual nutrients and should not be used to adjust energy intake levels assessed with 24-hour dietary recall.

### ***Biochemical Markers***

In recent years, biochemical markers have been used in nutritional research as a proxy measure of energy and nutrient intake. However, several problems have been found with this approach. Availability of the nutrients is influenced by individual metabolic variations in absorption and utilization rates. For example, the amount of calcium absorbed is affected not only by calcium intake but also by current levels of calcium within the tissues (Potischman, 2003) — that is, serum calcium levels may be within normal limits despite inadequate intake if calcium deposits within the body tissues are adequate; similarly, serum calcium levels may be low despite adequate or excessive intake when calcium levels in the tissues are low, indicating greater absorption. One of the most limiting features, however, is that there is no easily applied biomarker for energy intake or the macro-nutrient composition of the diet (Winkler, 2005).

Biomarker assays can also be affected by the existence of concurrent physiological processes, such as infections, and by the presence of other nutrients that may alter absorption rates. For example, serum ferritin levels, a reliable measure of physiological response to iron supplementa-



tion in developing countries, is affected by the presence of infection, a common occurrence in anemic populations. Furthermore, ferritin levels do not accurately indicate the degree of iron deficiency in persons lacking iron stores (Mei et al., 2005). Similarly, high fibre content in foods can decrease the absorption rate of carotenoids (Potischman, 2003). (See Margetts & Nelson [1997] and Willett [1998] for a detailed discussion of biomarkers in nutritional research.)

Anthropometric assessments, such as weight, body mass index, and mid-arm circumference, also have been used in international research as proxy measures of overall energy intake (World Health Organization, 1995). Whilst these measures provide a gross estimate of total caloric intake, they do not reflect intake of specific foods and nutrients and thus cannot be used to determine precise nutrient deficiencies (World Health Organization, 1995). For many nutrients, self-report methods will continue to constitute the primary means of dietary assessment. As a result, greater attention to managing measurement error in self-report methods is warranted in research.

### **Strategies to Enhance Accuracy of Dietary Intake Measurement**

Sample biases, systematic errors in reporting, and measurement errors complicate nutritional research. Use of complementary assessment methods at multiple measurement points may lead to findings that are more reliable when considering nutritional effects on a health outcome. For example, an age- and culture-sensitive FFQ to assess typical intake, combined with concurrent 24-hour dietary recall to assess current intake, will strengthen the reliability of the findings. Creating an atmosphere that encourages respondents to report complete dietary intake without judgement is critical to maximizing honest and thoughtful participation. Incorporating innovative computer-based technology, such as the Minnesota Nutrient Data System, for data collection may increase accuracy of dietary information and enhance participant motivation (see Table 1).

In addition, use of innovative statistical approaches may more accurately identify dietary patterns that contribute to disease development. For example, in an epidemiological study designed to identify dietary patterns associated with the incidence of type 2 diabetes in Germany, Hoffman, Schultze, Schienkiewitz, Nothlings, and Boeing (2004) compared traditional principal components analysis (PCA) with the reduced rank regression (RRR) statistical approach. The researchers noted that PCA, as an exploratory data analysis approach, ignores dietary patterns that are known risk factors for a particular disease. In contrast, the RRR analytical approach evaluates variation in dietary patterns that

have known links to the disease of interest. By subjecting the same data set to these two different statistical approaches, Hoffman and colleagues explained 93% of the variation in responses to the intake of nutrients related to type 2 diabetes using the RRR method, versus only 41.9% of the predictor variance using PCA. When examining the combined effects of foods, the RRR approach identified a dietary pattern that posed a significant risk for diabetes more effectively than the more traditional PCA.

### **Measurement of Dietary Quality in Health Research**

Emerging research suggests that, in addition to studying nutrient intakes, examining human nutrition from a food-based paradigm may be an important innovation in health research (Kant, Schatzkin, Graubard, & Schairer, 2000; McCullough et al., 2002). Assessing the effect of overall dietary quality, in addition to specific nutrient levels, is consistent with a holistic approach to interventions that improve health and is a valuable approach for research in nutrition, for several reasons (Kant, 1996). First, free-living individuals have complex diets consisting of combination foods with multiple nutrients such as stews. Second, the interaction effect of nutrients, such as calcium and phosphorus or iron and folate, obscure the ability to isolate the effects of any single nutrient. Third, the metabolism of many nutrients is interdependent. Finally, dietary changes necessary to prevent disease are not isolated but involve multiple nutrients; for example, one might decrease fat intake while increasing intake of whole grains to offset colon cancer (Kant et al.). The health effects of overall dietary quality need further study; this could result in a more thorough explanation of the relationship between diet and health (Bodnar & Siega-Riz, 2002).

Estimates of individual nutrient levels are complicated by the typical intake of nutrients that are consumed in combination with others in foods, and by individual metabolic variations in nutrient absorption. Examining the effects of overall dietary quality that incorporates culture-specific foods could clarify the relationship between these foods and health. Researchers examining the influence of overall dietary quality to identify nutrition-related risk factors might consider using food-based tools such as the Canadian Healthy Eating Index (Shatenstein, Nadon, Godin, & Ferland, 2005), the US Healthy Eating Index (US Department of Agriculture, Center for Nutrition Policy and Promotion), or the Dietary Quality Index (Patterson, Haines, & Popkin, 1994). These instruments assess dietary quality within a food-based framework that acknowledges complex interrelationships among nutrients rather than the influence of specific nutrients. Applying dietary

quality indices has the potential not only to respond to issues of excessive or inadequate intake of individual nutrients or energy intake but also to improve overall health and well-being.

In conclusion, measuring nutritional intake is an essential yet challenging component of research aimed at improving overall health and disease prevention. Nurses need to be knowledgeable about the limitations of the different dietary measurement methods when involved in research that includes nutritional assessments for determining disease risk and response to treatment. Incorporating methodological innovations designed to strengthen and enhance the measuring of nutritional intakes and patterns is vital for nurse researchers involved in clinical and research programs designed to manage chronic diseases and promote health.

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### Authors' Note

Development of this manuscript was supported in part by the National Institute of Nursing Research, T32 NR 07107.

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*Résumé*

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**La recherche de modes de prestation  
des soins sensibles aux valeurs culturelles :  
les enseignements de deux communautés  
autochtones de la Saskatchewan**

**Pammla Petrucka, Sandra Bassendowski et Carrie Bourassa**

La Southern Saskatchewan/Urban Aboriginal Health Coalition est une équipe interdisciplinaire et intersectorielle de chercheurs et de communautés voués à l'étude de modes de prestation des soins sensibles aux valeurs culturelles autochtones. Prenant appui sur un modèle de recherche communautaire, on a tenu des cercles de parole auxquels ont participé les membres de deux communautés autochtones de la Saskatchewan dans le but de déterminer les éléments qu'ils considèrent comme essentiels dans la prestation de soins bien adaptés à leur culture. La triangulation et l'analyse thématique ont permis de dégager neuf thèmes initiaux et quatre grandes thématiques. L'étude présente des enseignements susceptibles de guider de futurs travaux de recherche auprès des communautés concernées et d'autres groupes culturellement diversifiés, particulièrement en ce qui a trait au savoir-faire culturel aussi bien des prestataires de soins que des services de santé.

Mots clés : savoir-faire culturel, recherche communautaire

# **Seeking Paths to Culturally Competent Health Care: Lessons from Two Saskatchewan Aboriginal Communities**

**Pammla Petrucka, Sandra Bassendowski,  
and Carrie Bourassa**

The Southern Saskatchewan/Urban Aboriginal Health Coalition is an interdisciplinary, intersectoral team of researchers and communities dedicated to exploring culturally respectful care in Aboriginal communities. Through a community-based research approach, the communities and the Coalition used sharing circles to determine the key elements that 2 Saskatchewan Aboriginal communities see as requisite for culturally competent care. Through triangulation and thematic analysis, 9 initial themes and 4 broad thematic groupings were derived. The lessons from this study could inform further research with these communities and other culturally diverse groups with respect to cultural competency in terms of both health-care providers and health services.

**Keywords:** Aboriginal health, cultural competency, community-based research

The Southern Saskatchewan/Urban Aboriginal Health Coalition, a unique research team representing a range of health, educational, and Aboriginal sectors in the Canadian province of Saskatchewan, has been involved in a project spanning nearly 2 years. The Coalition comprises researchers from several organizations: First Nations University of Canada (Regina and Prince Albert), University of Saskatchewan College of Nursing (Regina and Saskatoon), Native Access Program to Nursing (Regina), Saskatchewan Institute of Applied Science and Technology Nursing Division (Regina and Saskatoon), Regina Qu'Appelle Health Region, Standing Buffalo First Nation, and Regina Métis Sports and Culture Centre.

The idea for this research project was initiated by individuals from three organizations who met in September 2002 at a meeting of a research consortium hosted by the University of Saskatchewan. Aboriginal health was a dominant topic at that meeting, and the three shared a mutual interest in establishing culturally respectful care for Aboriginal persons in both the education of health professionals and the health-care system. This common ground led to the formation of the Coalition and to the identification of communities of interest that pre-

icated the research. The composition of the Coalition is somewhat fluid but there is a core membership of between 16 and 20. In addition, an Advisory Committee comprising nine Aboriginal people has provided direction to the research team throughout the research process. This group was essential in forming the research team and bringing the communities together. Further, the Coalition has been supported at all stages by two Aboriginal elders working collaboratively as expert advisors to both the research team and the Advisory Committee.

The early meetings of the research team were spent in thoughtful discussion of what each member knew and understood about concepts such as culturally respectful care, Aboriginal knowing and healing, Aboriginal communities, education programs for health professionals, Aboriginal pedagogy, health-care delivery, and health. As the team began to explore and trust the process, the emphasis turned to developing health-care delivery systems and education programs that would incorporate indigenous knowledge and therefore be culturally appropriate for Aboriginal people. The research questions and methodologies were determined by the Aboriginal communities that served as partners and co-researchers in the project. The initial questions focused on Aboriginal healing, culture, and ways of knowing, in order to appropriately incorporate them into the health-care system and into the education of health professionals. These initial efforts led to the ongoing research and team-building efforts reflected herein.

The focus of the research was on capacity-building and respecting cultural competency in the academic research community and two participating Aboriginal communities. The Coalition anticipated that the research would lead to a better understanding of the diversity and commonalities in the Aboriginal communities in Saskatchewan regarding culturally respectful care and its relationship to the education of health professionals. Accordingly, two distinct but related research questions were identified: 1. *How can the curricula of education programs for health professionals be made more culturally respectful for Aboriginal people?* 2. *How can health-care delivery be made more culturally respectful for Aboriginal people?*

Essentially, the research team believed that addressing the fundamental issue of culturally respectful health-professional education and health-care delivery would provide a sound foundation for research into Aboriginal health in Saskatchewan. Although all health professions are of interest to the research team, nursing programs and nursing care were an early focus. This article describes the nature of the research partnership and presents the findings of the initial phase of the partnership efforts to enhance research capacity related to cultural competence in health-professional education and health-care delivery.

## Research Context

Since late 1996, following publication of the report of the Royal Commission on Aboriginal Peoples, the emerging paradigm for Aboriginal health has been developing. The 2002 document *Building on Values: The Future of Health Care in Canada* recommends “new initiatives to improve timely access to care, to enhance the quality of care the system provides, a more co-ordinated approach to health human resources planning, and a special focus on the health needs of Aboriginal peoples” (Romanow, 2002). It also cites the importance of addressing Aboriginal health-care needs and involving Aboriginal people in that process.

Health disparities between Aboriginal people and other Canadians are significant, persistent, and unacceptable. According to Romanow (2004), the disparities in life expectancy, prevalence of infectious diseases, rates of chronic disease (especially diabetes), and trends in mental health (i.e., suicide, substance abuse) require immediate and innovative interventions. Much of the research has addressed on-reserve Aboriginal people. The Canadian Community Health Survey found that approximately 800,000 Aboriginal people in Canada are living off reserve (Sibbald, 2002). Aboriginal people, both on and off reserve, have frequent interactions with the formal health-care system in relation to their self-care and informal caregiving roles, but little voice in articulating appropriate approaches to care, the incorporation of culture into the healing process, or approaches to teaching health-care practices that are consistent with Aboriginal ways of knowing (Sibbald).

Saskatchewan’s health-care system has been undergoing reform as it attempts to respond to fiscal and human resources challenges and to meet the needs of the population. *The Action Plan for Saskatchewan Health Care* identifies the challenges of addressing the health-care needs of Aboriginal people in the province (Government of Saskatchewan, 2001).

Saskatchewan has the highest percentage of Aboriginal people of all Canadian provinces — 13.5% of the total population — trailing only the northern territories (Statistics Canada, 2001). Yet self-identified Aboriginal health professionals continue to be underrepresented in the work force. Within the Saskatchewan health-care sector, only 5% of employees (approximately 1,800) self-identify as Aboriginal, and, significantly, most of those are in entry-level positions (Saskatchewan Association of Health Organizations, 2004). According to the Saskatchewan Job Futures Web site (<http://saskjobfutures.ca>), the following percentages of health-care personnel self-identify as Aboriginal: support staff (i.e., orderlies, nurse’s aides), 6.8; licensed practice nurses, 5.6; nurses and psychologists, 3.7; dental assistants, 3.1; family physicians, 0.9; occupational and physical therapists, 0.

The fall 2004 First Ministers' and Aboriginal Leaders' Special Meeting called for the development of a blueprint recognizing and respecting the unique, specific, and diverse needs of all Aboriginal peoples, including access to health care and health professionals (Office of the Prime Minister [OPM], 2004). The September 2004 federal budget included \$100 million for an Aboriginal Health Human Resources Initiative to increase the number of Aboriginal people choosing health professions; adapt current health-professional curricula for a more culturally sensitive focus; and improve the retention of health-care workers serving all Aboriginal peoples, including First Nations, Inuit, and Métis (OPM; this expenditure was confirmed in February 2005).

Education programs for health professionals, including nursing programs, have made strategic efforts to recruit and retain Aboriginal students, to promote culturally respectful teaching and learning environments, and to develop research opportunities for Aboriginal nursing students and graduates. Aboriginal people in Saskatchewan have become the focus of formal health-professional education, as evidenced by the growing number of Aboriginal students enrolled in nursing (University of Saskatchewan/Saskatchewan Institute of Applied Science and Technology), targeted bursaries for Aboriginal people entering the health professions (Saskatchewan Health), and dedicated seats for Aboriginal students in selected programs (University of Saskatchewan). However, persistent gaps and the need for further development of the education programs have been identified; the programs have not sufficiently addressed the need for culturally respectful health and education systems for Aboriginal people and Aboriginal ways of knowing (Roberts & Nagy, 2002; University of Saskatchewan – Health Sciences Deans Committee, 2004).

### **Literature Review**

The challenge of achieving cultural competence within the health-care sector is a multi-faceted challenge. According to Betancourt, Green, and Carrillo (2002), the complexity of cultural competence is evident in the actions of legislators who seek policies, administrators who strategize, academics who ask how to teach students in the health professions, and providers who struggle to deliver a culturally competent standard of care. What constitutes cultural competence remains unclear and is further confused by the interchange of the term with others, such as cultural sensitivity, cultural/transcultural awareness, and cultural knowledge (Adams, 1995; Texas Department of Health, National Maternal and Child Health Resource Center on Cultural Competency, 1997). This literature review looks at cultural competence as well as the knowns and

unknowns of cultural competence in terms of the delivery of health services and the education of health professionals.

### ***Cultural Competence***

According to Campinha-Bacote (1988), cultural competence is not an end in itself but an ongoing process of seeking cultural awareness, cultural knowledge, cultural skill, and cultural experiences. This definition has been extended to include behaviours, attitudes, and policies adopted by the system, agencies, or professionals so as to function effectively in cross-cultural situations (Cross, Bazron, Dennis, & Isaacs, 1989; Isaacs & Benjamin, 1991).

Cultural competence in health care is the ability of the system to provide care to clients with diverse values, beliefs, and behaviours, which means tailoring delivery to meet their specific social, cultural, ethnic, spiritual, and linguistic needs (Jecker, Carrese, & Pearlman, 1995). Applied to Aboriginal and other potentially vulnerable populations, culturally competent care has three attributes: cultural appropriateness (Jecker et al.; Lavizzo-Mourey & Mackenzie, 1995), cultural accessibility (Association for Older Americans, 2001), and cultural acceptability (Cross et al., 1989; Lavizzo-Mourey & Mackenzie).

Cultural competence is a developmental process that evolves over time. Both individuals and organizations are at various levels of awareness, knowledge, and skills along the cultural competence continuum (Cross et al., 1989; Issacs & Benjamin, 1991). Cultural competency is “a set of academic and personal skills that allow (health professionals) to increase our understanding and appreciation of cultural differences between groups” (Cross et al., p. 18). It can be achieved only by integrating knowledge with respect to individuals and groups into specific practices and policies applied in appropriate cultural settings (Antone, n.d.; Taylor & Brown, 1997).

The most common source of cross-cultural conflicts and problems is a lack of cultural education on the part of non-Aboriginal institutional staff and professionals. This is not to suggest that sincere efforts have not been made; rather, this realization points to the factors that have complicated otherwise well meaning program attempts and developments. (Ellerby, 2001, p. 6)

Health professionals must make a commitment to learn about cultural concepts, become aware of cultural values, and continually strive to develop and improve their cultural competence (Meleis, 1999; Swiggum, 1995; Wenger, 1999). A culturally competent professional establishes positive helping relationships, engages clients, and improves the quality of services that he or she provides (Antone, n.d.; Cross et al., 1989).

### **Summary**

The literature review yielded several working definitions of cultural competence, nearly all touching on the need for health-care systems and providers to be aware of and responsive to the cultural perspectives of patients. It is evident that the achievement of cultural competence depends on fundamental individual, collective, and systemic change.

## **The Research Process**

### **Methodology**

The initial research challenge for the Coalition was to identify appropriate ways of undertaking research with Aboriginal communities and to explore ways of improving the delivery of health services and the education of health professionals through the use of inclusive and culturally respectful methodology. Such methodology is necessarily based on the application of practical knowledge to locally defined issues and problems such that it leads to long-term improvement in the quality of life for a group of people.

### **Community-Based Research**

*The Action Plan for Saskatchewan Health Care* (Government of Saskatchewan, 2001) identifies the importance of community involvement in determining priorities and appropriate health-care approaches. Thus the study invoked community-based research rooted in the tradition of participatory action research. This model seeks to engage community members as equal and full participants in all phases of the research process. The two communities involved throughout the project were identified through previous relationships with members of the team, became full participants on the research team, and secured volunteers for the Advisory Committee. This strong linkage was imperative in establishing the long-term involvement anticipated for the project in light of the *Action Plan's* emphasis on community-based, long-term health outcomes.

### **Site Selection**

Two sites were selected based on the research team's mandate to include one First Nations community and one Métis community as well as one rural and one urban site. In addition, the participating communities had to be within driving distance of Regina and had to be part of the Regina Qu'Appelle Health Region (one of the research partners).

### **Data Collection**

On the advice of the Advisory Committee, the study used sharing circles in each community. The sharing circle, a traditional Aboriginal oral means

of sharing information and stories, was proposed as a culturally appropriate alternative to the focus group (Berthelette, Raftis, & Henderson, 2001). Smith (1999) describes the need to reclaim the authority of the oral tradition:

Indigenous peoples want to tell our own stories, write our own versions in our own ways, for our own purposes...a need to give testimony to and restore a spirit, to bring back into existence a world fragmented and dying. (pp. 28–29)

According to the Coalition for the Advancement of Aboriginal Studies (CAAS) (2002), the sharing circle symbolically and functionally reinforces, for all involved, the notion that “every issue has many aspects that can be viewed from both the inside and the outside and, at the same time, everything is connected” (p. 17). Central to the sharing circle is the respectful and equitable environment that it creates and perpetuates. Nabigon, Hagey, Webster, and MacKay (1998) view the sharing circle as a process that enables information-sharing and connecting and that seeks balance and harmony. Every individual decides whether and when to contribute, recognizing that active listening is an important feature of the sharing circle (CAAS, 2002). Further, all participants endeavour to stick to the matter under discussion, thus honouring the time and commitment of the other people present (CAAS).

The sharing circles served to affirm the communities as co-researchers. A total of seven sharing circles were held, either within the Standing Buffalo First Nations community or at the Regina Métis Sports and Culture Centre, between February and April 2004. Membership and participation were voluntary at each site. The groupings were subdivided according to gender and age to allow for the inclusion of a gender perspective and a youth perspective. The result was two sessions for men, three for women, one for boys, and one for girls, each with between six and nine participants. The gender/age segregation was undertaken on the advice of the elders, who stressed the variance among the groups and the likelihood of achieving optimal sharing with homogeneous groups.

Each session was guided by an elder and included a facilitator and a professional transcriptionist (note-taker/recorder) from outside the community. Each session opened with a prayer and included the sharing of food. The sharing circles followed a semi-structured instrument that was endorsed by the Advisory Committee. The instrument was used as a guide rather than as a script, enabling the facilitators to promote the openness and connectedness of a sharing circle environment. The questions were open-ended — for example, What makes you healthy? What makes your community healthy? The sessions lasted from 60 to 90 minutes and were audiotaped. Confidentiality was ensured in the tran-



scripts and recorded notes, with no names or personal identifying information being used.

### **Data Analysis**

The choice of research questions, interview guide, research sites, and research participants is an essential aspect of data analysis (Miles & Huberman, 1994; Patton, 1990). Simultaneous collection and analysis of data was an important feature of this study, enabling the research team to focus and direct the data-collection process more effectively.

**Thematic analysis.** The individual transcripts were analyzed using an iterative process: each transcript and associated recorded notes were reviewed as received. Themes were derived using the 13 strategies for extracting meaning as described by Miles and Huberman (1994). Thematic analysis of the first two transcripts and recorded notes yielded a tentative list of themes. This preliminary list was taken to the research team for process, content review, and resonance with the research experience. It was considered a “straw man approach” in order to begin the dialogue on the analysis phase and to provide an opportunity to develop research capacity with students and other research neophytes within the team. This initial list of themes was fairly detailed and was acknowledged as representing only the two transcripts reviewed. As the list was reviewed, all transcripts (including the two original ones) were considered in subsequent iterations and in the triangulation process used in this study.

Data triangulation, a means of enhancing credibility, serves to deepen and broaden the understanding of the phenomena of interest. The use of multiple sources of data in evaluating a phenomenon strengthens the rigour of the investigation. The transcripts and field notes from the seven sharing circles, minutes of meetings of the research and advisory teams, and literature-based evidence were triangulated in this study.

**Member checking** is an essential strategy for critical observation and interpretation of research data. In this study, member checking served to strengthen the inclusiveness requirement, hone the research skills of team members, and ensure cultural respectfulness in the interpretation phase of the study.

Upon completion of the analysis and receipt of the Advisory Committee’s endorsement, a subset of the research team (four members) reviewed the transcripts using the thematic template. This process led to a consolidation of the initial themes. The level of agreement with the coding and the indication of inclusiveness of the themes by the reviewers consistently led to increased trustworthiness of the final coding. The final thematic list was endorsed by the Advisory Committee.

## **Ethics**

One critical challenge in this research relates to the ethics of seeking information from the Aboriginal communities about Aboriginal ways of knowing, healing, and culture. Members of the research team expressed concern about whether “sacred knowledge” can be shared — a perplexity that continually challenged the adherence of research decisions to culturally respectful ethical principles. The project received ethics approval from three partnering agencies: the Regina Qu’Appelle Health Region, the University of Regina, and the University of Saskatchewan. Each participant was asked to complete and sign a consent form that also delineated the opportunity to withdraw one’s participation without penalty. Consent in this context was heavily rooted in trust, which is achievable only through prolonged engagement with the community. The issue of confidentiality was addressed with the participants both in terms of the researchers’ commitment to present findings in a non-identifiable format and in terms of the participants’ commitment to refrain from sharing comments or confidences outside of the sharing circle environment.

The ethics approval process was a unique challenge, as the partners adopted the Ownership, Control, Access, and Possession (OCAP) principles (Schnarch, 2004) as a framework for ethical research with Aboriginal communities. These principles configure a self-determination approach to research involvement by Aboriginal communities. This approach was essential in negotiating elements of ethics with the communities and the participants. However, the requirement to adhere to academic ethics approval was also imperative, and at times this second mechanism was confusing to the community stakeholders. This experience highlighted the lack of a culturally appropriate ethics approval mechanism.

## **Findings**

The initial analysis of two transcripts yielded nine tentative themes with a wide array of exemplars (see Table 1). These themes were rooted in three assumptions: (1) the determinants of health are foundational aspects of working with Aboriginal communities; (2) institutional racism must be acknowledged and addressed; and (3) vulnerability (i.e., over-use of Aboriginal communities for research purposes) and potential misuse (culturally disrespectful use) of information must be recognized and targeted as a part of capacity-building. These assumptions were articulated by members of the community and members of the research team.

The initial themes elicited challenging reflections within the analysis process. For example, the transcendence of time was described as an orientation and re-orientation embracing the recognition of time as

**Table 1** *Initial Themes and Exemplars*

Theme	Exemplar
Transcendence of time	(Aboriginal people) have lived a long life in a very short time (male participant)
Experience of choice, loss, and consequences	We lost our understanding of our old morals and values...loss of language, loss of identity; need to understand we are a proud people — proud of being Indian and of being Dakota (male participant)
Invoking of tradition	Can't take medicines into public places, have to keep them private; there is a lot of teaching behind this (elder)
Teacher must be taught/ caregiver must receive care	The family had an elder come in and pray...nurse would not allow it...doctor allowed family and elder to do it (elder)
Value of respect	I think it's good that they get to know the culture so they won't do nothing to offend other people, I guess, so they will show respect for those cultures (youth participant)
Non-hierarchical relationships	We are not going to the health system and seeing ourselves there — that needs to change (female participant)
Sacredness of water	Water is the first medicine (elder)
Way of life/living	Everyone is looking for spirituality... they need to take the time to understand it, can't learn these things out of a book — it is a way of life (elder)
Value of truth	In the old days we didn't have to sign anything because we told the truth; now we lie so we have to sign [a consent form]? (elder)

simultaneously reflecting past, present, and future. Participants emphasized the cyclical nature of life and the interconnectedness of generations that somehow transcend time. Much discussion about the experience of choice, loss, and consequences was rooted in the legacy of colonization. This theme evoked extensive discussion of control, self-image, and self-worth. The invoking of tradition highlighted the difference between what is public and what is private in traditional practices, such as issues related to spirituality. The elders were pivotal in the consideration of the appropriateness and parameters of sharing traditional practices and knowledge. A theme encapsulated in the phrase “the teacher must be taught/the caregiver must receive care” intimated that there is reciprocity in all aspects of the relationship such that those providing knowledge must also be receiving knowledge. The participants expressed the view that although professionals are recognized as knowledgeable, they have a unique opportunity to experience complementarity with Aboriginal/traditional ways of knowing. The value of respect was highly regarded by the participants in terms of mutual understanding, valuing, listening, and cultural openness. Non-hierarchical relationships within the research project were viewed as culturally desirable and requisite to moving forward. Participants indicated that power distinctions and devaluing of certain groups is a significant barrier to culturally competent care. A discussion of the meaning of water was replete with symbolism related to medicine, life-giving and life-sustaining attributes, and environmental responsibilities. The sacredness of water for individual, community, and global peoples is fundamental to the Aboriginal context of health. According to participants, health is holistic and is achieved as a way of life/living. The theme highlighted the individual and communal paths to wellness. Finally, the value of truth was a recurrent theme relating to openness, transparency, honesty, and trust. Participants perceived a high level of distrust and misinformation by both Aboriginal and non-Aboriginal partners in the current health-care environment.

The analysis of all seven transcripts led to a regrouping of thematic findings into four areas: trust, respect, communication, and understanding. The final broad thematic groupings were derived and viewed as conveying meaning and facilitating knowledge transfer to the community participants. Throughout this process there was consensus that these four thematic groupings fully encapsulated findings from the various data sources. In fact, the research team felt that the preliminary themes were subsumed under these broader thematic groupings, as reflected in Table 2. Some preliminary themes (i.e., way of life) were seen as fitting into more than one thematic grouping; however, this relationship was beyond the scope of this study and will be explored in subsequent projects.

**Table 2 Relationships of Final Thematic Groupings and Preliminary Themes**

<b>Thematic Grouping</b>	<b>Representative Preliminary Themes</b>
Trust	Experience of choice, loss, and consequences Non-hierarchical relationships Value of truth
Respect	Value of respect Sacredness of water
Communication	Teacher must be taught/ caregiver must receive care
Understanding	Transcendence of time Invoking of tradition

These initial findings provide significant insights with regard to the two study questions. The final themes were seen as guiding principles for the establishment of culturally competent curricula and health services. For example, respect as a theme encompassed cultural aspects of respect, holistic understanding, cultural symbolism, and shared meaning. These elements are seen as critical to achieving individual and collective cultural competence in health care. The research team continues to review the data for community-, gender-, and age-related trends. The research team and the community are currently seeking ways of interpreting and applying these themes in terms of the research questions and future research directions.

### **Lessons Learned**

This research process is a journey that has taken many paths and included many co-travellers. We have learned the importance of involving the community from the beginning, in all aspects of the research. The advice and guidance of elders are critical to the development of partnerships and the research process. Members of the community provide direction with respect to process and structures (i.e., sharing circles). The Coalition found that working in partnership takes additional time and resources, which must be considered in setting timelines and in organizing the research. For example, obtaining ethics approval from three organizations was time-intensive but critical to the success of the project. The use of a community-based approach to research was found to be appropriate and

facilitative. It highlighted the strengths of each subset of the research team and elicited potential areas for skills-acquisition with regard to all members of the team. This strategy explicated a need to work towards the identification and utilization of Aboriginal research methods that are rooted in traditional ways of knowing.

The dissemination strategy was critical to the learning process. Essentially, we learned that the findings of this research must be managed and circulated in a culturally appropriate manner, as the OCAP principles dictate that they ultimately belong to the communities. The community participants, the research team, and the Advisory Committee all had distinct information and communication requirements that needed to be addressed throughout the study. The research team, with the assistance of a summer student, developed a communiqué highlighting the findings and the next steps and disseminated it to the communities concerned.

A number of possible limitations of the study were identified. The findings are applicable to the specific communities and the participants from those communities and should not be considered generalizable. The presence of elders in the sharing circles may have influenced the viewpoints expressed by participants. The research did not accommodate dialogue in traditional languages, which may have limited the sharing and/or altered the meaning of the content.

The research team is committed to continuing its involvement with the two communities, working to develop research capacity and to more fully understand cultural competency in terms of both health-care providers and health services. At Standing Buffalo First Nations, the intention is to proceed with an integrated research and clinical project that will introduce students in nursing and allied health programs to culturally competent initiatives. The Regina Métis Sports and Culture Centre will be involved in a project aimed at building community research capacity and developing strategic priorities for the community related to individual, family, and community health. The research team continues to seek paths to an enhanced understanding of cultural competency and remains open to working with other culturally diverse groups towards the ultimate goal of culturally appropriate health care.

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University of Saskatchewan; Rick Kotowich, Regina Qu'Appelle Health Region; Herman Michel, First Nations University of Canada; Esther Sanderson, First Nations University of Canada; Gail Starr, First Nations University of Canada; Floralyn Wessel, Nursing Division, SIAST, Regina; Norma Wildeman, Nursing Division, SIAST, Regina.

The Advisory Committee consisted of the following members: Elder Ken Goodwill, Standing Buffalo First Nation; Elder Betty McKenna, Moose Jaw; Ken Akan, Regina; Bev Cardinal, Regina; Gail Starr, Starblanket First Nation; Nora Weber, student, Nursing Education Program of Saskatchewan; Rozella McKay, Standing Buffalo First Nation; Lea Beige, Regina Métis Sports and Culture Centre; Chief Rodger Redman, Standing Buffalo First Nation.

This project received financial assistance from the Prairie Women's Health Centre of Excellence, the Women's Health Bureau of Health Canada, and the Indigenous Peoples' Health Research Centre.

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## Happenings

# **Eureka! A New World of Discovery in Nursing at the McGill University Health Centre**

**Judith A. Ritchie, Jane Chambers-Evans,  
Lily Chin-Peuckert, Jan Lariviere, and Patricia Rose**

“Aha! I’ve figured it out!”

Since 2002, the Eureka! Fellowship in Nursing Research at the McGill University Health Centre (MUHC) has provided four clinicians with the time to ponder their clinical puzzles and seek better ways of caring for patients and their families. These four fellows have been able to take the time to make discoveries through clinical nursing research that have led to changes in nursing practice, education, and policy. The fellowship provides a full salary with benefits for 1 year and mentorship by an experienced researcher at the MUHC in order to carry out a research project. The four nurses who have held the fellowship completed projects that reflect the diversity of nursing and nursing research. We will briefly describe the types of projects that have unfolded so far during the Eureka! Fellowship year.

This fellowship is a unique opportunity for nurses who are passionate about finding answers to their clinical questions. It is a gift of time that enables the nurse to pursue a researchable question with the time and support needed to complete the project — all the way to preparing a manuscript for publication.

The Eureka! Fellowship in Nursing Research at the MUHC was founded with the generous support of Richard and Satoko Ingram of the Newton Foundation and the foundations of the Montreal General, Royal Victoria, and Montreal Children’s hospitals. It has been made possible because of the importance that these foundations attach to nursing and to the essential growth of nursing research.

Applications are reviewed by an interdisciplinary committee that includes researchers, clinicians, administrators, and a community representative. The successful candidate presents a high-quality, innovative

protocol with a strong research design that is relevant to clinical practice, has the potential to change practice, and can be completed in 1 year.

### **Eureka! Moments Leading to Research Questions**

In the case of all four fellows, a particular clinical situation had lit their fire and made them pursue a research application. Sometimes they reflected aloud on the situation and were “gently” encouraged by their Associate Director of Nursing. In each instance a comment crystallized the stimulus to pursue an answer through research.

Jane Chambers-Evans, a Clinical Nurse Specialist in intensive care, received a referral of a family having to make an end-of-life decision on behalf of their loved one. The referral was accompanied by the exasperated comment “This family just doesn’t *get* it!” For Patricia Rose, also a CNS in intensive care, the stimulus was ICU nurses complaining to her, “We are soooo tired of transferring patients upstairs and having nurses...say we don’t take good care of our patients just because the patient developed a pressure ulcer in ICU.” In the neonatal clinic, Jan Lariviere was puzzled by the dumbfounded expression on a mother’s face — as if to say, “Why on earth would I do that?” — when asked if she read to her 1-year-old child. While administering urodynamic tests, Lily Chin-Peuckert heard the children say, “That’s cold!” and began to wonder about the possibility of a different approach.

All four nurses were stimulated by those Eureka! moments to reflect on the comments they heard. They asked themselves, Why is this happening? What if we tried something different? Their reflections led to the following four research questions:

- What is the experience of those who have to make end-of-life decisions on behalf of others?
- What factors put critically ill patients at risk for developing a pressure ulcer?
- Does a nursing intervention encouraging parents to read to their infants in the neonatal intensive care unit result in parents reading more to their infants and having more positive parent-infant interactions after discharge from the NICU?
- What is the difference between two consecutive urodynamic tests performed on the same child? Does warming the filling solution during urodynamic testing have an effect on bladder capacity and bladder stability in children?

Working with a research mentor, the fellows developed their respective research approaches and protocols. As shown in Table 1, their methods reflect the nature of the state of knowledge, the type of question, and the diversity of approaches that mark research in nursing.

**Table 1 Research Question, Design, and Approaches**

<b>Question</b>	<b>Design</b>	<b>N</b>	<b>Approaches</b>
Experience of making end-of-life decisions	Qualitative interpretive phenomenology	8	In-depth interviews Interpretive analysis of themes and ideas: <ul style="list-style-type: none"> <li>• crafting narratives</li> <li>• participant validation of narratives</li> </ul>
Predictors of pressure ulcer in critically ill patients	Tool development	111	Item generation and reduction Literature, observation, focus groups Testing of 36-item scale through observation up to day 8: Braden scale, new scale, skin assessment
Parental reading in NICU	Non-randomized trial Historical control All participants blinded to the main outcome (reading)	116	Comparison of two groups 3 months post-NICU discharge: <ul style="list-style-type: none"> <li>• group demographics</li> <li>• parenting activities, reading habits, and parental stress evaluated by standardized questionnaires</li> <li>• thematic analysis of response to one open-ended question about reading</li> </ul>
Temperature of solution in urodynamic testing	Randomized controlled trial Crossover design	91	Two consecutive fillings with body temperature and room temperature saline (random order). Measure: <ul style="list-style-type: none"> <li>• bladder capacity and stability</li> <li>• child preference</li> </ul>

## Results

The studies all yielded important findings that have had an impact on practice. The findings are as follows:

- People making end-of-life decisions for a loved one have common areas of concern, such as needing individualized information, struggling to set aside one's own convictions at decision-making time, and above all wanting to preserve the dignity and identity of the patient. The surrogate decision-makers underwent a four-phase process in making a decision.
- There are 15 items that best predict pressure ulcers in the critically ill. This 15-item scale is more sensitive than the Braden Scale (Bergstrom, Bergen, Kemp, Champagne, & Ruby, 1998; Rose, Cohen, & Amsel, 2006) in this population, and equally specific. In other words, the 15-item scale is better than the Braden Scale in predicting which patients will develop pressure ulcers. The two scales perform equally in predicting which patients will *not* develop a pressure ulcer.
- Parents who received the reading intervention reported a significantly higher rate and frequency of reading. A significant number of parents reported that reading made them feel closer to their baby and that it was an enjoyable activity. The parents indicated that reading to their infant both in the NICU and at home increased their sense of control, their sense of intimacy with their infant, and their sense of normality, as well as humanizing the situation.
- While there was a significant difference between room-temperature and body-temperature infusions on the urodynamic test results, the magnitude of the difference was not clinically significant. The children differentiated between the temperatures of the two solutions but did not have a preference.

## So What?

Considering the substantial investment of time and money, what difference have these findings made in the day-to-day work of nurses and others at the MUHC?

### *End-of-Life Decision-Making*

- The findings have opened the door to change in practice. For example, discussions at the bedside now include family perceptions about the meaning of illness.
- The findings have been used as a basis for building process-oriented end-of-life policies.

- The findings have been used as a basis for interdisciplinary teaching sessions in the McGill network and in the ethics education in nursing curriculum at the baccalaureate and master's levels.

### ***Risk Assessment for Pressure Ulcers in Critically Ill Patients***

- The Rose Scale is a reliable and valid scale for assessing the risk for pressure ulcer in critically ill patients. It requires further testing before it is ready for implementation.
- Nurses working in other ICUs within the MUHC have expressed keen interest in the scale; they want to know when it will be ready for use.
- Having witnessed nursing research in action, ICU nurses now integrate it into their daily practice; for example, nurses have spontaneously approached the researcher about potential subjects.

### ***Parental Reading to Infants in NICU***

- The reading program is now a standard intervention in the NICU and funding has been secured to continue the program.
- Families continue to relate stories about what it means to them to be able to “do something normal” in the NICU.
- A pilot project is underway in four pediatric clinics to promote parental reading to children up to 6 years of age.

### ***Urodynamic Testing Study***

- The study provided evidence to support the use of room-temperature solutions for bladder-filling tests in children. Therefore, no change in practice is necessary.
- A single filling test is needed in the vast majority of children.
- Patient suffering is reduced when only one filling test is performed.
- The results represent a savings in nursing time and money, in terms of repeating bladder-filling tests and warming saline.

### ***Being Mentored***

For all four clinicians, the fellowship represented a gift of time. It allowed them to translate their clinical observations into a research study and to work on the project full time. They describe it as a rare gift and a privilege to experience the research world and to grow in new directions. In addition to their own intelligence, skills, clinical and life experience, and determination, mentoring of inexperienced researchers was a critical component of the fellowship. All four fellows were mentored by experienced researchers within the McGill network: Jane Chambers-Evans by Dr. Frank Carnevale, Patricia Rose by Dr. Robin Cohen, and Lily Chin-Peuckert and Jan Lariviere by Dr. Janet Rennick.

The fellows describe the roles and influences of their mentors:

*Offered encouragement, guidance, provided resources, and challenged my mind.*

*Supported my learning and research activities.*

*Was sure that I could do it, so I began to believe I could as well.*

*Until this project, matching a research question to a methodology and actually seeing how a theory guides your questioning and analysis remained intellectual conceptions learned in school.*

*Daily contact with seasoned researchers allowed me to build my knowledge of the process and politics of research.*

### **Eureka Moments and Personal Highlights**

The fellowship year brought many lessons, or what the fellows call “Eureka! moments,” beyond the development of knowledge and skills in clinical research. These included insights into the challenges of practice as the nurses stepped back and looked at their practice with fresh eyes. One fellow was moved by the willingness of families to participate in her study:

*I developed an appreciation for nurses performing technical procedures and diagnostic tests. I stood in awe as these nurses explained, taught coping strategies, and coached frightened children and parents through a highly invasive test. The 96% acceptance rate to participate in the study was overwhelming. Families were willing to help in any way they could.*

Another was moved by the response of parents and nurses to the intervention itself:

*A parent described her first visit to the NICU and not knowing what to say or do, but the nurse offered her a book and “then the words came.” She talked with other parents who planned to read to their child in order to give the child every opportunity to do well, or who had seen that her reading to the baby in the hospital had calmed the baby and reading was now a favourite activity at home.*

Some Eureka! moments were ones of insight into the academic aspects of the nurse’s role in a large academic health centre. For instance, the privilege of being removed from the challenges of daily practice for a year allowed them to discover how much could actually be accomplished given the time and space to focus.

The actual experience of data collection also provided important lessons:

*I was impressed by the “power of the interview” in a qualitative study. All of my participant group members were grieving the loss of a loved one within the last 6 months. Many said they still reviewed the sequence of events every day. Somehow, telling their story with a purpose helped them in a different way. It reminded me of the privilege and the responsibility we have as researchers to ensure that our processes are ethical and compassionate.*

Others were moments of pride. To their amazement, fellows have been approached to discuss their findings with nurses (“She had actually read it!”) and with researchers in the field in other countries. They have also been approached to have their study included in a systematic review or for “permission to use my scale to collect data in an RCT they will be conducting.” They have had abstracts accepted at large international meetings and manuscripts accepted for publication in prestigious journals (Chambers-Evans & Carnevale, 2005; Chin-Peuckert et al., 2003; Chin-Peuckert, Rennick, Jednak, Capolicchio, & Pippi Salle, 2004; Lariviere & Rennick, in press; Rose et al., 2006). Finally, three of the four fellows have already received both local awards and major international and interdisciplinary awards for their work.

- Patricia Rose won the National Pressure Ulcer Advisory Panel’s New Investigator Award for outstanding achievement in clinical or laboratory research. “Recognition at their international conference was an honour and a complete shock,” she says. “Since then, the homage paid to me by my MUHC colleagues has been extremely gratifying and humbling.” Rose also won the 2007 Lorine Besel Award for Nursing Leadership at the MUHC’s Royal Victoria Hospital site.
- Jan Lariviere was awarded the Award of Excellence for Nursing by the Montreal Children’s Hospital Foundation, based on nominations by peers, members of the interdisciplinary staff, and parents. The award provided partial funding for the pilot reading project in clinics and helped her to secure other grants.
- Lily Chin-Peuckert won the coveted Clinical Research Prize in Pediatric Urology at the American Academy of Pediatrics Meeting. After the award presentation, Dr. Stuart Bauer (to whom Chin-Peuckert refers as one of the “Fathers of Urodynamics”) shook her hand and said, “Well done.” She was also awarded the 2007 Montreal Children’s Hospital Award of Excellence for Professional Development as a “role model for evidence-based nursing practice.”

The year of research was not a year without challenges. The first challenge for each of the four nurses was to settle on a starting date for the fellowship, as it is not easy to replace skilled and experienced clinicians



in their clinical field. Other challenges related to data collection. For example, after a fairly lengthy period of data collection, Chin-Peuckert discovered a problem that resulted in the need to recruit more participants. "When faced with a problem of temperature calibration halfway through data collection, I was in total despair. I was forced to repeat the study. In hindsight, the setback helped to strengthen the final results." The fellows also found it difficult to move out of their usual clinical roles.

### Conclusion

At the beginning of this innovative program, many were dubious about its potential. Some worried that nurses lacking sufficient preparation in research would not be doing research at all. Some worried that clinicians might not be interested in conducting research. The success of the Eureka! program is evident. The question concerning clinician interest is best answered in a comment by Rose: "I really didn't think I had what it took to do clinical research. I've learned how wrong I was, and now am able to say that I've caught the research bug."

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## **CJNR Reviewer of the Year: Dr. Sally Thorne for the Year 2006**

The time has come once again for us to choose, from among all our reviewers across Canada and the world, one for special recognition. As our editorials over the last few years have made clear, we are well aware that the quality of the articles in *CJNR* hinges on the time and energy that reviewers put into helping us and the authors get the right articles into print and making sure that those articles are as strong as they can be. In selecting a Reviewer of the Year, we look for someone who has consistently responded to our requests to read and comment on submitted papers, but also someone who has written particularly helpful, high-quality reviews over the preceding year and who has been supportive of *CJNR*'s mission over the long haul.

This year, we found all of those qualities in Sally Thorne, PhD, RN, FCAHS, Professor and Director of the School of Nursing at the University of British Columbia in Vancouver. Dr. Thorne's research focuses on the human experience of chronic illness and cancer, especially as it intersects with the structural and ideological underpinnings of the health-care delivery system. Her active community involvement helps her scholarship to bridge the gap between the theoretical enterprise and social action and policy processes. Dr. Thorne is an expert in the application of qualitative research methodologies to health and health-care problems, and of late she has been analyzing the nature of knowledge claims in evidence-based health-care decision-making. She is both a longstanding contributor to Canadian nursing and a key figure in nursing knowledge internationally. For decades Dr. Thorne has been publishing articles and books that have been read by students and scholars around the world. Her productivity and her passion for nursing science are legendary. That this senior, very busy scholar and director of a leading nursing school continues to review for us speaks volumes about her commitment to scholars at all stages in their careers, to *CJNR*, and to the Canadian nursing research community. In fact, Dr. Thorne has twice served as Guest Editor for *CJNR*'s focus issue on Chronic Illness.

Our experience and the literature on peer review show that extensive research experience and a long track record in publishing are no guarantee that a reviewer will write complete, helpful reviews. Dr. Thorne, however, brings the full breadth of her expertise to the task of reviewing. Her reviews are detailed, thoughtful, scholarly, and unfailingly collegial. Here, in Dr. Thorne's own words, are her sources of satisfaction as a reviewer:

For me, reviewing is an opportunity to enter into a conversation with authors, helping them appreciate the effect that their arguments have on readers and encouraging them to strive toward higher levels of clarity and coherence. While the discovery of a truly wonderful submission is a reviewer's delight, some of the most satisfying experiences derive from finding the "teachable moment" within a struggling submission such that the critical review makes a genuine contribution to the development of a successful paper.

On behalf of the entire team at *CJNR*, I'd like to thank Dr. Thorne for her exemplary reviews, her support for our journal, and her willingness to fit us and our authors into her busy schedule and her exceptionally rich career.

**Sean P. Clarke**  
**Associate Editor**