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Ingram School of Nursing, McGill University

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EDITORIAL

Rogue Publishing, Journal Business Models, and the Future of the Middle Tier

Publish or perish — the imperative for scholars to demonstrate ongoing productivity in terms of articles (and, in some fields, monographs or books) in order to be hired, to be promoted, or sometimes even to keep one's position — has long been a feature of life in universities and research institutes. And while the standards vary slightly across disciplines, institutions, and regions, there is evidence that the pressures have been intensifying. There are many reasons for the trend, some that go well beyond the scope of this editorial. They involve a host of decisions taken over many decades that have led to competition among both individuals and institutions in terms of measurable outputs. The novice academic realizes early on that to never publish or to stop publishing is to jeopardize one's access to external research funding for projects, time away from one's teaching and service obligations to do scholarly work, and advancement opportunities. Many of those reviewing curricula vitae for various purposes have only a vague sense of important ideas and journals in any but their own subfield, so publication counts matter greatly — sometimes critically — while the actual content of the publications can matter little.

Doing research and publishing data and insights from original data, or performing syntheses or analyses of existing data or ideas, is a time-consuming and painstaking task. The academic faces many barriers in doing work of sufficient quality to clear the hurdles of peer review — starting with clearing the time needed to undertake the original fieldwork or intellectual labour and to write and revise a manuscript to submission-ready status with enough lead time to get it into circulation before one's CV or dossier comes under review. The delays in peer review and the uncertainties of the process can be very frustrating.

Is it any wonder that new, profit-making interests have jumped into the breach, "helpfully" offering scholars assistance with finding their place in the literature? Open access is an Internet-era creation whereby the costs of publishing journals are borne by scholars wishing to disseminate their work, rather than by libraries and other subscribers. Publishers of "predatory" or "rogue" journals have taken open access to another level for those willing to pay a fee: guaranteed fast publication, with essentially no peer review, in journals that have names very similar to those of peer-reviewed journals. Expert observers of the predatory journal movement, such as Jeffrey Beall, a librarian at the University of Colorado, provide useful lists of journals and publishers that are walking on the dark side of open access (http://scholarlyoa.com/publishers). Recently the trend has come to the attention of the popular press (see Spears, 2014), but it is unclear whether the general public understands much about the culture of "publish or perish" or the purposes and mechanisms of peer review.

A number of months ago I received a submission that was based on some data collection and analysis conducted in the authors' work setting. The framing of the paper would have needed adjustments to fit with *CJNR*'s mandate and the research approach had some weaknesses that would have required explanation and softening of the conclusions. I provided a fairly extensive list of modifications that we would require before considering it for publication. Recently I heard back from the authors explaining that they had decided to submit to another journal, and a few days later I received a copy of the newly published article. The publisher of the journal in which the article appeared is on Beall's list.

I know that these are well-meaning individuals trying to respond to pressures to publish. So on one level I understand their decision to seek out an open access venue and even to go to the specific journal that they selected. Now the article and their names will be easily pulled up in a Google search and the casual browser of their CVs or of the Internet will conclude that they are published authors who have done research on a topic related to their jobs — even though the work they have published was not well screened or well edited.

Is peer review becoming a luxury, fully present only at the upper end of the publishing gamut? At this end will be the "high impact" journals, where articles are screened by well-resourced editorial offices that can manage the peer-review process with ease. Many authors attempt to publish in these (as both a cause and an effect of being selective and prestigious), but few will have their works chosen. The authors of most articles that appear in high impact journals have the resources, connections, and highly developed skills necessary to identify the topics, approaches, and methods that will be accepted. Access to these articles is highly valued, which in turn demands large subscription fees so that the journals can operate with big budgets.

At the other end of the publishing range will be the crudest forms of open access that verge on vanity publishing, with production costs carried by authors needing exposure and wishing to add lines to their CVs, and with readers left entirely on their own to judge quality. Journals at this lower end will cut costs and time to publication by essentially eliminating screening and editing but, unless things change dramatically, will continue to find paying authors/customers.

And in the middle? In traditional journal publishing, subscription prices that offset production costs are based on perceived value and quality, which are ensured by free editorial expertise, reviewer time, and, of course, content. Open access with some form of review and screening and with expenses covered mainly or exclusively by authors is another area of middle ground. With journals in this category, dependence on scholarly altruism as a means of screening, shaping, and editing content is more challenging, since money passes from author to publisher in a more overt way, for all to see. With external funding agencies increasingly allowing investigators to include publication fees in their budgets and insisting on early open access, and with the most selective journals also being the most prestigious, more and more scholars appear willing to trade money for less scrutiny and less delay to publication.

We cannot pretend any longer that the advancement of knowledge is but one of many motivations in journal publishing. Nor can we pretend that scholarly publishing is free when there are significant undocumented but serious implications of cost shifting to achieve high-quality content. It is time to discuss the underlying problems faced by all of the stakeholders and look at our options not only as institutional leaders but also as publishers, authors, and readers. I for one would be an advocate of putting quality over quantity and greater recognition of high-level and high-quality voluntary contributions to selection and promotion decisions in both mid- and upper-tier journals. The choices we make now are sure to have an influence on which scholarly venues survive in the coming years. Journals that fall between elite ranking and the lower tier of open access may have a very different future from that anticipated by their founders as part of the natural order of things. However, it seems that more discussion would be wise given the wide-ranging consequences for everyone involved.

Sean P. Clarke, RN, PhD, FAAN
Editor-in-Chief

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Commentary

The Enduring Challenge of Cultural Safety in Nursing

Louise Racine

Cultural differences, cultural diversity, and cultural safety have been discussed lucidly in the pages of *CJNR* on many occasions (Allen, 1999; Anderson, 2004, 2006). They have been recurring topics for good reason: the challenges around cultural issues in contemporary nursing practice and research continue. In the 21st century, the digital revolution has brought many positive changes, including increased access to nursing education for students living in remote areas and for a growing number of international students (Racine, Springer, & Udod, 2013). Similarly, globalization and technological advances have facilitated, among international colleagues, the sharing of common interests in global health (Mill, Ogilvie, Astle, & Opare, 2005). Environmental sustainability, health inequities, nurse migration, and privatization of health and social services are global issues affecting health-care delivery (Dominelli, 2010).

Given these complex contexts, the delivery of culturally safe care remains an unachieved goal. Cultural safety is defined as "nursing or midwifery action to protect from danger and/or reduce risk to patient/client/community from hazards to health and well-being" (Papps & Ramsden, 1996, p. 493). Consequently, any action or lack of action that does not respect the ethnocultural background of individuals, groups, and communities or demeans their racial background is culturally unsafe (Papps & Ramsden, 1996). The investigation of cultural safety has revealed racial, ethnic, class, and language discrimination in nursing and in other health professions.

There has been remarkable growth in research and writing on this topic in nursing. Cultural safety is now embodied in standards of practice and codes of ethics set by nursing regulatory bodies and professional associations in Canada and abroad. One might assume that culturally safe care is everyday practice for all nurses. But is it?

The expressions of racial and ethnic intolerance in our discipline that I witness in my research and in other areas of my professional life remain very distressing. Very little appears to have changed since the publication of early Canadian research concerning racialized patients and immigrant nurses (Das Gupta; 2009; Hagey & MacKay, 2000; Ogilvie, Leung, Gushuliak, McGuire, & Burgess-Pinto, 2007; Reimer-Kirkham, 2003; Turrittin, Hagey, Guruge, Collins, & Mitchell, 2002).

Why do nursing and other health professions still struggle with cultural safety? While I acknowledge that the concept of cultural safety may be novel to some (Papps & Ramsden, 1996), the persistence of culturally unsafe practice in health care indicates a need to revisit basic ideas around culture and cultural safety. How nurses understand culture as a norm of the majority group underpins cultural stereotypes. As Allen (1999) asserts, "cultures and cultural differences are not 'discovered,' they are constructed" (p. 230). Although the construction of cultural stereotypes remains problematic, the fundamental issue is the way in which mainstream nurses use power associated with their privileges to ascribe racial, ethnic, and cultural differences. Reimer-Kirkham and Anderson (2002) persuasively argue that nurses have an obligation to look beyond conventional ways of thinking about race and ethnicity. We must come to terms with how racial categories marginalize groups and reflect outdated and dehumanizing value systems. Drawing upon Bhabha (1994), I believe that the discipline of nursing is at a critical moment of historical transformation in terms of embracing cultural diversity. But how should nurses seize this opportunity to effect change?

Anderson (2004) suggests that cultural safety can be understood through the notion of "situated vulnerabilities." She states that no one is "immune to the experience of marginalization, dehumanization, and human suffering" (p. 14) and, furthermore, that the division of human beings along racial lines has "dehumanized all of us" (p. 14). The notion of situated vulnerabilities puts everyone on a plane of vulnerability, as we have all felt excluded at least once in our lives. Cultural safety is a perspective whereby culture is seen as a changing or hybrid concept inclusive of diverse vulnerabilities. Cultural hybridity can be developed only through exposure to and acceptance of cultural diversity. Reflecting on our own vulnerabilities may help us to understand how racial discrimination affects the delivery of nursing care. Scholarly efforts in nursing should be directed at making the effects of racialization visible and suggesting measures for concretely addressing the issue through knowledge generation. But how?

The ontological and epistemological assumptions of postcolonial feminism could guide this work. One way to make race, gender, and class visible is to always start the process of scholarly inquiry from the everyday experience of research participants. Everyday experience is the point of departure for postcolonial feminist inquiry (Reimer-Kirkham & Anderson, 2002). The goals of critical and postcolonial inquiry lie in interventions and other measures to achieve social justice and eliminate racial discrimination.

Translating postcolonial feminist research into practice will not be an easy enterprise. Thorne (2009) points out that "while it is undoubtedly laudable that nurses are embarking in increasing numbers into the world of working with large and complex ideas, the problem of translating the products of that work into the practice knowledge of a discipline is decidedly not self-evident" (p. 150). The status quo in nursing in terms of racialization cannot hold. We can achieve culturally safe care and culturally safe health-care workplaces only by thinking critically about cultural research in nursing and translating our ideas into practice realities.

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Louise Racine, RN, PhD, is Associate Professor, College of Nursing, University of Saskatchewan, Saskatoon, Canada, and a CJNR *Associate Editor.*

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Knowledge Transfer and Dissemination of Advanced Practice Nursing Information and Research to Acute-Care Administrators

Nancy Carter, Maureen Dobbins,
Gladys Peachey, Heather Hoxby, Sandra Ireland,
Noori Akhtar-Danesh, Alba DiCenso

The objective of this study was to ascertain the information needs and knowledge-dissemination preferences of acute-care administrators with respect to advanced practice nursing (APN). Supportive leadership is imperative for the success of APN roles and administrators need up-to-date research evidence and information, but it is unclear what the information needs of administrators are and how they prefer to receive the information. A survey tool was developed from the literature and from the findings of a qualitative study with acute-care leaders. Of 107 surveys distributed to nursing administrators in 2 teaching hospitals, 79 (73.8%) were returned. Just over half of respondents reported wanting APN information related to model of care and patient and systems outcomes of APN care; the majority expressed a preference for electronic transmission of the information. Researchers need multiple strategies for distributing context-specific APN evidence and information to nursing administrators.

Keywords: advanced nursing practice and education, health services, nursing administration–inpatient, nursing roles

Résumé

Transfert des connaissances et diffusion d'information et de résultats de recherches sur les pratiques infirmières avancées aux administrateurs de soins actifs

Nancy Carter, Maureen Dobbins,
Gladys Peachey, Heather Hoxby, Sandra Ireland,
Noori Akhtar-Danesh, Alba DiCenso

L'objectif de cette étude était de déterminer les besoins en information et les préférences en matière de transmission du savoir des administrateurs de soins actifs en ce qui concerne les pratiques infirmières avancées (PIA). Les infirmières et infirmiers en PIA doivent impérativement bénéficier du soutien de leur direction pour accomplir adéquatement leur travail. Les administrateurs ont quant à eux besoin d'information et de résultats de recherche à jour pour offrir ce soutien, mais l'information dont ils ont besoin et la façon dont ils souhaitent la recevoir demeurent incertains. Un outil de sondage a été élaboré à partir de la littérature sur le sujet et des résultats d'une étude qualitative menée auprès de dirigeants de services de soins actifs. Sur un total de 107 formulaires distribués à des administrateurs de soins infirmiers dans deux hôpitaux d'enseignement, 79 (73,8 %) ont été remplis et retournés. Un peu plus de la moitié des répondants ont indiqué vouloir de l'information liée aux PIA portant sur les modèles de soins et les résultats des PIA pour les patients et le système, et la majorité d'entre eux ont dit avoir une préférence pour l'information transmise par voie électronique. Les chercheurs doivent user de stratégies multiples pour diffuser auprès des administrateurs de soins infirmiers l'information et les résultats de recherche sur les PIA propres à divers contextes.

Mots-clés : pratiques infirmières avancées (PIA), transmission du savoir, soins actifs, modèles de soins

Introduction

Health-care administrators play a key role in the integration of advanced practice nurses (APNs) into acute-care settings. Supportive leadership facilitates successful integration of APN roles and contributes to APN job satisfaction (Carter et al., 2010; Reay, Golden-Biddle, & Germann, 2003). However, as health-care settings face challenging economic times, nurse leaders must have access to current APN-related research in order to make evidence-informed decisions about the best ways to utilize these roles.

In Canada, there are two types of APN: the clinical nurse specialist (CNS) and the nurse practitioner (NP). Both have existed in the country for over 40 years and have consistently been shown in randomized controlled trials to be effective. When compared to physicians, NPs provide safe, high-quality care with high levels of patient satisfaction. CNSs can reduce length of stay and cost of care for hospitalized patients (Laurant et al., 2009; Newhouse et al., 2011). Core role dimensions of these APNs include direct patient care, research, leadership, consultation, and collaboration (Canadian Nurses Association, 2008). Although they share similar core attributes, there are differences between CNS and NP roles; there are also differences within the roles, depending on the patient population and the health-care setting. This variation has led to confusion among policy-makers, health-care administrators, team members, and members of the public about the scope and roles of APNs (Donald et al., 2010). While there is an active APN research agenda in Canada that may help address their effective integration and barriers such as lack of role clarity, the challenge is to successfully transmit the research findings to those best situated to make use of them.

Literature Review

The Canadian Institutes of Health Research (2013) defines knowledge translation (KT) as a "dynamic and iterative process that includes the synthesis, dissemination, exchange, and ethically sound application of knowledge to improve health, provide more effective health services and products, and strengthen the healthcare system." Research related to KT and knowledge dissemination in health care has generally been directed to *clinical* as opposed to *administrative* decision-makers. A component of KT, knowledge dissemination is specifically focused on communicating research evidence by tailoring findings to targeted audiences (Lomas, Cuyler, McCutcheon, McAuley, & Law, 2005).

Barriers to the use of evidence by administrators include knowledge issues (lack of awareness, lack of recall), attitudes (lack of applicability or agreement), and behaviours (lack of time, organizational constraints)

(Legare, 2009). Also, there may be a reluctance to use scientific evidence because of the administrative culture of health care and the value placed on personal experience, pragmatism, and self-generated knowledge (Walshe & Rundall, 2001). A number of KT strategies have been developed to facilitate use of evidence by decision-makers, including evidence briefs (Lavis, Permanand, Oxman, Lewin, & Fretheim, 2009) and deliberative dialogues (Boyko, Lavis, Abelson, Dobbins, & Carter, 2012). A body of research focusing on Canadian public health managers has found that decision-makers want accessible, easy-to-use research information and personalized updates of new reviews related to their clinical settings (Dobbins, deCorby, & Twiddy, 2004). They prefer to receive both hard and electronic copies of information, including systematic reviews, executive summaries, and clear implications for practice (Dobbins, Jack, Thomas, & Kothari, 2007), from a variety of sources, such as websites, academic journals, e-mail, conferences and workshops, in a number of formats, including executive summaries, abstracts, and articles (Dobbins, Rosenbaum, Plews, Law, & Fysh, 2007).

Few studies have focused on identifying effective KT strategies for hospital administrators, who, perhaps because of lack of time or organizational constraints (Legare, 2009), make minimal use of research evidence in health-care management (Nicklin & Stipich, 2005). In particular, middle managers have been largely overlooked in studies of health research uptake, even though they are often the ones most involved in applying research findings on a day-to-day basis (Birken, Daniel Lee, & Weiner, 2012). Limited use of research evidence to guide decision-making is one of the many issues influencing CNS and NP role development, implementation, and evaluation (Bryant-Lukosius & DiCenso, 2004). Carter and colleagues (2013) used qualitative methods to explore knowledge gaps about APNs and the type of information used by acute-care leaders. Administrators reported that nurses, administrative colleagues, and physicians misunderstood the value-added of APNs and felt that CNSs were less understood than NPs. The participants preferred to contact CNSs, NPs, and administrative colleagues for research information and rarely searched for evidence on their own, despite wanting information on role implementation and cost-effectiveness of CNS and NP utilization.

In summary, few studies have attempted to identify the best ways to disseminate research evidence to administrators and no studies have quantified the need for APN information or the type of information needed. Little is known about acute-care administrators' APN-related information needs or their preferred means of receiving such information. In order to address issues related to role clarity and support the uptake of NP and CNS roles in our health-care system, we need a better understanding of KT strategies and APN information.

Study Objectives

The objective of this study was to develop and pilot-test a survey tool that could be used with a sample of health-care administrators to learn about their APN information needs and their preferred means of receiving APN research evidence. The survey addressed three primary questions:

1. Do health-care administrators need information and research evidence about NP and CNS roles?
2. If they do, what information and research evidence do they want?
3. How do they want the information and research evidence disseminated to them?

In this article we describe the survey development process and provide descriptive statistics from the pilot study.

Theoretical Framework

To inform our work, we used the framework for guiding dissemination of research findings to decision-makers developed by Lavis, Robertson, Woodside, McLeod, and Abelson (2003). The framework uses five questions to shape KT strategies with decision-makers: 1. What should be transferred to decision-makers? 2. To whom should research knowledge be transferred? 3. By whom should the research knowledge be transferred? 4. How should research knowledge be transferred? 5. To what effect should research knowledge be transferred?

This study focuses on questions 1 and 4: the research *messages,* or what APN information should be transferred, and the KT *processes,* or how APN information and research evidence should be disseminated.

Methods

Research Design

The study was approved by the Research Ethics Board of McMaster University and the two participating hospitals. We developed and piloted a survey to describe APN-related information needs and preferred dissemination strategies for APN information.

Sample

Study participants worked in one of two urban teaching hospitals in south-central Ontario, Canada. They were identified from mailing lists provided by administrative assistants at the two hospitals and included vice-presidents, directors, managers, and professional practice leaders. To be included in the study, potential participants had to be situated within an area or program where an APN was deployed.

Survey Development

The initial content for the survey was identified through review of the APN- and KT-related literature and through qualitative interviews with 15 administrators, physicians, NPs, and CNSs (Carter et al., 2013). Interview participants were asked about their experience developing, implementing, and evaluating APN roles. The survey comprised 26 questions in four sections: demographic data, respondent setting and role, experience with APNs in the work setting, and information needs about APN. Specifically, questions addressed information needs, current sources of information, and preferred means of receiving information and research findings. Drafts of the survey were reviewed by a group of researchers and graduate students who were part of an APN research program. The survey and pretest were structured according to Dillman's (2007) tailored method. This included writing the covering letter for the survey and ensuring a respondent-friendly questionnaire with personalized messages.

The survey was pretested for face and content validity with three administrators, a nursing faculty member with administrative expertise, and a researcher with experience in designing surveys. Content validity was assessed in the following ways: use of results from qualitative interviews, review of drafts by researchers with content expertise, and comments about comprehensiveness by the five individuals who pretested the survey.

Data Collection

Surveys were mailed directly to participants through inter-hospital mail in the fall of 2011. All surveys were anonymous and were sent with a self-addressed return envelope. A coupon from a national coffee shop chain was included with the survey to promote participation. Consent was inferred through return of the completed survey. A data-entry system was maintained by the research assistant. The principal investigator was blinded to participants' names. Surveys were coded and the document that linked names and codes was kept by the research assistant. The research assistant used this data system to generate reminders. Two weeks after the initial mail-out, the research assistant sent a reminder letter to non-respondents.

Data Analysis

The data were analyzed using descriptive statistics and means and frequencies were calculated to summarize the demographic data and responses to questions. Chi-square tests were used to compare differences between participants.

Results

Respondent Characteristics

A total of 107 surveys were distributed and 79 were returned, for a response rate of 73.8%. Two surveys were removed from the analysis because only minimal questions were answered. Demographic characteristics of the respondents are shown in Table 1. The majority (75.3%) were

Table 1 ***Respondent Characteristics***

	Total Respondents ***N* = 77 (%)**	**Wanting APN Information** ***n* = 41 (%)**	**Not Wanting APN Information** ***n* = 36 (%)**
Primary Role			
Chief nurse executive	1 (1.3)	0	1 (2.7)
Executive director/administrator	3 (3.9)	1 (2.4)	2 (5.5)
Director	13 (16.9)	9 (21.9)	4 (11.1)
Clinical manager	58 (78.3)	31 (75.6)	27 (75.0)
Professional practice leader	2 (2.6)	0	2 (5.6)
Profession			
Nurse	67 (87.0)	34 (82.9)	33 (91.7)
Administrator	3 (3.9)	2 (4.8)	0
Respiratory therapist	3 (3.9)	2 (4.8)	2 (5.6)
Psychologist	2 (2.6)	1 (2.4)	1 (2.8)
Social worker	1 (1.3)	1 (2.4)	0
Speech/language pathologist	1 (1.3)	1 (2.4)	0
Highest Educational Credential			
Diploma	13 (16.9)	2 (4.9)	11 (30.6)
Baccalaureate	29 (36.4)	18 (43.9)	11 (30.6)
Master's degree	33 (42.9)	20 (48.8)	13 (36.1)
Doctorate	2 (2.6)	1 (2.4)	1 (2.8)
Mean years in current position (min–max)	4.3 (0–21)	4.1 (0.5–10)	4.6 (0.5–21)
Mean years of administrative experience (min–max)	10.2 (0.5–30)	10.7 (2–22)	9.6 (0.5–30)

clinical managers and most (87%) had a nursing background. Almost equal numbers of respondents had completed master's (42.9%) and bachelor's degrees (36.4%). The average number of years that respondents held their current position was 4.3 and the total number of years in an administrative role was between 0.5 to 30, with an average of 10.2.

In the following sections we report on respondents' experience working with APNs, reasons for wanting APN information, type of information needed, preferred methods for receiving the information, characteristics of respondents not wanting APN information, and priorities for future APN research.

Experience Working With APNs

Almost two thirds (64.9%) of the respondents had worked with APNs in the past, and approximately the same proportion (63.6%) were working with APNs in their current position. A review of responses found that 44.9% were working with either an NP or a CNS, and 34.5% were working with both NPs and CNSs.

Respondents Wanting More APN Information and Research Evidence

Just over half of the 77 respondents (53.2%) reported wanting more information and research evidence about APNs. Table 2 reports on the reasons why these 41 respondents wanted more information and research evidence. The main reasons were to help evaluate roles (73.2%) and to determine the need for roles (70.7%). Only one respondent wanted APN information in order share it with other members of the team.

Table 2 ***Reasons for Wanting APN Information and Research Evidence (n = 41)***

	n (%)[a]
To help evaluate impact of roles	30 (73.2)
To determine the need for new roles	29 (70.7)
To justify new or existing roles	23 (56.1)
To assist with budget decisions	23 (56.1)
To implement new roles	23 (56.1)
To assist with integration of current roles	20 (48.8)
To sustain current APN positions	16 (39.0)
To share with other members of the team	1 (2.4)

[a] Percentages sum to more than 100 because respondents chose more than one reason.

Information and Research Evidence Favoured by Respondents

The 41 respondents who wanted more APN information were asked what type of information and research evidence about CNSs and NPs would be helpful in their current administrative role. The three most common responses were models of APN practice (82.9%), studies reporting APN impact on patient outcomes (80.5%), and studies reporting APN impact on organizational/system outcomes (73.2%). The least desired type of information was APNs' educational preparation (24.4%). A breakdown of responses can be found in Table 3.

Table 3 *Type of APN Information and Research Evidence Favoured (n = 41)*

	n (%)[a]
Models of APN practice	34 (82.9)
Studies reporting patient outcomes	33 (80.5)
Studies reporting organizational/system outcomes	30 (73.2)
Cost-effectiveness of APNs	29 (70.7)
Studies reporting health-care provider outcomes	27 (65.9)
Methods for role evaluation	26 (63.4)
How to utilize APNs	25 (61.0)
Clear role definitions of CNS and NP	23 (56.1)
Information on interprofessional collaboration	14 (34.1)
Educational preparation for APNs	10 (24.4)

[a] Percentages sum to more than 100 because respondents favoured more than one type.

Preferred Methods for Receiving Information and Research Evidence

The 41 respondents who wanted APN information and research evidence chose a variety of ways they wished to have it formatted, preferring research abstracts with commentary (75.6%), case studies or illustrative examples (70.7%), and one-page briefing notes (63.4%). The formats least chosen were newsletters (24.4%) and educational outreach (2.4%). When asked how they wanted APN information and research evidence delivered to them, the 41 participants chose dissemination through electronic means, with 78% of respondents wanting to receive e-mail alerts and 56.1% wanting to be able to access information on a dedicated website. The least preferred delivery methods were teleconference

(19.5%), videoconference (17.1%), podcast (4.9%), and distribution through professional organizations (2.4%).

Respondents Not Wanting APN Information and Research Evidence

In order to determine if there were differences between participants who wanted APN information (53.2%) and those who did not (46.8%), chi-square analysis was used. There were no differences between the two groups except that respondents who did not want APN information and research evidence on average reported a lower level of education. Table 1 provides more details from this analysis.

Priorities for APN Research

The 77 respondents selected three priority APN research topics. The two most commonly selected were outcomes research of integrated APN care related to patients (55.8%) and economic evaluations of APNs (46.8%). The lowest-priority research topics were evaluations of APN education programs (6.5%) and development of tools to determine which type of APN is needed (2.6%). There were no statistically significant differences in priorities for future research between respondents who did and did not want APN information. Differences between the two groups were the priority for economic evaluation (53.7% vs. 38.9%), evaluations of new APN roles (12.2% vs. 27.8%), and evaluations of health-care provider satisfaction with APN roles (22.0% vs. 8.3%). A complete breakdown of responses can be found in Table 4.

Discussion

Our findings provide information to fill two gaps in the KT and APN literature: what APN research and evidence would be helpful to administrators, and how administrators want research evidence disseminated to them. To effectively disseminate research findings, researchers may need to develop research messages unique to each target audience. The framework described by Lavis and colleagues (2003) guided the formulation of the two objectives of our survey. Context is a key consideration, and administrators' needs for APN information and research specific to acute care have been reported previously (Carter et al., 2013). Participants wanting information chose a variety of topics, including information to assist them in their current work with CNSs and NPs (to evaluate, integrate, and sustain roles) and to help them develop new CNS and NP roles (to determine the need, justify the new role, and budget for it). Dobbins and colleagues (Dobbins et al., 2004; Dobbins, Jack, et al., 2007; Dobbins, Rosenbaum, et al., 2007) have used qualitative studies to

Table 4 ***Priority APN Research Identified by Respondents***

	Total Respondents ***N*** **= 77 (%)**	**Wanting APN Information** ***n*** **= 41 (%)**	**Not Wanting APN Information** ***n*** **= 36 (%)**
Outcomes of integrated APN care related to patients	43 (55.8)	25 (55.5)	18 (50.0)
Economic evaluation of APN roles	36 46.8)	22 53.7)	14 38.9)
Evaluation of interventions provided by APNs	29 (37.7)	14 (34.1)	15 (41.7)
Outcomes of integrated APN care related to organizations and systems	27 (35.1)	13 (31.7)	14 (38.9)
Determination of the need for a new APN role	25 (32.5)	12 (29.3)	13 (36.1)
Outcomes of integrated APN care related to health-care providers	18 (23.4)	10 (24.4)	8 (22.2)
Evaluation of APN practice patterns	17 (22.1)	10 (24.4)	7 (19.4)
Evaluation of new APN roles	15 (19.5)	5 (12.2)	10 (27.8)
Evaluation of interprofessional collaboration	15 (19.5)	6 (14.6)	9 (25.0)
Evaluation of health-care provider satisfaction with APN roles	12 (15.6)	9 (22.0)	3 (8.3)
Evaluation of APN education programs	5 (6.5)	1 (2.4)	4 (11.1)
Development of tools to determine which APN is needed	2 (2.6)	2 (4.9)	0
No response	1 (1.3)	1 (2.4)	0

[a] Percentages sum to more than 100 because respondents identified more than one priority.

explore Canadian public health decision-maker preferences for receiving research knowledge and have found that administrators prefer setting-specific reviews. Dissemination strategies intended to reach a specific person or group, based on their unique characteristics, are known as "tailored strategies." In randomized controlled trials, tailored messages were found to significantly improve evidence-informed decision-making among public health decision-makers (Dobbins et al., 2009).

Approximately half of the respondents did not want more APN information and research at the time of our survey, despite reporting priorities for future APN research. It is not clear from our findings why they did not want information, and the only significant difference between the groups was that those who did not want APN information reported lower levels of education than those who did want information. Most respondents were working with an APN at the time of data collection, and over a third of respondents were working with both NPs and CNSs. This suggests that they had a good understanding of the roles and the differences between roles. Alternatively, the participants may have been receiving APN research information from their colleagues. CNSs and NPs play an important leadership role in evidence-based practice for both clinicians and administrators. In a study exploring knowledge gaps regarding APN, acute-care leaders first sought out information from colleagues within their organization, particularly CNSs and NPs (Carter et al., 2013). However, this may not be possible in organizations that employ few APNs.

Nevertheless, the key finding that half of the administrators do not want APN information is a concern. Leaders in health care are responsible for the dissemination of research evidence and supporting integration of findings (Newhouse, 2007), and at the very least it can be expected that more research and information would be useful for the members of their team. Interestingly, however, this group identified priority APN research, so they clearly were keen for specific research questions to be addressed and presumably to be told the results of the research.

Issues of role clarity and a lack of understanding of the differences between CNS and NP roles are a barrier to integration of roles, and it has been reported that frontline nurses and other health-care providers do not understand APN roles (DiCenso et al., 2010; Donald et al., 2010). One hypothesis is that in an age of information overload, administrators dislike the idea of more paper, e-mails, or alerts. There seems to be evidence, however, that this finding is more related to a lack of use of research evidence by administrators, despite the expectation of evidence-informed decision-making (Nicklin & Stipich, 2005; Walshe & Rundall, 2001; Williams, 2006). Williams (2006) suggests that nurse leaders are in an optimal position to critically review literature as a basis for management decision-making because of their clinical, administrative, and basic appreciation for the research process. Cummings and McLennan (2005) found that one of the key discoveries in implementing an APN role in an oncology centre was that evidence alone was not sufficient; in their experience, research evidence was important to physicians, but information regarding the knowledge, skills, and ability of the actual CNS or NP was needed to convince others of the importance of the role.

Our respondents had preferences with respect to both the format of material and the methods for its delivery. Echoing the results of Dobbins, Jack, and colleagues (2007), our participants wanted information e-mailed to them, distributed in hard copy, and posted on dedicated websites, suggesting that researchers need to use multiple strategies to disseminate their findings. Original research papers, newsletters, and educational outreach were the least preferred dissemination methods. A deeper understanding of the least helpful dissemination strategies is just as important, to prevent a waste of time and resources.

Strengths and Limitations

To our knowledge, this is the only survey to explore the information needs of administrators about APN and the only survey to explore the KT preferences of acute-care administrators. The survey tool was pilot-tested with administrators working in large urban teaching hospitals. This is not representative of all of the settings in which NPs and CNSs work. However, demographic questions included in the survey distinguish between the types of work setting and geographic areas for future use. The response rate of 73.8% (79 of 107) suggests that the tool is easy to complete and understand and was of interest to the intended audience.

Implications

Supportive leadership contributes to successful integration of APN roles and to increased job satisfaction (Carter et al., 2010; Reay et al., 2003) and poor planning for APN roles is associated with unsuccessful integration of NPs and CNSs into the workplace (Bryant-Lukosius et al., 2007). Carter and colleagues (2010) report the results of a Canadian decision-support synthesis on APN, as follows: leadership strategies to optimize successful role integration include initiating systematic planning to develop the roles based on patient and community needs, engaging stakeholders, using established role implementation toolkits, ensuring utilization of all dimensions of the role, communicating clear messages to increase awareness about the roles in the organization, creating networks and facilitating mentorship for those in the role, and negotiating role expectations with physicians and other members of the health-care team. These multiple strategies require that administrators know and understand the research evidence on APN, but, as reported by Cummings and McLennan (2005), they must also have an understanding of the skills and expertise of the CNSs or NPs with whom they are working. Emerging literature demonstrates that mentoring is a strategy for influencing change in KT and evidence-based practice (Gifford, Davies, Ploeg, Eldred, & Bajnok, 2013). By seeking out and utilizing research evidence to make decisions about APN, administrators can role model its importance with nurses, other health-care providers, and administrative colleagues.

Formal leaders may also need education and mentorship in order to seek out and utilize APN research evidence. Currently there is an emphasis on evidence-based practice in nursing curricula to prepare future clinicians, but there are fewer opportunities for senior or experienced administrators. The Executive Training for Research Application (EXTRA) program was developed through a consortium of health-services management organizations, including the Canadian Nurses Association and the Academy of Canadian Executive Nurses. Its goal is to increase the skills of health-care executives in using research evidence and bringing about organizational change (Lavoie-Tremblay & Anderson, 2007). In an evaluation of the first cohorts of the program, individuals rated their research literacy, knowledge, and skills substantially higher after the program; however, organization impacts were difficult to assess (Denis, Lomas, & Stipich, 2008).

Our results have a number of implications for researchers. APN research designed to clarify the value-added component of APN roles in acute care is indicated. The identification of key health-care and health-system outcomes relevant to CNS and NP roles, and the means by which the outcomes can be measured, will be useful in this regard (Lavis, 2011). The development of active partnerships with acute-care leaders has the potential to inform the development of APN-related research questions. In the current economic climate, where resources are routinely prioritized, research focusing on evaluating outcomes of acute-care APN roles may result in sustained administrative support for these roles. Our participants wanted information to help them articulate the value-added of APN roles, particularly the CNS role, and this need may shape the next wave of APN research. Our findings indicate the importance of researchers implementing KT strategies that target hospital administrators. They also suggest the need to collect, organize, and make available colloquial evidence to complement more traditional research evidence. Additionally, CNSs and NPs should have access to similar materials, since our findings suggest that they often assume the role of knowledge brokers for administrators.

This pilot study provides preliminary information about the knowledge needs of administrators with respect to APN. In future we will conduct a national survey to provide a more comprehensive understanding of what APN information Canadian administrators want. Both of the settings in our study included large numbers of CNSs and NPs. A national survey would include locations that have smaller numbers of APNs and would help us to understand more fully the role that NPs and CNSs play in supporting the information needs of administrators.

Conclusion

Health-care administrators and nurse researchers need to work together to ensure that research evidence about APN is in the hands of leaders who can apply it for the best patient and organizational outcomes. A culture of evidence-based administration is needed to support leaders as they apply models of nursing care delivery and promote evidence in the coming decade (Newhouse & White, 2011; VandeVelde-Coke, 2010). The preliminary results from this survey provide a first step in understanding how research and information may support acute-care administrators' decision-making about APN. Nursing leaders will have to lobby for continued nursing research funds and funds to disseminate research. Researchers, educators, and CNSs and NPs need to work together to share research and other forms of information with health-care leaders regarding how APN roles can address patient care and organizational needs in innovative ways.

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Nancy Carter, RN, PhD, is Assistant Professor, School of Nursing, McMaster University, Hamilton, Ontario, Canada. Maureen Dobbins, RN, PhD, is Professor, School of Nursing, McMaster University. Gladys Peachey, RN, PhD, is Assistant Professor, School of Nursing, McMaster University. Heather Hoxby, RN (EC), MHSc, NP-PHC, is Director of Nursing, St. Joseph's Healthcare, Hamilton. Sandra Ireland, RN, PhD, is Assistant Professor, School of Nursing, McMaster University. Noori Akhtar-Danesh, PhD, is Associate Professor, School of Nursing, McMaster University. Alba DiCenso, RN, PhD, is Professor Emeritus, School of Nursing, McMaster University.

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Cognitive Load Theory: Implications for Nursing Education and Research

Ruth Chen, Kelly Dore, Lawrence E. M. Grierson, Rose Hatala, Geoffrey Norman

This article provides an overview of cognitive load theory (CLT) and explores applications of CLT to health profession and nursing education research, particularly for multimedia and simulation-based applications. The article first reviews the 3 components of cognitive load: intrinsic, extraneous, and germane. It then discusses strategies for manipulating cognitive load variables to enhance instruction. Examples of how CLT variables can be modulated during instruction are provided. Lastly, the article discusses current applications of CLT to health profession and nursing education research and presents future research directions, focusing on the areas of multimedia and simulation-based learning.

Keywords: cognitive load, multimedia and simulation education

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Résumé

Théorie de la charge cognitive : répercussions sur la formation et la recherche en soins infirmiers

Ruth Chen, Kelly Dore, Lawrence E. M. Grierson, Rose Hatala, Geoffrey Norman

Le présent article offre un aperçu de la théorie de la charge cognitive (TCC) et explore les applications de la TCC dans la recherche sur la formation des professionnels de la santé et des soins infirmiers, plus particulièrement les applications multimédias et fondées sur la simulation. L'article revoit tout d'abord les trois types de charge cognitive : intrinsèque, extrinsèque et germane. Il examine ensuite les stratégies permettant de manipuler les variables de la charge cognitive en vue d'améliorer l'enseignement. Des exemples montrant comment les variables de la TCC peuvent être modulées pendant l'enseignement sont fournis. Enfin, l'article discute les applications actuelles de la TCC dans le domaine de la recherche sur la formation des professionnels de la santé et des soins infirmiers et présente les orientations futures de la recherche, l'accent étant mis sur les secteurs de l'apprentissage multimédia et fondé sur la simulation.

Mots-clés : charge cognitive, apprentissage multimédia et fondé sur la simulation

Cognitive Load Theory in Nursing Education and Research

Ruth Chen, Kelly Dore, Lawrence E. M. Grierson, Rose Hatala, Geoffrey Norman

Students in nursing and health education programs acquire a body of knowledge, skills, and attitudes during their education in preparation for future practice. One goal of an educator, therefore, is to create an environment of instruction where learning can take place. Cognitive load theory (CLT), derived from an understanding of human learning and memory, is explored extensively in the cognitive and education psychology literature and may be beneficial for nurse educators when designing and implementing instruction. The purpose of this article is to provide an overview of CLT and to discuss the impact of cognitive load on working memory and learning. The article will also explore how CLT has been applied in health profession education, particularly for multimedia and simulation-based applications. Finally, the implications of CLT on nursing education and research will be discussed.

Working Memory, Cognitive Load Theory, and Learning

For the purposes of this review, we present an operational definition of learning as the student's acquisition of knowledge, skills, or attitudes (Van Merriënboer, Kirschner, & Kester, 2003) that results in changes to long-term memory (Norman, 2013) and that produces an observable knowledge, behaviour, or action outcome. Central to this definition of learning is that a student receives information through multiple sensory pathways (e.g., visual, auditory inputs through pictures, words, and sounds) and creates visual and auditory representations within the cognitive system (Mayer, 2002). These representations are processed within the structures of working memory with the goal of transferring and storing the information into long-term memory.

There are three assumptions about the cognitive architecture of working memory and long-term memory. The first is that working memory is constrained and limited. Our understanding around limited working memory was first detailed by Miller (1956), who stated that an individual is capable of retaining only "seven plus or minus two" units of information at any point in time. Thus, if the quantity of information presented exceeds the capacities of a learner's working memory, then the information cannot be retained. In contrast, the second assumption is that there is virtually unlimited long-term memory, and working memory and long-term memory structures can interact. Therefore, inasmuch as information processing within working memory can be retained in the infinite stores of long-term memory, information can be brought forth from long-term memory to interact with and facilitate working memory processes (Schnotz & Kürschner, 2007). The final assumption is that the cognitive load imposed on a learner's working memory during instruction can be modulated. Thus, the student's cognitive load can be increased or decreased, impacting information processing in working memory (Mousavi, Low, & Sweller, 1995).

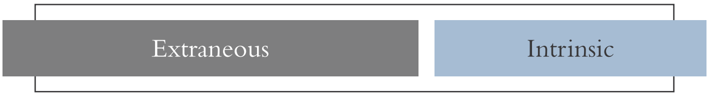
Our understanding of CLT is historically rooted in John Sweller's (1988) work on understanding learners' problem-solving strategies. Sweller terms the cognitive resources required for complex problem-solving "cognitive processing capacity" and argues that the cognitive load imposed on a learner during problem-solving can interfere with learning. In other words, the cognitive work required to figure out how to solve a problem can interfere with one's ability to learn the actual principles that the problem is intended to teach. Given a learner's limited working memory, it is helpful for nurse educators to understand the components of cognitive load that can impact student learning.

In CLT, there are three components of cognitive load: intrinsic, extraneous, and germane (Van Merriënboer & Sweller, 2005). Intrinsic cognitive load describes the actual learning goal or task and is directly related to the quantity and complexity of the learning material. Along with the learning goal or units of information provided during instruction, intrinsic cognitive load considers the inherent difficulty of the learning goal and the learner's level of expertise in the subject matter. One measure of intrinsic cognitive load is its degree of element interactivity, which describes the number of separate components in the learning goal that would need to be held simultaneously in working memory (Leahy & Sweller, 2005). The greater the complexity of the learning goal, the greater the intrinsic cognitive load (Paas, Renkl, & Sweller, 2003). Extraneous cognitive load is attributed to features of instruction that are not necessary for learning and that therefore impose a burden on the cognitive processing ability of working memory (Sweller, Van Merriënboer, & Paas, 1998). CLT assumes an additive model for the intrinsic and extraneous cognitive load variables such that, for any particular learning task or goal, the sum of the intrinsic and extraneous load must not exceed working memory capacity (Sweller, 1994). Germane load describes the processing that promotes automation of information into long-term memory, thus facilitating learning (Paas & Van Merriënboer, 1994). Germane load has been described elsewhere as "generative cognitive processing" (Mayer, 2010) that allows the learner to "make sense of" and understand the presented material. Germane load, while increasing the overall cognitive load of the learner, is identified as distinct from extraneous load in that the instructional approaches promote, rather than detract from, understanding of the learning material. Figure 1 depicts the additive nature of the cognitive load variables. Based on these CLT principles, nurse educators must seek to keep intrinsic cognitive load within the limits of the student's working memory and to decrease extraneous cognitive load in the instructional design. Instructional design that facilitates learning, the germane load component, can then be incorporated if the extraneous load is decreased.

Identifying the appropriate amount and type of cognitive load imposed on a learner during instruction is a significant factor in the success of an educator's instructional intervention (Paas, Tuovinen, Tabbers, & Van Gerven, 2003). Poorly designed learning goals that require complex processing of multiple ideas or skills and that exceed the capacity of a learner's working memory lead to cognitive overload and decreased learning (Doolittle, McNeill, Terry, & Scheer, 2005). Either too much learning material (or material that is too complex) (high intrinsic load) or poorly designed instruction that includes unnecessary information or instructional features (high extraneous load), or a combination of both, can lead to an overload in working memory (see Figure 1, A). Instructional design can be optimized to decrease extraneous cognitive load (Figure 1, B) such that the additional working memory capacity could be used for germane cognitive processing (Figure 1, C).

Figure 1 ***Optimizing Learning by Adjusting Cognitive Load***

A Overload to working memory



B Decreased extraneous load

C Optimizing germane load

Source: Adapted from Van Merriënboer and Sweller (2010).

Manipulating Cognitive Load to Optimize Working Memory

Given the nature of the three components of cognitive load, it is possible to construct instructional materials for nursing students that optimize the cognitive load imposed on working memory and facilitate long-term retention.

Approaches to Adjusting Intrinsic Cognitive Load

The first variable, intrinsic cognitive load, describes the inherent nature of the learning task at hand and the student's expertise in the subject matter. Therefore, modifying intrinsic cognitive load necessarily involves changing the learning task by either adding or subtracting the amount and complexity of the material to be learned. If a learning goal remains unchanged, the intrinsic cognitive load is considered unchangeable.

Approaches to Minimizing Extraneous Cognitive Load

The cognitive and educational psychology literatures contain many studies of strategies for minimizing extraneous cognitive load. Even a basic survey of these strategies can yield significant applications for nursing education. This review will not provide a comprehensive overview of all strategies that have been explored to minimize extraneous load but will highlight a few strategies.

The Worked Example Effect was one of the first reported strategies for minimizing extraneous cognitive load. Research compared students who were provided with explicit details regarding the steps necessary to solve a problem and students who were not provided such details and were therefore required to figure out what those steps might be on their own (Sweller et al., 1998). Through seeing worked examples, students were able to focus on the particular learning goal in the instructional session rather than expending cognitive resources attempting to solve the problem in an unsystematic or trial-and-error manner. Another approach to minimizing extraneous cognitive load is the Split Attention Principle (Ayres & Sweller, 2005). Studies by Ayres, Sweller, and others have found that students who were required to focus on multiple disparate objects at once (e.g., a diagram and text description that were separated on a page) experienced increased extraneous cognitive load compared to students who focused on objects that were integrated (e.g., a text description placed next to the appropriate part of a diagram) (Chandler & Sweller, 1991). This principle was applicable not only for visual information but also when there was competing auditory information during instruction. In one study, learning and retention significantly decreased when students received instruction that included narration and accompanying background music in comparison to students who received the narration without background music (Moreno & Mayer, 2001). A third strategy for reducing extraneous cognitive load is the Modality Principle (Low & Sweller, 2005). Even as working memory is limited, the learner's visual and auditory pathways within working memory can function synergistically to process instructional material. For example, if a diagram has accompanying text, educators can decrease extraneous cognitive load by converting the text into an auditory narration while maintaining the diagram in the visual format. Through the Modality Principle, instructional design is optimized when visual and auditory processing pathways can both be engaged.

Approaches to Fostering Germane Load

Germane load is the cognitive load resulting from activity in working memory that facilitates learning beyond simple task performance (Schnotz & Kürschner, 2007). While extraneous cognitive load interferes with learning by unproductively overtaxing working memory, germane cognitive load promotes acquisition and automation of information into long-term memory (Paas et al., 2003). Therefore, efforts both to decrease extraneous load and to increase germane load during instruction are advocated, with the goal that the total cognitive load does not exceed working memory capacity (Van Merriënboer & Sweller, 2005). Paas and Van Merriënboer (1994) discuss the Variability Effect, whereby increases in the variability of learning tasks may contribute to increased cognitive load but result in improved learning outcomes. This would seem to contradict the previous examples highlighting the negative effects of increased extraneous cognitive load on learning. Indeed, the initial explorations of CLT variables focused on intrinsic cognitive load and strategies for decreasing extraneous cognitive load. The concept of germane load was introduced later, when researchers discovered that some forms of instruction that ostensibly increased cognitive load were found to be beneficial for learning. Another strategy for fostering germane learning processes was to encourage students to make active comparisons and to articulate the differences across examples from different categories (Gerjets, Scheiter, & Schuh, 2008). This approach, while increasing cognitive demands on the learner, facilitated, rather than detracted from, learning. Another study explored both providing worked examples (to decrease extraneous cognitive load) and prompting students to identify underlying principles illustrated by the examples of instruction (to enhance germane load). In this study, worked examples were gradually phased out as the learners improved their understanding of the instructional materials and were then encouraged to articulate the underlying principles for the worked examples (Atkinson, Renkl, & Merrill, 2003). This instructional approach was found to significantly improve learning and transfer. The results are consistent with those of other instructional approaches that attempt to facilitate germane cognitive load by asking students to provide self-explanations of the principles highlighted in the instructional material (Chi, Bassok, Lewis, Reimann, & Glaser, 1989).

Defining what constitutes extraneous cognitive load versus germane cognitive load can be difficult. Depending on the learning goal, the instructional design, and the level of learner expertise, factors contributing to extraneous load in one group of learners may serve to facilitate germane load in another group (Paas, Renkl, & Sweller, 2004). Therefore, instructional strategies that increase the cognitive load on working memory may end up contributing to extraneous or germane load. Determining which form of cognitive load is attributable to the instructional design may at times be done post hoc (De Jong, 2010).

Measurement of Cognitive Load Variables

Sweller (1988) proposed a few strategies to measure cognitive load variables given that direct measures were not available; intrinsic cognitive load could be correlated with the number of units of information a learner was required to hold in working memory or with the degree of complexity in the instructional material. Two decades later, Schnotz and Kürschner (2007) reiterated that there was no definitive way to measure cognitive load variables beyond the general estimating approaches employed in the literature. Three strategies the authors highlight are as follows: asking learners for subjective ratings of perceived cognitive load, measuring physiologic parameters, and applying performance-based measures. While elaboration of the three approaches described by Schnotz and Kürschner is beyond the scope of this review, it is helpful to know that quantitative measures of cognitive load are beginning to appear in the literature (Leppink, Paas, Vleuten, Gog, & Merriënboer, 2013). Such measurement scales may be useful in instructional design and evaluation of instructional variables.

Current Applications of Cognitive Load Theory in Education Research

The principles of CLT and its applications to health profession education research have been discussed with increasing frequency over the past several years, especially with respect to CLT and multimedia learning (Cook et al., 2012; Grunwald & Corsbie-Massay, 2006; Mayer, 2010; Van Merriënboer & Sweller, 2010). Multimedia learning in health profession education includes any approach that incorporates visual, auditory, and/or multisensory experience(s) into the instructional design. Therefore, with the increase in multimedia applications and other learning technologies such as high-fidelity simulation, there has been a concomitant increase in discussion regarding how these learning aids might impact on cognitive load and working memory. The literature on health profession education research includes studies that call for the application of CLT principles to instructional design, studies that have used CLT as the framework for instructional design, and review articles providing support for how to apply CLT to health profession education.

The literature calling for the application of cognitive load principles to instructional design includes studies with virtual patients and the use of computer animations in medical education (Cook, 2009; Ruiz, Cook, & Levinson, 2009). The authors highlight the need to evaluate technology- and multimedia-based instruction through the lens that these more technologically sophisticated instructional formats might hinder learning by placing increased extraneous cognitive load on the learner. They challenge an unquestioning uptake of learning technologies and multimedia applications that do not adequately consider the instructional aims, the learner characteristics, and the evaluation metrics from a cognitive load perspective.

Other health profession education studies have applied the principles of CLT to the instructional design (Holzinger, Kickmeier-Rust, Wassertheurer, & Hessinger, 2009; Stark, Kopp, & Fischer, 2011) and illustrate how CLT offers a useful framework for evaluating the effectiveness of instructional designs and approaches. Holzinger et al. (2009) evaluated the effectiveness of a hemodynamics simulation instructional group in comparison with a text-based instruction group and a group who received the simulation instruction with additional feedback and support. The learning benefit occurred only when additional instructional feedback and support were provided to the simulation-based learning group; otherwise, the simulation group did not demonstrate improved learning outcomes in comparison with the text-based instruction group. Because a fourth intervention group (text-based instruction with instructional support) was not included, it was difficult to ascertain whether these same learning benefits would persist if the additional support were provided to students in a text-based learning environment. The authors interpreted the findings through the lens of CLT and interpreted the simulation-only instruction format as resulting in cognitive overload, but providing the additional support of instruction with the simulations facilitated learning and processing of hemodynamics instruction. Furthermore, simulation-only instruction could be seen as contributing to excessive extraneous cognitive load, but providing the additional feedback and support during instruction could facilitate germane processing.

Stark et al. (2011) explored the variables of example format and feedback in managing the cognitive load of medical students receiving hypertension and hyperthyroidism instruction. Results suggest that offering students erroneous examples with feedback that elaborated on the correct responses improved student performance, whereas erroneous examples without the elaborated feedback resulted in decreased performance. Furthermore, there was a greater positive learning effect of elaboration feedback when the difficulty of the learning domain increased (i.e., from instruction in hypertension to instruction in hyperthyroidism). Such studies demonstrate the ways in which CLT, and evaluation of instructional design with the goal of minimizing extraneous cognitive load and facilitating germane load, can contribute to nursing education and research.

Several review studies have highlighted the contributions that CLT-based approaches can make to health profession education, from general overviews discussing CLT as a potential framework (Patel, Yoskowitz, & Arocha, 2009; Rikers, Van Gerven, & Schmidt, 2004; Valcke & De Wever, 2006), to specific applications in the development of anatomy animations in medical education (Khalil, Paas, Johnson, & Payer, 2005a, 2005b). Discussion of CLT for the design of instructional material in health profession education includes strategies that reduce extraneous cognitive load, facilitate germane cognitive load, and incorporate learner expertise into instructional approaches (Van Merriënboer & Sweller, 2010).

Applications of Cognitive Load Theory in Nursing Education and Research

Currently, there are no known studies employing CLT as a framework for the design and evaluation of nursing education and research. General areas such as cognition and decision-making in nursing practice are explored and many other frameworks are discussed in the literature. For example, high-fidelity simulation and other multimedia applications are being incorporated into nursing education with enthusiasm and rapid acceptance. Frameworks used to guide the development of simulation-based learning include behavioural, constructivist, and experiential learning approaches (Kaakinen & Arwood, 2009) and focus on instructional design within a paradigm similar to that in a study by La Rochelle et al. (2012) evaluating an authenticity-based or context-based approach to instruction. The underlying premise of these approaches is that students learn best when placed in authentic learning environments that closely approximate clinical settings, because this optimizes learner motivation and emotional engagement. As stated in the study by La Rochelle et al. (2012), evaluating these learning modalities through the lens of cognitive load imposed on learners would allow educators to consider how best to use these applications and modalities in nursing education. Some have called for reconsideration of frameworks such as constructivist or experiential learning approaches (Kirschner, Sweller, & Clark, 2006). Others in simulation-based nursing education have called for a similar reconsideration (Sanford, 2010; Schiavenato, 2009). Therefore, application of CLT to nursing education research presents a promising avenue for exploration.

Implications and Future Directions for Nursing Education Research

This article has provided an overview of cognitive load theory and presented principles that have been explored in cognitive and education psychology. CLT as a framework for instructional design and evaluation is the subject of increasing attention in health profession education research, particularly within the realm of multimedia and simulation-based learning applications. Nurse educators and researchers can contribute to nursing education research by applying CLT principles to evaluate instructional design and educational effectiveness.

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Ruth Chen, RN, PhD, is Assistant Professor, School of Nursing, McMaster University, Hamilton, Ontario, Canada. Kelly Dore, PhD, is Assistant Professor, Department of Medicine and Program for Educational Research and Development, McMaster University. Lawrence E. M. Grierson, PhD, is Assistant Professor, Department of Family Medicine and Program for Educational Research and Development, McMaster University. Rose Hatala, MD, MSc, is Clinical Associate Professor, Department of Medicine, University of British Columbia, Vancouver, Canada. Geoffrey Norman, PhD, is Professor, Department of Clinical Epidemiology and Biostatistics and Program for Educational Research and Development, McMaster University.

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Exploring the Impact of Prostate Cancer Radiation Treatment on Functions, Bother, and Well-Being

Maher M. El-Masri, Susan M. Fox-Wasylyshyn,
Colvin D. Springer, Sheila Cameron

Though many studies have explored the effects of radiation therapy on urinary, sexual, and bowel function and/or bother, few have focused on symptom experiences from diagnosis through the first year following completion of radiation therapy. The purpose of this study was to compare the effect of 3 types of radiation treatment on functions, bother, and well-being in men with prostate cancer at 1, 6, and 12 months after completion of treatment. A repeated measures survey (N = 73) found that none of the function, bother, emotional, social, or functional well-being scores were significantly different among the 3 groups. However, within-subjects-only repeated measures ANCOVA suggested that emotional well-being and social well-being are different over time. The findings show that clinical treatment of prostate cancer has an impact on functions, bother, and well-being of patients. Thus, it is important that nurses and other health-care providers listen to what patients are saying before, during, and after treatment.

Keywords: adult health, cancer, quality of life, social support

Résumé

Étude des effets du traitement du cancer de la prostate par radiothérapie sur les fonctions corporelles, les gênes physiques et le bien-être

Maher M. El-Masri, Susan M. Fox-Wasylyshyn,
Colvin D. Springer, Sheila Cameron

Bien que de nombreuses études aient examiné les effets de la radiothérapie sur les fonctions ou les gênes urinaires, sexuelles et intestinales, peu ont mis l'accent sur les symptômes ressentis à partir du diagnostic jusqu'à la fin de l'année suivant le traitement. L'objectif de cette étude était de comparer les effets de trois types de radiothérapie sur les fonctions, les gênes et le bien-être d'hommes atteints d'un cancer de la prostate un mois, six mois et douze mois après la fin du traitement. Un sondage intégrant des mesures répétées (*N* = 73) a permis de constater qu'il n'y avait pas de variation importante entre les trois groupes quant aux mesures touchant les fonctions corporelles, les gênes physiques ou le bien-être social, émotionnel ou fonctionnel. Toutefois, l'analyse de covariance des mesures répétées touchant les sujets uniquement laisse entendre que le bien-être émotionnel et le bien-être social évoluent dans le temps. Les conclusions de l'étude indiquent que le traitement clinique du cancer de la prostate a une incidence sur les fonctions corporelles, les gênes physiques et le bien-être des patients. Il est par conséquent important que le personnel infirmier et les autres professionnels de la santé prennent le temps d'écouter les patients avant, pendant et après leur traitement.

Mots-clés : cancer de la prostate, cancer, qualité de vie, bien-être social

Background

Prostate cancer remains one of the most commonly diagnosed cancers in men, despite reports of a decline in incidence (Canadian Cancer Society, 2011; Jemal, Seigel, Xu, & Ward, 2010). The Canadian Cancer Society (2011) estimates that prostate cancer accounts for 10% of all cancer-related deaths in men. While advances in early diagnosis and radiation treatment (Choi & Hung, 2010; Leibel et al., 2003; Mangar et al., 2005; Tangney, Ahmad, Collins, & O'Sullivan, 2010) contribute to improved survival among this patient population (Bellmunt et al., 2009), such treatment has been reported to have a negative influence on the functions, bother (i.e., the extent to which problems are perceived by the individual patient), and well-being of men with prostate cancer (Eton & Lepore, 2002). However, little is known about whether different radiation therapies have different effects on functions, bother, and well-being throughout the first year following treatment.

Routine screening tests such as prostate-specific antigen (PSA) or digital rectal examination are often used to diagnose prostate cancer prior to the onset of clinical symptoms. Consequently, the occurrence of treatment-related symptoms/problems may suggest to otherwise asymptomatic patients that treatments are harmful rather than helpful or that their cancer is worsening. It is therefore important that the effects of treatment on patients' functions and feelings of well-being are understood so that they can be clearly communicated to the men and their families. However, it is not clear how men's reports of functions, bother, and well-being vary across different types of radiotherapy over time. This gap is especially disconcerting because accurate knowledge about the differential effects of treatments are needed as health professionals assist patients with the selection of cancer therapies and their understanding of the effects of such therapies on their functions, bother, and well-being. Further, It is important that health-care providers give the same attention to the impact of the clinical treatment on functions, bother, and well-being of patients and their families.

Although a plethora of studies have explored the effects of various types of radiotherapy on urinary, sexual, and bowel function and/or bother, few (Guedea et al., 2009; Litwin et al., 2007; Pinkawa et al., 2009; Tanaka et al., 2010) have focused on these effects from diagnosis through the first year following completion of therapy. Further, although a number of studies (Eller et al., 2006; Joseph et al., 2008) have explored feelings of well-being among men with prostate cancer, their findings are inconsistent. Using the Functional Assessment of Cancer Treatment for patients with prostate cancer (FACT-P) to measure well-being, Eller et al. (2006) report a difference between patients who received radical prostatectomy and those who received two different combinations of brachytherapy in a study comparing the three groups at baseline, 1 month, and 3 months. Although the investigators report between-group differences, they did not adjust for baseline scores (time 1) while comparing times 2 and 3. Instead, they compared the scores across all three times. Failure to adjust for baseline differences poses a significant threat to the validity of their findings. However, in a comparison of health-related quality of life between men receiving external beam radiotherapy (EBR) and men receiving high dose radiation brachytherapy in combination with EBR (HDR/EBR), Joseph et al. (2008) found no between-group differences in physical, social/family, emotional, or functional well-being at 12 months post-treatment.

The aforementioned literature shows a need to further study the impact of prostate cancer radiotherapy on functions, bother, and well-being of patients throughout the year following treatment. This is particularly important in light of reports (Balderson & Towell, 2003; Nelson, Balk, & Roth, 2010) suggesting that social/family, physical, and functional well-being are all inversely associated with psychological distress, depression, and anxiety among these patients. Thus, the purpose of this study was to compare the effect of three types of radiation treatment (brachytherapy, HDR/EBR, and EBR) on functions, bother, and well-being of men with prostate cancer at 1, 6, and 12 months after completion of treatment. This study is the second of two studies conducted using this sample. The first (Cameron, Springer, Fox-Wasylyshyn, & El-Masri, 2012) explored the effect of radiotherapy on functions and bother 1 month after treatment and examined the predictors of post-treatment perceived health state.

Findings from this study can be used to support evidence-based decision-making by nurses and other health-care providers as they care for men with prostate cancer throughout the first year following treatment. The psychosocial focus of our study is especially important in achieving a balance between the clinical and psychosocial aspects of treating men with prostate cancer: nurses and other health-care providers need to consider the experiences of patients and their families with regard to the impact of clinical treatments on the men's perceived functions, bother, and well-being.

Methods

Design

A repeated measures survey was conducted with a convenience sample of 73 men with localized non-metastatic prostate cancer to explore the impact of three radiation treatment modalities on their functions, bother, and well-being. The sample constituted all available patients who attended a Regional Cancer Centre that provides a range of cancer services in southwestern Ontario, Canada. Eligible participants (a) had a confirmed diagnosis of localized prostate cancer; (b) were about to undergo radiation treatment (brachytherapy, HDR/EBR, or EBR alone); (c) were able to read and understand English; and (d) were able to provide informed consent. The participants were asked to complete the survey prior to treatment initiation and at 1, 6, and 12 months following completion of their treatment.

Procedures

Prior to commencement of the study, ethical clearance was obtained from the respective research ethics boards (i.e., university and hospital boards). The principal investigator and a research assistant then described the study to potential participants during a routine orientation class that registered nurses at the Regional Cancer Centre provide to introduce patients and their families to their course of treatment (i.e., type, times, and place of treatments). After the presentation, the researchers gave potential participants written information about the study, described the role and expectations of participants, answered their questions, and invited them to enrol. Consenting patients were then asked to complete the baseline survey (described below) either onsite or offsite. Participants who opted to complete the survey offsite mailed it to the investigators in a stamped, addressed envelope that was provided. To minimize the burden on participants and thus increase the likelihood of their continued participation, the research assistant called participants at home to complete the post-treatment questionnaire via telephone. Given that treatment periods varied by type of therapy, patients completed their first post-treatment survey at 1 month following completion of their respective treatment protocol (i.e., 4 weeks for the brachytherapy group, 4 to 6 weeks for the HDR/EBR group, and 6 to 8 weeks for the EBR-only group). The content of the pre- and post-treatment surveys was identical except that the demographic section was not included in the latter.

Instrumentation

Our survey was composed of demographic and psychometric questionnaires. The demographic questionnaire elicited information pertaining to age, marital status, living arrangement, history of cancer, stage of cancer, and mode of cancer detection. The psychometric questionnaire elicited information pertaining to self-perceived functions, bother, and well-being using the Expanded Prostate Cancer Index Composite (EPIC) survey

(Wei, Dunn, Litwin, & Sandler, 2000) and the Functional Assessment of Cancer Therapy-General (FACT-G),Version 3 (Cella et al., 1995).

The 50-item EPIC evaluates patient function and bother in each of four domains: urinary, bowel, sexual, and hormonal. An example of a function item is "How often have you had bloody stools during the last four weeks?" while an example of a bother item is "How big a problem, if any, has having bloody stools been for you during the last four weeks?" Items on the EPIC are measured on a five-point Likert scale ranging from 1 to 5, later transformed to standardized weighted scores ranging from 0 to 100. Responses were coded such that higher scores indicated better function and less bother. The scoring was performed in accordance with published guidelines for the EPIC (Sanda, Wei, & Litwin, 2002). The 50-item EPIC was modified in this study, with a reduced number of items. All items in the urinary and bowel domains were retained. Four of the original nine items pertaining to sexual function were deleted due to their sensitivity (these items pertained to quality and frequency of erections, frequency of sexual intercourse, and frequency of waking with an erection). Only one of the four sexual bother items was retained. This asked how problematic sexual functioning or lack of sexual functioning was for the participant. The impact of hormonal domain was not explored in our study due to the very small number of participants who reported receiving hormonal therapy.

Wei et al. (2000) report high internal consistency (Cronbach's alpha ≥ 0.82) and test-retest reliability ($r \geq 0.80$) for each of the EPIC's domain scales (i.e., urinary, bowel, and sexual) and suggest that internal consistency and test-retest reliability were satisfactory when the domains were further reduced to function and bother sub-domains. In our sample, the Cronbach's alpha coefficients were 0.75 for urinary function, 0.89 for urinary bother, 0.81 for bowel function, 0.93 for bowel bother, and 0.95 for sexual function. Internal consistency testing was not required for the single-item sexual bother scale.

Three subscales of the FACT-G — functional well-being (FWB), emotional well-being (EWB), and social well-being (SWB) — were used to measure health-related quality of life. The FACT-G was developed to measure quality of life among patients with any type of cancer (Cella et al., 1995) and it has well-established evidence of reliability and validity (Cella et al., 1993, 1995; McQuellon et al., 1997). Cella et al. (1995) recommend that scores for each of the FACT-G subscales be calculated by multiplying the number of items in the subscale by the sum of the scores for these items and then dividing by the number of items answered. In this study, we implemented case-mean substitution to impute missing data on individual items; thus, scores on each subscale were calculated by summing the scores on all items in the subscale. Given that a number of items in the FACT-G were administered in reverse form (i.e., higher scores represented poorer quality of life), back reversing of these items was performed prior to scoring. One item pertaining to sexual activity and satisfaction in the SWB subscale was deleted because this improved its Cronbach's alpha from 0.66 to 0.75. Deletion of this item resulted in a six-item SWB subscale. Cronbach's alpha on the EWB (6 items) and the FWB (7 items) was 0.85 and 0.92, respectively. Each item on the FACT-G subscales was measured on a Likert scale ranging from 1 to 5, with higher scores reflecting better well-being.

Data Analysis

Data analyses were conducted using SPSS Version 20. Basic descriptive statistics were performed to describe the demographic characteristics of the sample and compare these across the three treatment groups. Scores on each outcome measure were calculated based on the guidelines outlined in the instrumentation section. Between-subjects repeated measures analysis of covariance (RM-ANCOVA) was performed to compare each study outcome among the three treatment groups at 1, 6, and 12 months while adjusting for baseline scores. Given that no group differences were found across any of the outcomes, the analysis was also performed in the context of a within-subjects RM-ANCOVA to compare the scores on each of the study outcomes at 1, 6, and 12 months while adjusting for their baseline scores. Post hoc pairwise Bonferroni adjustments were then made to examine the difference in the scores across each pair of time periods (i.e., 1 vs. 6 months, 1 vs. 12 months, and 6 vs. 12 months). All data analysis procedures were performed using a two-tailed alpha of 0.05 as the criterion for statistical significance.

Results

Sample Characteristics

The mean age of the participants was 67.6 years (*SD* ± 5.9). The majority of participants were either married or living common-law (*n* = 61; 83.6%). Forty participants (54.8%) had high-school education or less, while 33 (45.2%) had postsecondary education. While 15.1% (*n* = 11) had a personal history of cancer, a slim majority had a family history of cancer (*n* = 51; 69.9%). Further, 63% of participants (*n* = 46) had stage 1 cancer, 31.5% (*n* = 23) stage 2, and 5.5% (*n* = 4) stage 3. The mean PSA score was 7.47 (*SD* ± 7.4; median = 5.84). The results further suggest that the three treatment groups (brachytherapy, HDR/EBR, and EBR) were not significantly different on any of the aforementioned sample characteristics.

Repeated Measures Results

Table 1 displays the results of the mixed between-within-subjects RM-ANCOVA and suggests that, overall, the three treatment groups were not statistically different on any of the study outcomes after adjusting for baseline scores. While there were no significant interactions between time and treatment in any of the study outcomes, within-subjects differences (i.e., scores over time) were found in all outcomes except urinary function ($F = 1.59$; $p = .208$), bowel function ($F = 1.21$; $p = 0.303$), sexual bother ($F = 0.21$; $p = 0.810$), and emotional well-being ($F = 0.39$; $p = 0.676$).

Table 1 ***Function, Bother, and Well-Being in Men With Localized Prostate Cancer, Across Radiation Treatment Groups***

Variable	**Brachy-therapy ($n = 29$)**	**HDR/ EBR ($n = 23$)**	**EBR Only ($n = 21$)**	**Between Groups F ($df = 2$)**	**Within Subjects F ($df = 2$)**	**Inter-action F ($df = 2$)**
Urinary function	438.6 (12.1)	438.9 (13.2)	463.74 (15.6)	1.12	1.59	1.22
Urinary bother	501.9 (16.3)	492.9 (16.9)	534.5 (28.9)	1.13	3.89*	1.34
Bowel function	625.3 (17.3)	593.7 (19.2)	580.2 (20.8)	1.03	1.21	.64
Bowel bother	593.3 (16.0)	551.0 (17.6)	549.0 (19.8)	1.17	5.87**	1.46
Sexual function	88.9 (7.3)	104.4 (7.8)	97.0 (8.5)	1.27	5.70**	.32
Sexual bother	67.4 (4.1)	61.8 (4.6)	67.8 (4.8)	.49	.21	.54
Social well-being	22.9 (.3)	23.0 (.4)	23.2 (.4)	.31	4.85**	1.9
Emotional well-being	23.1 (.4)	22.7 (.4)	23.4 (.4)	.84	.39	1.35
Functional well-being	28.7 (.6)	28.5 (.7)	28.8 (.8)	.22	5.88**	1.69

Notes: HDR = high dose radiation; EBR = external beam radiation; *F*'s and significance levels from mixed between-within-subjects RM-ANCOVA with interaction effects.
* $p < .05$, ** $p < .01$

Table 2 ***Function, Bother, and Well-Being in Men With Localized Prostate Cancer, Over Time***

Variable	**Time 1 (1 Month) *M (SD)***	**Time 2 (6 Months) *M (SD)***	**Time 3 (12 Months) *M (SD)***
Urinary function	388.4 (96.4)$_a$	448.0 (66.8)$_b$	464.7 (58.9)$_c$
Urinary bother	442.4 (141.7)$_a$	525.3 (103.1)$_b$	557.5 (99.5)$_c$
Bowel function	572.8 (140.0)$_a$	611.3 (119.2)$_{a,b}$	626.0 (104.0)$_b$
Bowel bother	561.9 (158.8)$_a$	604.1 (131.6)$_{a,b}$	616.1 (120.4)$_b$
Sexual function	77.3 (103.6)$_a$	104 (110.0)$_{a,b}$	123.9 (118.3)$_b$
Sexual bother	65.8 (30.6)$_a$	64.7 (28.2)$_a$	66.8 (29.5)$_a$
Social well-being	27.5 (3.0)$_a$	21.3 (2.1)$_b$	21.5 (2.2)$_b$
Emotional well-being	12.8 (2.5)$_a$	26.4 (3.4)$_b$	26.5 (3.5)$_b$
Functional well-being	28.3 (4.9)$_a$	28.9 (4.6)$_a$	29.2 (4.8)$_a$

Note: Means in the same rows with different subscripts are significantly different from each other at $p < .05$ according to Bonferroni-adjusted pairwise comparisons following within-subjects-only RM-ANCOVA.

Table 2 displays the within-subjects-only analyses performed on each of the study outcomes, highlighting the adjusted mean scores at each time period and the *p* values of their respective Bonferroni-adjusted pairwise comparisons. These pairwise results suggest that there were time-related changes in all outcomes except sexual bother and functional well-being.

Discussion

After adjusting for baseline scores, our between-subjects repeated measures findings suggest that there were no differences among the three radiation treatments with regard to any of the outcome variables. However, the within-subjects comparisons showed time-related changes in urinary bother, bowel bother, sexual function, social well-being, and functional well-being, which are important changes for men and their families to understand. No interaction effects were found between treatment groups and time in any of the study outcomes. Given the absence of between-group differences and interactions, subsequent within-subjects ANCOVA (which ignored treatment groups) with Bonferroni-adjusted pairwise comparisons revealed that there were time-related changes on all outcomes except sexual bother and FWB.

Although other prospective studies have compared the impact of different treatments over time (Huang, Sadetsky, & Penson, 2010; Lev et al., 2009; Litwin et al., 2007; Talcott et al., 2003), our study is unique in comparing three radiation treatments (brachytherapy, HDR/EBR, and EBR) over time. Further, ours is one of only a few longitudinal studies (Huang et al., 2010; Lev et al., 2009; Talcott et al., 2003) to control for baseline scores of the outcome variables. Lastly, of the studies that we reviewed, none examined the same time intervals that were used in our study. These differences make it difficult to compare our findings with those of other studies.

The finding of an absence of between-treatment differences suggests that the impact of treatment on functional/bother domains and well-being may not be an important factor to consider when selecting among these three approaches to radiotherapy. However, this finding is not consistent with those of previous studies. We caution that the lack of between-group differences in our study may be unique to our sample and/or issues with statistical power, given our relatively small sample. In fact, post hoc power analysis revealed that our actual power for RM-ANCOVA among the three groups was 69% and that a sample of 105 participants was needed to yield 80% power based on a small to medium effect size ($f = 0.25$). Thus, we recommend that these findings be investigated with a larger sample.

Our findings suggest a significant improvement in bowel function between 1 and 12 months. As expected, this corresponded with improvement in bowel bother as indicated by higher scores for bowel bother. Although sexual function was low across all three time periods, the within-subjects analysis suggests that participants experienced significant improvement in sexual function between 1 and 12 months. However, this improvement was not accompanied by an improvement in sexual bother. This apparent discrepancy between the sexual function and sexual bother findings is not surprising, as others (Penson, Litwin, & Aaronson, 2003) have found that function and bother do not always correlate. It is also possible that the slight functional improvements are not satisfactory and thus lead these patients to experience feelings of bother as their problems linger over time.

Consistent with our findings with respect to the sexual and bowel domains, urinary function demonstrated significant improvement between 1 and 12 months. Unlike the sexual and bowel domains, urinary function also showed significant incremental improvements between 1 and 6 months and between 6 and 12 months. Corresponding improvements in urinary bother were seen for all three time frames, suggesting that urinary bother diminished as function improved.

It is interesting that when function scores were high over time, as with urinary and bowel functions, patients experienced statistically significant improvements in their sense of bother. However, despite statistically significant improvement in the relatively low sexual function scores, there was no corresponding improvement in sexual bother. These findings suggest that a patient's sense of bother is only somewhat linked to their sense of function — that is, an improvement in function may not necessarily decrease the sense of bother if the function improvement is marginal and does not change the score from a low to a high range, as in this study. Thus, it is important that nurses not only consider whether a function improves over time, but also pay attention to the degree of improvement. Patients who experience relative functional improvement but continue to experience lower than optimal functions are likely to experience a sense of bother that needs to be addressed.

Our results indicate that there were no changes in functional well-being throughout the course of the study. This finding is likely related to the relatively high levels of functional well-being at 1 month, which left little room for improvement in subsequent months. At 1 month, participants had relatively low levels of EWB. By 6 months, EWB scores had nearly doubled, at which point they levelled off and showed no further change between months 6 and 12. This improvement in EWB corresponds to improvements in the sexual, urinary, and bowel functions and thus may reflect a sense of optimism with respect to their progress and prognosis.

Participants in this study reported high levels of SWB at 1 month post-treatment. This is likely related to the tendency of family and friends to rally around individuals during the time frame following a cancer diagnosis and subsequent initiation of treatment. By months 6 and 12, participants had experienced a significant drop in SWB in comparison to their scores at 1 month. These lower scores may be related to the fact that the acute crisis phase of a cancer diagnosis and its treatment had passed, resulting in a possible reduction in the high level of support that is typically provided to patients during the crisis phase of their illness.

Implications for Practice

Given that men with prostate cancer may not experience problems when the cancer is first diagnosed, and that symptoms are likely to manifest after radiation treatment, it is important that nurses and other health-care providers prepare both patients and families for the nature of those potential symptoms during the first follow-up year. Since most scores were lowest at the initial phase of treatment completion (i.e., at 1 month), nurses and other health professionals may need to pay special attention to emotional concerns during this critical time. Functional impairment due to treatment may be misinterpreted by patients and their families as a sign of health deterioration. Our findings pertaining to sexual function and bother scores indicate that improvement in sexual function might not translate to a reduction in sense of bother and thus nurses may need to assess sexual function and bother separately.

We caution nurses against generalizing our finding concerning the seemingly similar impact of the three radiation treatments on functions, bother, and well-being among men with prostate cancer. We recommend that our results be further investigated before our suggested implications for practice with regard to this finding are considered. We also recommend that the observational self-report nature of our study and the fact that it was conducted with a relatively small sample be considered. We recommend that it be replicated with a larger sample that will provide sufficient power to analyze the data while adjusting for the clustered nature of observations and the collinearity among multiple outcomes.

In conclusion, our results suggest that the functions, bother, and well-being scores of men with prostate cancer who receive radiotherapy are likely to improve over time, regardless of the nature of that therapy. Although sexual function improved over time, persistent low scores indicate that sexual function continues to be a problem a year after completion of treatment. Finally, the findings of our research add to the growing literature that highlights the fact that clinical treatment of cancer has an impact on functions, bother, and well-being of patients and their families. Thus, it is essential that patients' experiences and concerns be considered before, during, and after radiation treatment. Specifically, nurses and other health-care providers need to inform patients and their families about what to expect during the first 12 months after completion of radiation treatment. Furthermore, it is important that patients feel that they are being listened to and that their experiences are being considered by their health-care providers.

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Quality of Life After Radiation Therapy for Prostate Cancer

Maher M. El-Masri, Susan M. Fox-Wasylyshyn, Colvin D. Springer, Sheila Cameron

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Maher M. El-Masri, RN, PhD, is Professor and Research Chair, Faculty of Nursing, University of Windsor, Ontario, Canada. Susan M. Fox-Wasylyshyn, RN, PhD, is Associate Dean and Associate Professor, Faculty of Nursing, University of Windsor. Colvin D. Springer, MD, is Radiation Oncologist, Department of Oncology, Windsor Regional Cancer Centre. Sheila Cameron, RN, EdD, DSc, is Professor Emeritus, Faculty of Nursing, University of Windsor.

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Social Marginalization and Internal Exclusion: Gay Men's Understandings and Experiences of Community

Patrick O'Byrne, Alyssa Bryan, Andrew Hendriks, Cynthia Horvath, Christiane Bouchard, Vera Etches

A total of 27 gay and bisexual men were interviewed about how they perceived the criminal prosecution of persons living with HIV who do not disclose their HIV status. The stories that emerged from the interviews raise questions about the nature of the gay community. The findings centre on the participants' descriptions of (1) the heterosexual meta-culture, (2) the locales of gay life, and (3) unsupportive elements in the gay community. Analysis of the interview data situates the gay community as a place of both inclusion and exclusion and as a heterogeneous environment.

Keywords: community health nursing, culture, HIV, public health, sexual and reproductive health

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Résumé

Marginalisation sociale et exclusion au sein du groupe : perceptions et expériences des gais à l'égard de leur communauté

Patrick O'Byrne, Alyssa Bryan, Andrew Hendriks,
Cynthia Horvath, Christiane Bouchard, Vera Etches

Des entrevues ont été menées auprès de 27 hommes gais et bisexuels afin de sonder leurs perceptions à l'égard des poursuites criminelles intentées contre les personnes vivant avec le VIH/sida qui n'ont pas divulgué leur état. Les récits qui en découlent soulèvent des questions sur la nature de la communauté gaie. Les données touchent aux descriptions des participants concernant 1) la méta-culture hétérosexuelle; 2) les lieux de la culture gaie; 3) les éléments non solidaires au sein de la communauté gaie. L'analyse des données d'entrevue situe celle-ci comme un espace à la fois d'inclusion et d'exclusion et comme un milieu hétérogène.

Mots-clés : culture gaie, VIH, communauté gaie, méta-culture hétérosexuelle, inclusion, exclusion

Introduction

As part of research on the relationships between public health HIV-prevention outcomes and prosecution of persons living with HIV for nondisclosure of HIV status (see O'Byrne et al., 2013), we undertook semi-structured interviews with 27 gay and bisexual men. Because this approach to data collection allowed our participants to discuss ideas beyond the prescribed limits of the initial study, it yielded unexpected findings. For example, our participants described the gay community in ways that, through thematic analysis, made it appear both excluded and exclusionary. In opposition to "assumptions of solidarity among homosexuals, [which] developed in the seventies political movement and through the AIDS crises of the eighties" (Ridge, Minichiello, & Plummer, 1997, p. 148), our participants did not describe the gay community as a monolith that is open and accepting. Instead, they commented on how the gay community is fragmented and exclusive.

Such descriptions caused us to reflect both on the meaning of "gay community" and on how we employ this phrase in our daily work as HIV-prevention workers, clinicians, and researchers. For example, because many HIV-prevention initiatives for gay men appear to operate on "assumptions of solidarity," our participants' descriptions of the gay community caused us to ask how we should understand the idea of gay community for our HIV-prevention work. To answer this question, in this article we use our participants' descriptions of and narratives about the gay community to (1) reconsider the idea of solidarity among gay men, (2) reflect on the word "community," and (3) consider what the notion of community could mean from different perspectives. To situate this reflection, we provide definitions of community and outline the current research with respect to the gay community. We believe our findings are important for nurses and other HIV-prevention workers and clinicians who work with gay and bisexual men because they help situate the context of HIV prevention for these men.

Background

Defining "Community"

While there are many definitions of "community," that of the World Health Organization [WHO] (1998) succinctly captures the intricacies embedded in the concept. For the WHO, community defines a

> specific group of people, often living in a defined geographical area, who share a common culture, values and norms, are arranged in a social struc-

> ture according to relationships which the community has developed over a period of time. Members of a community gain their personal and social identity by sharing common beliefs, values and norms which have been developed by the community in the past and may be modified in the future. They exhibit some awareness of their identity as a group, and share common needs and a commitment to meeting them. (p. 5)

The WHO (1998) definition suggests that communities are either (a) location-specific, in that they describe persons who are clustered due to some boundary, or (b) based on the existence of common characteristics (Holt, 2011; Peacock, Eyre, Quinn, & Kegeles, 2001). Aligning with the WHO definition, nurses typically use the word "community" in one of these two ways to describe persons who are geographically or characteristically similar (Smith & Maurer, 2000). This use of the word, however, excludes other groupings that may have emerged due to shared experiences or beliefs. Indeed, communities can also be defined in a relational manner, meaning that a group is a community due to shared experience or identity or mutual feelings of belonging (Holt, 2011). An important aspect of this second definition is the fact that relational communities possess factors that contribute to or protect the well-being of group members (Smith & Maurer, 2000). This meaning of community thus goes beyond the WHO (1998) definition: "members of a community not only share common elements such as locale but also view each other as equals and feel socially connected" (Ridge et al., 1997, p. 147–148). Community, then, is not an entity but an experience of emotional attachment wherein "the less universal the experience, the stronger . . . the emotional bond" (Woolwine, 2000, p. 31). Based on this expanded description, important aspects of community membership are collegiality and a sense of connectedness (Smith & Maurer, 2000).

There are, however, two important issues concerning the above descriptions of community. First, with their focus on unity and similarity, current understandings efface the divisions that exist in many communities (Fraser, 2008; Ridge et al., 1997); that is, because the word "community" is permeated with the idea of homogeneity, its usage ignores the heterogeneity that is imbedded in many communities. Second, most contemporary ideas of community assume that individuals precede communities, that communities are the result of people with similarities coming together; this idea contrasts with the communitarian perspective, that individuals are the outcome of community life (Dowsett, 2009; Fraser, 2008). While these points may seem pedantic, they are important caveats that one must consider when thinking about community.

The Gay Community

For at least 40 years, authors, researchers, and activists have debated the idea of a gay community (Dowsett, Wain, & Keys, 2005; Ridge et al., 1997; Watney, 1996; Woolwine, 2000). Our review of the literature specifically from the last two decades finds that it consists primarily of abstract descriptions of the gay community, personal narratives of experiences in this community, and theoretical discussions about what is required to join this community. The literature also describes what is posited as a trend towards individualism (Adam, 2005; Davis, 2008; Sheon & Crosby, 2004).

The first commonality in the literature is that it describes the gay community in multiple ways varying from inherently good to intrinsically bad, or both simultaneously (Fraser, 2008; Holt, 2011; Ridge et al., 1997; Robinson, 2009; Rowe & Dowsett, 2008). For example, based mostly on interviews but also on survey data, it identifies all of the following findings: gay communities comprise small networks of similarly oriented men who congregate and form friendships and social networks due to their exclusion from mainstream heterosexual culture (Bérubé, 2003; Dowsett et al., 2005; Dowsett & McInnes, 1996; Flowers, Duncan, & Frankis, 2000; Peacock et al., 2001; Ridge et al., 1997; Woolwine, 2000); they are increasingly fragmented due to a proliferation of diverse expressions of erotic desire among homosexually active men (Dowsett, 2009; Dowsett & McInnes, 1996; Fraser, 2008; Holt, 2011; Peacock et al., 2011; Rowe & Dowsett, 2008; Woolwine, 2000); they have become increasingly exclusionary, rather than inclusive, and are sharply divided based on HIV status (Courtenay-Quirk, Wolitski, Parsons, Gomez, & Seropositive Urban Men's Study Team, 2006; Flowers et al., 2000; Holt, 2011; Peacock et al., 2001; Sheon & Crosby, 2004); they are dissolving due to generational shifts as homosexuality is accepted or assimilated by mainstream culture (Holt, 2011; Rosser, West, & Winmeyer, 2008; Zablotska, Holt, & Prestage, 2012); virtual and personal gay communities have increased, while geographic communities have decreased (Holt, 2011; Robinson, 2009; Rosser et al., 2008; Zablotska et al., 2012); and they are considered mythical or mournfully lost (Dowsett et al., 2005; Fraser, 2008; Holt, 2011).

In contrast to these abstract perceptions of the gay community, the next common theme in the literature relates to participants' narratives about their experiences with the gay community. These findings highlight a gap between the abstract ideations of the gay community and one's actual experiences, some positive and others negative (Dowsett et al., 2005; Fraser, 2008; Holt, 2011; Ridge et al., 1997; Robinson, 2009). We will now summarize these findings. Some research indicates that the gay commercial scene, such as bars, clubs, festivals, and parades, plays a primary role in the gay community, either as entry point or as offering places to form "social memories" (Flowers et al., 2000; Ridge et al., 1997; Robinson, 2009). Other research reveals that gay community life is more than "the scene" — described as superficial and not a place for meaningful relationships — and involves HIV/AIDS organizations, social groups, and political activism (Ridge et al., 1997; Robinson, 2009; Woolwine, 2000). Still other research finds that the distinctions between the scene, the community, and other aspects of gay life are academic distinctions between inextricable aspects of people's lives (Dowsett et al., 2005; Holt, 2011; Rowe & Dowsett, 2008). Lastly, the research examining relationships between people's involvement in gay community life and their uptake of HIV testing and/or engagement in unprotected sex has yielded mixed results (Courtenay-Quirk et al., 2006; Lelutiu-Weinberger et al., 2013; Ridge et al., 1997; Zablotska et al., 2012).

The third main focus in the literature on the gay community comprises discussions about what is required to join this community. This work points out that a homosexual orientation is not sufficient; one has to, to use Dowsett's (2009) term, "do gay"[1] properly in order to be accepted (Dowsett & McInnes, 1996; Fraser, 2008; Rowe & Dowsett, 2008). For example, doing gay involves conformity with gay norms regarding fitness, fashion, and drug use, such as which drugs and routes are permitted (Dowsett et al., 2005; Fraser, 2008; Ridge et al., 1997). According to Sheon and Crosby (2004), doing gay also means "attaining credentials for membership in the gay community" by building an acceptable "gay résumé" through unimpeded sexual expression and activity (p. 2109). This literature also notes that isolation and marginalization are the consequences of not conforming to established ways of doing gay (Dowsett et al., 2005; Ridge et al., 1997; Robinson, 2009).

Methodology

Recruitment and Ethical Considerations

To be included in the study, a person had to self-identify as gay, bisexual, or a man who has sex with men; reside in the local region (Ottawa, Canada, and environs); speak English or French; and be aware of recent media stories about the criminal prosecution of a local person living with HIV who had allegedly not disclosed his HIV status to his sexual partners. Recruitment involved raising awareness of the project within local AIDS service agencies (e.g., we arranged meetings to describe the project

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[1] Dowsett (2009) describes "doing gay" as performative, which is "a regularized and constrained repetition of norms . . . [that] is not a singular act or event, but a ritualized production" (Butler, 1993, p. 95).

to key stakeholders within these agencies); distributing posters in venues frequented by gay men (e.g., STI testing clinics, gay bars, bathhouses); and snowball sampling. As part of snowball sampling, we gave participants a supply of the research assistant's business cards to pass along to others who might be willing to take part. Participants were under no obligation to distribute recruitment material.

The project was approved by the Research Ethics Board at Ottawa Public Health.

Data Collection

We conducted semi-structured interviews with everyone who met the inclusion criteria. Each interview lasted from 60 to 90 minutes and was immediately transcribed and subjected to initial analysis. In an iterative fashion, we continued data collection and preliminary analysis until we reached data saturation — that is, the point when the interviews became repetitive and no new data were emerging. Saturation occurred after 27 interviews. While the goal of the interviews was to explore perceptions about prosecution for nondisclosure and about public health and HIV prevention, the semi-structured nature of this data-collection strategy meant that each point raised by the participant was fully addressed and explored during the interview. These unexpected topics were therefore not considered extraneous or off-topic during the interview. Not surprisingly, participants discussed items that did not relate to the primary research objectives but that became noteworthy during analysis — for example, descriptions concerning the gay community.

Data Analysis

We analyzed the entire data set using a multi-step thematic approach. First, based on the meaning, language, and sentence structure of participants' statements, we generated an initial list of codes. Second, we grouped and ranked similar codes. Third, we grouped the codes into themes; we articulated the content of each theme both independently and in relation to the other themes. Fourth, we ensured that combined codes were coherent and that themes were distinct. Fifth, we produced an overarching narrative that described the interview data. As part of this process, we grouped themes based on their relevance to the intended (and funded) study focus concerning nondisclosure prosecution, public health, and HIV prevention. The results that relate to this topic have been published elsewhere (O'Byrne et al., 2013). After we completed the initial data synthesis, we reviewed the additional findings. Another important area of focus within the data was the gay community. These data are presented here.

Results

Demographics

We interviewed 27 gay and bisexual men (12 self-reportedly HIV-positive, 15 HIV-negative), 23 of whom provided demographic information. Of the 23, 48% (*n* = 11) were in the 19–30 age group; the next-largest age group was 31–40. In terms of income and education, 52% (*n* = 12) had an annual income of $0–$20,000 and 17% (*n* = 4) $61,000–$80,000, while 43% (*n* = 10) held a bachelor's degree and 17% (*n* = 4) a college diploma. Lastly, 87% (*n* = 20) self-identified as Caucasian, 4% (*n* = 1) as Black, and 4% (*n* = 1) as Aboriginal.

Interview Findings

An array of findings emerged in the interviewing of participants to better understand the population health effects of criminal prosecution of persons with HIV who do not disclose their HIV status. The findings of interest in the context of this study include descriptions of (1) the heterosexual meta-culture, (2) the locales of gay life, and (3) unsupportive elements in the gay community. Please note that the participants' names are replaced by pseudonyms.

Theme 1: The heterosexual meta-culture. The first noteworthy finding emerged from the participants' perceptions that, within dominant social perspectives, homosexuality is construed as a deviation from a natural or pre-eminent heterosexuality, a divergence from the normative state. Two participants described this view, one in relation to the heterosexist norm of language, the other in relation to numbers:

> *[Assumptions of heterosexuality] are relatively harmless but still force you to be in a difficult situation when you have to respond. . . . The whole use of language and everything like that in society is based on heterosexism.* (Ethan, HIV-, 19–30 age group)

> *. . . we, statistically, are a minority [and] minorities are stereotyped. How do you describe something that is statistically uncommon? You try to either find a trend with it or push a trend upon it. I know straight people who are way more promiscuous than gay people.* (Seamus, HIV-, 19–30 age group)

As is evident in these quotes, Ethan and Seamus believed that heterosexuality is considered the overarching normative state in relation to both acceptability and frequency. Another participant, George, also referred to the heterosexualist undertones of the English language and perceptions about prevalence. He raised the issue of "coming out," which indicates that, socially, persons are assumed to be heterosexual until proven otherwise. Again, heterosexuality is the normative state from which people who are gay deviate (i.e., come out as different). George explained that coming out, by self-identifying as an individual who resides outside the heterosexual meta-culture, is a struggle that requires reflection and privacy:

> *Here's an example. A few years ago, when I was thinking of coming out, I called [agency] and I said, "Do you have any kind of counselling services for men my age?" They said, "Yes, we have a group session once a week for men between 25 and [I think it was 45]." I said, "Group! I'm struggling with the decision. I don't want to sit in a group." I said, "I'm talking private." They said, "No, we don't," and I said, "Well, how is that helping somebody who's struggling with it, putting me in a group of other people who are struggling with it so my privacy is gone?"* (George, HIV-, 41–50 age group)

George's struggle with coming out indicates that accepting one's minority sexuality is fraught with challenges, and therefore was something he wished to do in private. When analyzed in relation to community and social organization, coming out can thus be understood as a process of attaching oneself to a subculture or "contra-culture," which means exclusion from the hegemonic (heterosexual) meta-culture, and as an act of accepting that one is part of a minority that is often the target of derogatory and hateful comments. Two participants explained:

> *Because we live in the marginality of the system, we have to go through several steps. For younger men [it] is not that complicated, not for most. But for a minority, they feel there's a positive side to it that says, "I'm gay and I'll show it." I never thought like this. I felt . . . I was in a subculture, a contra-culture.* (Martin, HIV-, 19–30 age group)

> *I spent a year in teachers' college and I was really shocked at the homophobic stuff you hear in the classroom. I had students saying, "Oh, this computer is so gay!" And I'm, like, "Why is your computer a homosexual?" They just don't connect gay with homosexual. I think that gay is almost like this nebulous thing. Unless you actually know somebody who is gay, it's just so alien and so foreign and easy to make fun of. I know plenty of people who aren't racist, aren't sexist, aren't critical of people with disabilities, but when it comes to gay people they'll be offensive. I think it's one of the last groups that it's still okay to hate.* (August, HIV-, 19–30 age group)

The comments of Martin and August show that the process of coming out is complicated by the fact that one must acknowledge a personal association with a group that is seen negatively from a mainstream social perspective. Coming out, therefore, is not only a process of revealing one's sexual identity, orientation, or practices, but also an act of saying that one is not part of the heterosexual meta-culture. It is to declare that one belongs to what Martin called a subculture or contra-culture. Another participant added an important nuance about the rejection of sexual minorities by stating that the rejection is not outright but forces minority groups into specific regions of purported acceptance:

> *It also functions like pretty much any . . . minority group. It's not that somebody who's sexist wants all women to go away. It's not like somebody who's racist never wants to see a Black person. It's not like somebody who's homophobic doesn't want to see a gay person anywhere. It's all about where there are acceptable spaces in society for these individuals. So somebody who's sexist might like women to be a housewife or a secretary, just [as] somebody who's homophobic might say, "I don't mind gay people. They can be performance artists or in arts and culture. But having them in politics — that's a completely different story."* (Ethan, HIV-, 19–30 age group)

While Ethan described a location-based acceptance of homosexuality, Seamus stated that, although homosexuality may be less stigmatized today than it used to be, it is still not fully accepted:

> *I remember, 10 years ago, I got a real sense that — not just being gay and knowing that I was gay — we were thought of as freaks, pedophiles, deviants . . . we were just making this horrendous choice that was unnatural. . . . people have to stop thinking that way. . . . It's not a choice . . . who would, at that age, choose to be gay? It's hard.* (Seamus, HIV-, 19–30 age group)

George echoed Seamus's belief that homosexuality is marginalized. George said that he would lose friends if he revealed his sexual orientation:

> *I'm trying to come out, generally, and two of my best male friends would probably drop me, because they're homophobic, because they're prejudiced, because they're narrow-minded. And one of them has been my friend for 8 years, and I know [that] if I told them, the friendship would end. People say, "That's not very much of a friend." . . . I say, "Yeah, he is, but he just can't come around." My mother's struggling [to accept my sexuality]. If I lost a friend, it wouldn't surprise me.* (George, HIV-, 41–50 age group)

The prejudice described by George, however, is not expressed exclusively by individuals who self-define as heterosexual. The following statements, when read in combination, reveal a self-propagation or internalization of meta-cultural norms. Cedric used the word "normal" to describe the traditionally heterosexual institution of marriage and children and stated that he disapproved of non-monogamous behaviour. Jacob, meanwhile, suggested that Cedric's beliefs about monogamy did not relate to normality but, rather, were manifestations of meta-cultural norms[2]:

> *I'm interested in a normal lifestyle, like, having kids and stuff. I live in [region] and there's lots of gay couples that have kids, and I think that's great. That's the kind of life that I want. I'm definitely getting married.* (Cedric, HIV-, 19–30 age group)
>
> *I know there [are] people that are like me and my boyfriend, who are monogamous. And I don't really like — I definitely don't approve of [non-monogamous] behaviour. And I don't understand how anyone can maintain a relationship if you don't have anything that's private. . . . Disgusting.* (Cedric, HIV-, 19–30 age group)
>
> *I'd disagree that there's not strong pressure to get, like, a long-term relationship. There's definitely pressure, even within the gay community, to couple up, partner off, and be monogamous, and basically be heterosexual, I'd say. And, personally, I'm not strongly drawn towards a committed relationship, to put it politely, but I feel a fair bit of pressure that maybe I should be.* (Jacob, HIV+, 19–30 age group)

Jacob's comments about the *heterosexualization* of gay life and culture contrast with Cedric's view of marriage and family and monogamy as normal, thus indicating that other behaviour is abnormal. This suggests that heterosexual meta-cultural norms are not imposed exclusively by an oppressive *other*. Gay men partake in the process by internalizing and externalizing meta-cultural modes of believing and thinking. While idealizing monogamy as the sexual norm serves to heterosexualize gay culture, it also signals the heterosexual meta-culture. The heterosexual-

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[2] Internalized meta-cultural norms should not be conflated with internalized homophobia. In our usage, internalization of the meta-culture means the adoption and replication of mainstream social norms. In the comments where this point is raised, some participants discuss marriage and monogamy as "normal," while others describe this behaviour as heterosexual. By comparison, internalized homophobia relates to the personal adoption of negative perceptions about oneself due to one's homosexuality. Internalized homophobia thus goes beyond preferences, to feelings of self-loathing and revulsion for being anything other than heterosexual. The narratives of our participants suggest that this process is more appropriately described as an internalization of meta-cultural norms rather than as internalized homophobia, because there are no signs of self-hatred or loathing in their descriptions; it is simply an adoption of meta-cultural preferences and idealizations of monogamy.

ization of gay culture is evidence of an overarching normative culture against which other cultures are measured.

Theme 2: The locales of gay life. The participants described the importance of gay bars for a group of men who do not belong to the mainstream, who are part of what Seamus called an "invisible minority." Simply put, for the participants, gay bars were, on the one hand, the outcome of their invisible minority status, and, on the other hand, locales where safety was ensured:

> *There's stigma, marginalization, ostracization. That's why gay clubs exist, right? It's not for the dancing and the drinking, because you can do that in any club, in any straight club. It's because you feel safe with your own kind.* (George, HIV-, 41–50 age group)

Because he was gay and because some gay men feel they do not belong to the heterosexual meta-culture, George frequented special milieux to be among other homosexuals. Another participant explained that he visited gay bars to meet gay men because, in such milieux, assumptions of heterosexuality become assumptions of homosexuality. Such gay spaces invert normative assumptions about sexuality, making homosexuality the norm and according heterosexuality minority status. This reversal of sexual norms results in a feeling of safety. There, one need not worry about people reacting negatively to one's sexual advances:

> *I've always heard that gay people are promiscuous, that we meet people in bars and online, and perhaps that's a little true, but how else are we going to find each other? I wish we could just go up to anyone and say, "I think you're really attractive," or talk to someone if they're interesting. But what if they get offended if you ask if they're gay or, you know, they're straight and they really don't want a gay person hitting on them? That's a social risk for people, and although we can be out, we can't be out enough that we can openly pursue people. So we go where we know gay people are, and that carries the perception of being a slut or promiscuous.* (Seamus, HIV-, 19–30 age group)

While George and Seamus felt safe in gay bars, Henry recalled that gay bars were not safe for him when he was younger. Instead, they created an image in his mind about *what* gay men do, *how* they behave and look, and *who* he should be as a gay man. Henry's lack of "connections" with and awareness of other gay men left him feeling alone and vulnerable as he matured as a gay man:

> *[When] I came out I was 13. I was alone. When you're so young, and when you know so much about yourself but you don't have the resources or necessarily the connections . . . if I [had] an older sister [who] was a*

> *lesbian, I don't think I would have ended up in the bars. I think I ended up in the bars, and I think that every young man here in [city] will end up in bars, because that is all you got here.* (Henry, HIV-, 19–30 age group)

In addition to noting how a lack of mentorship correlated with his visiting gay bars at 13 years of age, Henry problematized this type of introduction to gay culture and identity:

> *I remember growing up gay, going to [location], and that was the best thing. But you go in there and you don't see books about young gay men who are trying to make friends. You see porn and big dicks and nice asses and six packs and you see those beautiful boys that they feature on every wall.* (Henry, HIV-, 19–30 age group)

Based on his experience, Henry favoured the idea of non-gay-bar safe zones where gay men can interact with one another and learn about gay rights, gay history, and the gay community:

> *What is lacking are safe zones. A lot of gay youth don't have a place to go. Whether it be [a] coffee shop with the rainbow, you know that this is a safe zone, that you can go there and be safe, be it that the owner is gay or that people who work there are gay-friendly. I think that's what we need: different zones.* (Henry, HIV-, 19–30 age group)

> *As a young gay man, [I] had no one to say, "Hey, don't do that — watch* Priscilla, Queen of the Desert,*" or, "Don't do that. You should read up on Stonewall. You should really go research Harvey Milk. You want to know where your rights come from? Then go research it." I wish I [could] have had more.* (Henry, HIV-, 19–30 age group)

Henry's comments, along with those of George and Seamus, indicate that gay bars play a particular role in gay culture. They are safe spaces for approaching men in sexual and erotic ways while also preserving the sexualization of gay identity. They provide a safe environment for seeking sexual partners who are not members of the heterosexual meta-culture, but they do so while propagating assumptions about gay men and sexuality/promiscuity. Thus, the participants described gay bars as places to safely cruise other men.

Theme 3: Unsupportive elements in the gay community. The final theme emerged from the participants' many descriptions of how gay men mistreat each other, which included judgemental comments and behaviours and racism towards one another:

> *There are things going on: gay men being victimized by other gay men.* (George, HIV-, 41–50 age group)

> *I think that a lot of gay guys who are White are often racist against gay guys who are Black and often think that they're the source of HIV, and that's harmful, because you're literally playing the same game that straight people play.* (Ethan, HIV-, 19–30 age group)

> *There have been a few occasions at [gay bars] when I've heard people make comments about my ethnicity. I was out with my friends and there was this guy who said, "What's happening at this bar? Now we let Black men in?" When I heard this, I turned around, and I sort of knew the guy, and I said, "Hi," and he said, "Don't worry, everyone, I know this guy." It's sad that such jokes are acceptable. It's ignorance, but what can you do about it? Nothing. The other racist thing that I've found in gay milieux is comments like "I love Black men. You guys have such big penises." It's exoticism. It's not a person they see. I've also heard this discussion among my Asian friends.* (Nelson, HIV-, 31–40 age group) (authors' translation)

> *It tends to be very cordial . . . but there's a lot of backstabbing after. [Gay men] are very pleasant to each other face-to-face, but they seem to talk a lot, put them down, behind their back.* (Steve, HIV-, 19–30 age group)

These comments by George, August, Nelson, and Steve show that the gay community is not a cohesive collection of individuals who trust and support one another, and it is not a united front for equal rights and social acceptance. Instead, our participants described the gay community as a relatively small network of men who simply have similar sexual preferences:

> *[The gay community] is like a web of sex. And everyone's had sex with each other. And that leads to a lot of conflicts. There's obviously little feuds because of all the sex that's been going on.* (Cedric, HIV-, 19–30 age group)

Reinforcing the idea that gay men constitute a "web of sex" rather than a supportive or collegial community were statements about how the gay community is a collection of men who are sexually attracted to one another:

> *The one thing that most of us have in common is just that we're gay. . . . So you have a lot of people in one area, or in one community, where the only thing that, frankly, they have in common is that they like dick.* (Seamus, HIV-, 19–30 age group)

> *As a whole, the only thing we have in common is our sexual preference. . . . you fill a room full of straight people, a lot of them are going to find people who they don't like because they don't have anything else in common with them. . . . it's really hard sometimes to blend together,*

> *because it's like strangers — you don't have anything in common with them.* (Seamus, HIV-, 19–30 age group)
>
> *In talking with people, I either get the answer, "Well, we are [promiscuous]" or, "No, that's not a good depiction." That's the problem with calling it a gay community; there's so much variability that it's not really one cohesive unit. . . . it's more like a collection of communities, but I think any social network is. . . . there are many aspects that share almost nothing in common other than the fact we're attracted to the same sex. So "community" may not necessarily be the best term, but . . . it's pretty much the only term you've got, so you go with that.* (Jacob, HIV+, 19–30 age group)

Besides Seamus and Jacob, other participants noted not only that the gay community is little more than a collection of men who are sexually attracted to men but also that these men are not always supportive of one another:

> *I think there's this perception in the non-gay community that all gay men support all gay men and we're all friends and we all go to knitting bees or quilting bees together. That's not the way it is.* (George, HIV-, 41–50 age group)
>
> *You're going to have a lot of people who don't get along and don't treat each other well, and people who try to form friendships just on their sexual attraction. And there's a pecking order that forms, and it's very like an 18th-century court system in Europe: you have your queens at the top and all the little worker bees and courtiers below them. And a lot of people aren't nice to each other, I find.* (Seamus, HIV-, 19–30 age group)
>
> *We're a community that came together to advance our cause, but, regarding the spirit of the community, it's not very strong. For those who work hard for the community, it goes well, but most just want to go to bars. Having been a witness to a lot of things, I'm certain that there are problems.* (Maxwell, HIV+, 31–40 age group) (authors' translation)

In the above excerpts, George, Seamus, and Maxwell refute the idea that gay men support gay men by providing examples of the converse. Below, Ethan and Olivier report that a community that is based on sexual attraction exposes young and newly out gay men to sexualized understandings of gay men and thus leaves them vulnerable. In other words, as noted earlier by Henry, young and newly out gay men are forced to develop without any form of mentorship:

> *I think there's also a difference between identifying as bisexual and identifying as gay, because if you identify as bisexual you're still attracted to women; you still feel . . . you're following the path that's laid before you by generations of people. When you're gay you don't know other people that you struggle with. I think that being gay and being out and having gay friends is very hard.* (Ethan, HIV-, 19–30 age group)

> *These young guys who had sex with [media case], I wouldn't be surprised if they had low self-esteem. They just discovered they're gay and they want to experiment, so they go home with the first person who pays attention to them. [Media case] didn't infect 40-year-olds. It was young guys who are still in the closet and whose parents don't know they're gay. They have gay porn under the mattress, but it finishes there. They don't talk about it. Why? Because they don't have any education. There's no way [HIV-prevention organizations] can provide education in the schools. The schools want nothing to do with it, even though the best way to reach these young gay men is to go into the schools. But we don't talk about it.* (Olivier, HIV+, 31–40 age group) (authors' translation)

These comments, when combined with those presented earlier, demonstrate how a lack of community support and sexual health education leaves gay men vulnerable when they enter the locales of gay life (e.g., bars). According, we take our participants' statements to suggest that the gay community is a fictional construct.

Discussion: Understanding Community

Our participants reported, first, that exclusion from the heterosexual meta-culture is still occurring; second, that gay men gather in specific places, which are the locales of gay life; and third, that the gay community is itself internally exclusionary. These results highlight our participants' perception that, within the heterosexual meta-culture, they continued to be marginalized based on sexual orientation and that, within the so-called gay community, they were similarly excluded by other gay men based on their actions, attributes, and physical characteristics (e.g., ethnicity).

With few exceptions, such findings are consistent with the literature on gay communities. Specifically, our results align with the research that details abstract descriptions of people's experiences with gay communities. These similarities relate to beliefs that the gay community is divided, non-existent, or dissolved, or that "gay community" is an umbrella phrase to describe persons whose only common feature is a specific sexual orientation (Dowsett, 2009; Dowsett et al., 2005; Fraser, 2008; Holt, 2011; Rowe & Dowsett, 2008; Woolwine, 2000). Regarding social exclusion from the heterosexual meta-culture, our results likewise reflect previous findings with regard to ongoing exclusion (Flowers et al., 2000; Peacock et al., 2001).

Our results differ slightly from previous findings, however, on the idea of "doing gay" (Dowsett, 2009). While Dowsett (2009) describes doing gay as a performance, as coined by Judith Butler (1993) in her writings about gender performativity, in our study doing gay was not limited to behaviour. Among our participants, physical characteristics, such as skin colour, were also important elements in doing gay properly. Acceptance by the gay community thus relied not only on the demonstration of particular behaviours, but also on the possession of specific (desirable) physical characteristics. While this finding may relate to the fact that our sample was mostly Caucasian (87%), the importance of physical attributes nevertheless means that, in certain instances, only specific people can ever do gay properly, as a result of a combination of their behaviour, appearance, physique, and physical characteristics. For some, therefore, doing gay properly is unattainable.

Taken as a whole, our data suggest that, in addition to the social marginalization of gay men by members of the heterosexual meta-culture, there is exclusion within the gay community that is imposed by gay men. Consequently, gay men are (a) still identified as different from the hegemonic sexual majority, (b) forced into minority groupings in which the "only thing . . . in common is [to] like dick" (Seamus, HIV-), and (c) subject to further judgement and exclusion within the minority groups to which they belong. These findings are disconcerting, because such marginalization serves to neither reduce discrimination against gay men nor affirm positive gay identities (Istar, 2010; Tuerk, 2011).

Such cultural marginalization, moreover, can correlate with various health issues (Allen, 2008; Betrie & Lease, 2007; Hatzenbuehler, Nolen-Hoeksema, & Erickson, 2008; Shelby, 1999; Wright & Perry, 2006). According to McKay (2011), gay men share "health disparities related to the stigma and discrimination they experience, including disproportionate rates of psychiatric disorders, substances abuse, and suicide" (p. 393). Other research, meanwhile, has found that these health issues, which can relate to social marginalization, correlate with higher rates of the practices that serve to transmit HIV — for example, unprotected anal sex with anonymous or casual partners of unknown or serodiscordant HIV status (Hatzenbuehler et al., 2008). Accordingly, our results, which situate gay men as members of a minority group who are forced to come out, highlight the problems that can result when individuals are socially constructed as distinct or different due simply to a non-hegemonic sexuality or sexual orientation. Indeed, psychosocial difficulties can arise, in turn exacerbating HIV transmission.

Compounding this burden of ill health among gay men is our finding that, although the gay community may have originally emerged as a congregation of people who had been excluded from and ostracized by the heterosexual meta-culture, it now appears to be internally reproducing those same exclusionary meta-cultural mechanisms. Just as the gay community was formed in response to neglect by governments and public health officials when gay men were faced with the devastating effects of AIDS (Flowers et al., 2000), sub-communities are now forming within the gay community as exclusionary elements rise within that community. This is the sub-marginalization of gay men who do not "do gay" according to accepted social standards. Dowsett and colleagues (2005) see this process in the fact that Melbourne's gay community does not offer HIV-prevention services to gay men who use intravenous or injection drugs: "Because the prevailing view of drug use within the gay community discounts the possibility of drug injection, those who engage in such practice are often left at a distance from potential community interventions to prevent HCV transmission" (p. 33). Such internal exclusion could leave some of the most marginalized gay men — for instance, those who engage in intravenous or injection drug use, exclusive bareback sex, or bug chasing/gift giving — without access to appropriate services for HIV and hepatitis C prevention. Yet these men are increasingly vulnerable to HIV and hepatitis C based on both their sexual practices and their use of injection and intravenous drugs.

Accordingly, as the gay community moves towards increasing social acceptance in many regions, with gay marriage being legal since 2005 in Canada (the jurisdiction where our research was conducted), there is a cautionary tale to tell. Despite — or perhaps because of — these social advances, only those gay men who do gay according to mainstream ideations of gay behaviour and physical characteristics appear to be *bona fide* gay community members (Dowsett, 2009). Others may experience increasing levels of stigmatization and exclusion and become marginalized within their already liminal grouping.

Another of our noteworthy findings is the relationship between marginalization, the spaces of gay life, and behaviours that consistently have been identified among gay men, such as elevated rates of smoking, drinking, and HIV transmission (Allen, 2008). Although our data-collection approach was such that we cannot establish any definitive or causal links between social norms, space, and behaviour, it is interesting to note that the visible, and thus most readily available, spaces of gay life are those that are related to substance use and casual sex: bars, clubs, bathhouses, the Internet, and smartphone cruising applications. While the emergence of such spaces likely relates to historical exclusion and safety (Bérubé, 2003), our findings suggest that the contemporary outcome of smoking, substance use, and casual or anonymous sex relates not only to a state of internalized homophobia (Simon Rosser, Bockting, Ross, Miner, & Coleman, 2008) but also to the spaces where marginalization (and illegality) has historically resulted in gay men congregating (Bérubé, 2003). The longstanding exclusion of homosexuality has created a subculture in which, as noted by our participants, the only commonality is a same-sex sexual preference. These data are important for nurses, other health professionals, and researchers who work in the field of HIV prevention. Although more research on this topic is needed, we hypothesize that targeting HIV-prevention efforts at individual gay men, rather than at the social structures that result in social segregation and isolation, is a misguided approach. Addressing social inequities and longstanding stigmatization might be an important public health HIV-prevention initiative. This question and hypothesis constitute an area in need of research.

Notwithstanding sociopolitical changes within both the meta-culture and the gay community, many health and social services for gay men continue to operate on definitions of the gay community that apply to only a small number of gay men, who may be less engaged with this community now that they have gained the acceptance they fought for decades ago. According to Graydon (2013), the gay community began to lose its sociopolitical importance for White middle-class gay men after these men — as opposed to those who were much more marginalized, such as transgendered, young, or visible-minority gay men — won the rights and freedoms they desired. Graydon (2013) argues, however, that this does not mean that equality was achieved; only mainstream — or coupled, employed, and socially presentable — gay men acquired the luxuries afforded to people who are accepted by the heterosexual meta-culture. The rest acquired the status of being excluded among the already marginalized.

For HIV-prevention workers, researchers, and clinicians, therefore, failing to grasp the meaning of gay community and continuing to base HIV-prevention work on antiquated definitions of this community can reproduce historically discriminatory approaches to HIV prevention and care, wherein only mainstream populations have access to services. Prevention must be based on new, contextualized definitions that apply to the contemporary world. Failure to acknowledge modifications within the gay community could result in HIV-prevention workers propagating sub-marginalization instead of addressing the increased number of health issues presented by gay men who do not do gay according to the prevailing norms in a city or region.

Final Remarks

Returning to our original focus, which was to examine how our participants described the gay community, the results suggest that, while our participants may have used the phrase "gay community" in a variety of ways, all of their descriptions included same-sex sexual attraction. More specifically, our participants described the gay community in ways that ranged from a synonym for gay men to an understanding of how gay men are expected to behave in the local context. Nurses and other clinicians working in HIV prevention who undertake community interventions should, therefore, reflect on what they mean when they use the phrase. Who is this community? What are the commonalities that hold it together? Are so-called community members collegial, or simply bound by time and space? As noted both here and in the research literature, the meaning of gay community is neither universally understood nor well accepted. Moreover, it is highly variable and subject to modification over time and as the sociopolitical context changes.

Nurses and other workers engaged in HIV prevention should be aware that while communities provide a sense of inclusion and solidarity based on shared characteristics, they simultaneously exclude people who do not possess these characteristics. It cannot be simplistically argued that community inherently denotes unity and solidarity. The idea of community is a double-edged sword. While the gay community may be a place of inclusion for gay men who do gay according to mainstream gay definitions, there is a subset of gay men who are marginalized in society in general and further marginalized within the gay community. As the gay community emerged in response to the social and political exclusion of gay men in most industrialized nations, so too many subcultures (e.g., barebackers, bug chasers, and other minority groups) begin to assemble in opposition to the gay meta-culture. Accordingly, our results indicate that the gay community should be seen as dynamic, not monolithic, and as heterogeneous, not homogeneous. HIV-prevention strategies, similarly, should be built on the premise that the gay community has multiple factions and that multiple, and diverse, interventions may be needed for the various subgroups. Indeed, the diverse and multifaceted nature of Ottawa's gay community illustrates the need for researchers, clinicians, and HIV-prevention workers to understand the variable dynamics and nature of regional gay communities and to tailor their work accordingly.

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Patrick O'Byrne, RN, PhD, is Associate Professor, School of Nursing, University of Ottawa, Ontario, Canada. Alyssa Bryan, RN, MScN, is Researcher, School of Nursing, University of Ottawa. Andrew Hendriks, RN, BScN, is Program Manager, Healthy Sexuality and Risk Reduction Program, Ottawa Public Health. Cynthia Horvath, RN, MScN, is Public Health Nurse, Healthy Sexuality and Risk Reduction Program, Ottawa Public Health. Christiane Bouchard, MSW, is Project Officer, Healthy Sexuality and Risk Reduction Program, Ottawa Public Health. Vera Etches, MD, is Associate Medical Officer of Health, Ottawa Public Health.

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Acute Coronary Syndrome Pain and Anxiety in a Rural Emergency Department: Patient and Nurse Perspectives

Sheila O'Keefe-McCarthy, Michael McGillion, Sioban Nelson, Sean P. Clarke, Jeremy Jones, Sheila Rizza, Judith McFetridge-Durdle

Rural patients can wait up to 32 hours for transfer to cardiac catheterization (CATH) for events related to acute coronary syndrome (ACS). Pain arising from myocardial ischemia can be severe and anxiety-provoking. Pain management during this time should be optimized in order to preserve vulnerable myocardial muscle. This qualitative focus group study solicited the perspectives of ACS patients and emergency staff nurses on the rural patient experience of cardiac pain and anxiety and priorities and barriers to optimal assessment and management of ACS pain. Patients described ACS pain as moderate to severe, with pain in the chest, arms, back, shoulders, and jaw. Pain was well assessed and managed upon arrival in the emergency department but anxiety was not routinely assessed or treated. Barriers identified were poor management of patients with different acuity levels, high patient volumes, and assumptions regarding patients' communication about pain. Research related to ACS pain and anxiety management in the rural context is recommended.

Keywords: cardiology, cardiovascular disease, pain, rural and remote health care

Résumé

La douleur et l'anxiété associées au syndrome coronarien aigu : le point de vue des patients et du personnel infirmier d'un service d'urgence en milieu rural

Sheila O'Keefe-McCarthy, Michael McGillion,
Sioban Nelson, Sean P. Clarke, Jeremy Jones,
Sheila Rizza, Judith McFetridge-Durdle

Les patients atteints d'un syndrome coronarien aigu (SCA) en milieu rural peuvent attendre jusqu'à 32 heures avant d'être transférés pour un cathétérisme cardiaque (CATH). La douleur associée à une ischémie myocardique peut être aiguë et provoquer de l'anxiété. La gestion de cette douleur devrait être optimisée afin de protéger le muscle myocardique, qui est en situation de vulnérabilité. Cette étude qualitative menée auprès d'un groupe cible visait à solliciter le point de vue de patients atteints d'un SCA et du personnel infirmier d'un service d'urgence en milieu rural concernant l'anxiété et la douleur cardiaque ressenties par les patients et concernant les priorités à adopter et les obstacles à surmonter pour une évaluation et une gestion optimales de la douleur liée à un SCA. Les patients ont décrit la douleur liée à un SAC comme étant légère ou aiguë et ont indiqué qu'elle se situait dans la poitrine, les bras, le dos, les épaules et les mâchoires. Selon les participants à l'étude, la douleur est évaluée et gérée adéquatement au moment de l'arrivée des patients au service d'urgence, mais l'anxiété, quant à elle, n'est pas évaluée ou traitée de façon systématique. Les obstacles mentionnés sont une mauvaise gestion des patients présentant des degrés de gravité différents, un volume important de patients et une tendance du personnel soignant à entretenir des a priori relativement à la communication par les patients de leur douleur. L'étude recommande que des recherches soient menées sur la gestion de la douleur et de l'anxiété liées au SCA en milieu rural.

Mots-clés : cathétérisme cardiaque, syndrome coronarien aigu, ischémie myocardique, douleur, anxiété, services d'urgence en milieu rural

Introduction and Literature Review

Acute coronary syndrome (ACS) refers to manifestations of coronary artery disease (CAD), including unstable angina (UA), non-ST-elevated myocardial infarction (NSTEMI), and ST-elevated myocardial infarction (STEMI) (Eftekhari, Bukharvoich, Aziz, & Hong, 2008; Grech & Ramsdale, 2003). In Canada, there are an estimated 70,000 ACS-related myocardial infarctions annually (Chow, Donovan, Manuel, Johansen, & Tu, 2006; Statistics Canada, 2010). In 2008–09 there were 109,109 ACS-related hospitalizations, with Ontario having a larger number (38,465) of hospitalizations for ACS events than any other province or territory. Further, that same year, there were 21,474 deaths attributed to ACS (Canadian Institute for Health Information, 2010).

National guidelines for the treatment of UA, NSTEMI, and STEMI stipulate that the gold standard of ACS treatment include emergent triage with rapid access (i.e., within 90 minutes of ischemia) to diagnostic catheterization (CATH) and reperfusion with percutaneous coronary intervention (PCI) (Antman et al., 2004; Bassand et al., 2007; Chow et al., 2006; Erhardt et al., 2002). Specifically, there is agreement that the ischemic time should not exceed 120 minutes (Antman et al., 2004; Bassand et al., 2007; Erhardt et al., 2002). However, access to rapid CATH can be problematic. In Canada, 50% of the population lives outside urban centres in rural or remote-rural communities, and evidence suggests that wait times for reperfusion therapies can be as long as 32 hours for those who live in rural areas (Cantor et al., 2009).

In Canada, "rural" is classified according to geographical location — that is, the population under consideration is living outside the commuting zone of an urban centre with a population greater than 10,000 (Statistics Canada, 2001). In terms of access to interventional cardiac care, "rural" is a function of distance and time from an urban centre where cardiac reperfusion services exist (Statistics Canada, 2001). Canada is a geographically vast country where a large number of patients live far from reperfusion facilities (Fitchett, 2011; Statistics Canada, 2010). This presents geographical inequities in terms of immediate access to critical cardiovascular treatment for anyone diagnosed with ACS. Despite efforts to promote access to timely angiography, within Canada there is considerable interprovincial and regional variability in access to CATH (Faris, Grant, Galbraith, Gong, & Ghali, 2004; Graham et al., 2005; O'Neill et al., 2005). Ontario, in particular, has long wait times for CATH due to a lack of cardiac intervention facilities in numerous rural and remote-rural locations (Cantor et al., 2009; Faris et al., 2004; Graham et al., 2005; O'Neill et al., 2005).

Delay to CATH has negative consequences for patients. For example, prolonged wait time for CATH is a strong independent predictor of increased infarct size (73 ± 22%, < 180 minutes; 78 ± 14%, 180–360 minutes, 86 ± 14%, > 360 minutes, $p = .04$) (Hahn et al., 2008); in-hospital mortality (OR 1.42, 95% confidence interval [CI] = 1.24–1.62, $p < 0.01$) (McNamara et al., 2006); and 30-day mortality risk (OR 12.6, 95% CI = 1.85–86.2, $p = 0.01$) (Nakayama et al., 2009). Moreover, more than a 30-minute delay to PCI is associated with a 7.5% increase in relative risk of 1-year mortality (95% CI = 1.008–1.15, $p = 0.041$) (DeLuca, Suryapranata, Ottervanger, & Antman, 2004).

Adding to the prohibitively long wait for cardiac interventional care, patients report ongoing pain and anxiety. Cardiac pain, like other forms of pain, is individual and complex. Information related to ACS pain ascends the spinal column to cortical and subcortical areas in the brain, with somatic receptive fields in the chest and arms (Foreman, 1999). The noxious or painful stimulus is assessed and evaluated in these structures as threatening, activating the limbic and autonomic nervous systems and leading to a sense of impending doom and apprehension about further pain and anxiety (Heinricher, 2005).

It is understood that cardiac pain related to myocardial ischemia occurs late in the ischemic cascade. The ischemic cascade is activated minutes after ACS and is caused by a reduction in blood flow to the myocardium, secondary to obstructive atherosclerosis of coronary arteries, resulting in an imbalance in oxygen supply and demand (Joshi, Herzog, & Chaudhry, 2008). There is mounting evidence that anxiety may impact negatively on cardiac pain. Whitehead, Strike, Perkins-Porras, and Steptoe (2005), in a descriptive-correlational, repeated measures design across four urban hospitals, examined anxiety at 48 hours after an acute myocardial infarction (AMI) ($n = 184$). Results indicate that increased fear and anxiety scores (Hospital Anxiety and Depression Scale ≥ 8) are significantly associated with severe chest pain intensity (≥ 8/10 Numeric Rating Scale [NRS], OR 5.33, 95% CI = 1.40–20.4, $p < 0.001$). Concomitant anxiety in the context of ischemic myocardial pain produces high levels of adrenergic activity, which in turn increase myocardial oxygen demand, potentiate atherosclerosis, myocardial ischemia, pain, and dysrhythmias, as well as in-hospital cardiac mortality (Heinricher, 2005; Moser & Dracup, 1996; Ploghaus et al., 2001; Procacci, Zoppi, & Maresca, 2003; Rosen, 2012). In lieu of rapid access to CATH, ACS care needs to focus on effective pain assessment and management in this at-risk population.

There is some evidence that, following initial assessment and stabilization, rural ACS patients awaiting CATH for prolonged periods are at risk for recurrence of chest pain and related anxiety (Nakano, Mainz, &

Lomborg, 2008; Tanabe & Buschmann, 1999). ACS patients have reported receiving inadequate and/or ineffective analgesia, despite ongoing moderate to severe chest pain prior to CATH (Nakano et al., 2008). When immediate access to CATH is not available, ACS pain assessment and management are critical, to preserve vulnerable myocardial muscle. Emergency department (ED) trends observed in urban centres demonstrate that the frequency of pain assessment and management generally wanes following primary assessment and management (Motov & Khan, 2009; Tanabe & Buschmann, 1999; Todd et al., 2007). We are unaware of any studies exploring cardiac pain and its related anxiety in the context of pain management for rural ACS patients awaiting diagnostic CATH. Little attention has been given to nurses' perspectives on assessment and management of ACS patients in a rural ED.

Purpose

The primary purpose of this study was to examine rural ED patients' experience of ACS pain and anxiety while awaiting transfer for cardiac CATH. Its secondary purpose was to uncover priorities of and barriers to assessment and management of ACS pain and anxiety.

Methods

Design

A qualitative focus group design was used in one rural ED setting in southeastern Ontario, Canada. Focus groups provide concentrated amounts of qualitative data (Sandelowski, 2000), allowing for observation of group dynamics and spontaneity of group interaction while maintaining an interview structure through the use of a moderator (Kruger, 1994; Morgan, 1997). Dynamic interactions observed in focus groups as compared to individual interviews allow for greater depth and a higher level of inquiry, wherein the subject matter (currently, pain assessment and management practices; facilitators and barriers) may result in highly charged discussions (Morgan, 1997). Qualitative description, via content analysis, as outlined by Sandelowski (2000), was the analytic method employed. This type of description entails the presentation of current clinical practice using everyday language (Kruger, 1994).

Participants

ACS patients and ED registered nurses were recruited. Patient inclusion criteria were (a) confirmation of a recent rural ED admission for ACS (i.e., within the past 6 months); (b) recent diagnostic CATH to confirm a diagnosis of ACS; and (c) ability to read, speak, and understand English.

Patients who had recent cardiac surgery involving sternotomy and/or a major cognitive disorder were excluded; cardiac-related surgery with median sternotomy can result in the development of persistent post-operative pain, which could confound patients' descriptions of acute ACS-related pain. The nurse inclusion criterion was active involvement in the care of ACS patients in the study setting.

The study was approved by the research ethics board at the University of Toronto and the research ethics committee at the hospital site.

Data Collection

Three focus groups were conducted between September 2010 and February 2011, one with ACS patients and two with registered nurses. Focus groups were held in a quiet room at the hospital site and lasted between 45 and 90 minutes. The principal investigator moderated the focus groups and the research assistant documented the interactions within each group. All interviews were audiorecorded and field notes were made during and immediately after the interviews to record impressions of both patient and nurse responses to the questions.

Focus group guides (see Appendix 1) were used, featuring an introductory stem with open-ended questions and probes to elicit dialogue about patients' experiences of ACS pain and related anxiety and nurses' experiences of ACS assessment and management practices. Throughout the sessions, questions were modified as key themes emerged during discussion. Prior to each session, participants completed a demographic questionnaire designed for this study.

Data Analysis

The focus group interviews and field notes were transcribed verbatim by a hired transcriptionist. Two members of the research team read and reviewed all transcripts. The transcripts were compared with the recordings for accuracy. Any disagreements (e.g., wording, categorization of themes) were handled by a consensus-building procedure between analysts.

Thematic data analysis was an ongoing process whereby codes were identified and revised as each focus group was conducted (Kruger, 1994). The research objectives and semi-structured interview questions guided the first reading of the transcripts. Saturation was achieved when repetition of information, confirmed by team members, occurred within and across focus groups (Morse & Field, 1994) — that is to say, during data analysis, themes would recur and no new material was revealed by the end of the analysis. The frequency, extensiveness, and specificity of participants' comments guided the coding of the data (Morgan, 1997; Sandelowski, 2000). Codes were then organized into categories. As the analysis progressed, frequent similarities in the data provided a strong indication of triangulation for the emergence of themes. In addition to member checking of the findings, the thematic analysis was reviewed by two of the co-authors to determine interrater reliability in order to enhance credibility of the results. Pseudonyms were used by participants to ensure anonymity. Descriptive statistics were used for analysis of nurse and patient demographic data (SPSS Inc., 2010).

Results

The results describe patients' experiences of ACS pain, their anxiety-related care, and nurses' priorities for and barriers to management of ACS pain and anxiety in a rural setting. Three overarching themes were identified: *ACS pain presentation, the emergency environment,* and *barriers to pain management.* The first theme, *ACS pain presentation,* was extracted down to include varied chest pain symptoms, symptom interpretation, and anxiety and fear. *The emergency environment* was divided into two subthemes: (a) wait time, and (b) high patient volumes and lack of time. The third theme, *barriers to pain management,* comprised problematic pain knowledge and beliefs held by nurses.

Demographic and Clinical Characteristics

The demographic and clinical characteristics of the patient sample (N = 4) are shown in Table 1. The nurse sample (N = 8) consisted of females only. Although recruitment extended to physicians, nurse practitioners, and ED nurses, only ED nurses responded to the recruitment call. Lack of male ED nurse representation was not intentional; no male RNs agreed to participate in the study. The mean age was 40.25 ± 11.39 with an average of 11.44 years' experience in the ED. All eight RNs had professional certification in advanced cardiac life support (ACLS); see Table 2 for other characteristics.

ACS Pain Presentation

Varied chest pain. Patients described individual experiences of ACS pain and reported that while they waited in the ED their chest pain was of moderate to severe intensity. They described their ACS pain as a mix of "typical" and "atypical" chest pain presentations (i.e., mid-sternal pain radiating to the jaw, between the shoulders, or down the arm) as well as angina-equivalent symptoms, including diaphoresis, burning, nausea, fatigue, and increasing shortness of breath.

Nurse participants indicated that approximately half of their patients described typical ACS pain. Yet the word "pain" was not often used by patients. "Burning," "stabbing," "tightness," "heaviness," and "discomfort"

Table 1 *Characteristics of Patient Sample (N = 4)*		
Variable	***M***	***SD***
Age (years)	57	± 2.5
	N	**%**
Gender		
Male	4	100
Marital status		
Married/cohabiting	4	100
Employment		
On disability	1	25
Retired	3	75
Education		
College	2	50
High school	2	50
Comorbidities		
Hypertension	4	100
Diabetes	1	25
Hyperlipidemia	4	100
Thyroid disease	2	50
Other	1	25
Cardiac conditions		
Acute myocardial infarction	2	50
Angina	2	50
Followed by cardiologist	4	100
Followed by family doctor/nurse practitioner	4	100

Table 2 *Characteristics of Nurse Sample (N = 8)*		
Variable	***M***	***SD***
Age (years)	40.25	±11.39
	N	**%**
Gender		
Female	8	100
Employment		
Full-time	7	87.5
Part-time	1	12.5
Education		
Baccalaureate	4	50
Diploma	4	50
Pain education	2	25

were typical descriptors used by patients to describe their ACS-related symptoms:

> Patient #1: *It was like stabbing chest pain, but, I mean, it [was] quite severe. It was pretty well in the centre of my chest.*

> Patient #2: *It began with a pain down my left arm, pretty typical, and then heaviness on the chest and shortness of breath, sweating — really sweaty.*

Symptom interpretation. Patients indicated that unusual or atypical chest pain confused them and that they found it difficult to interpret the significance or meaning of their ongoing chest pain. They said that once they were triaged into the ED and had initial assessment and treatment, their pain often returned. Recurrence of chest pain was viewed as problematic in two ways: (1) if they had further chest pain after they had received their initial assessment and treatment for chest pain and had been categorized as stable, they were unsure whether it was important enough to notify the nurse; and (2) they found it difficult to differentiate between their cardiac pain and coexisting persistent pain problems:

> Patient #1: *I don't know how you tell the difference between . . . a muscle pain, like a sharp — . . . or an angina attack or whatever . . . what's the difference in the kind of pain?*

> Patient #3: *I've had pain so many times, this chest pain . . . but the pain, whether it's been my heart, or maybe my chronic back pain or whatever . . . you're wondering which it is.*

Anxiety and fear. Patients reported feelings of anxiety and fear in addition to chest pain. Both patients and nurses commented that pain was anxiety-provoking, which in turn increased the pain. Patients reported feeling anxious during bouts of pain and said that their anxiety often increased relative to what they thought the painful episode might mean to their life situation:

> Patient #1: *You're worried when you're first there [in the ED] and you're feeling all the pain and — okay . . . what's going to happen now?*

> Patient #3: *When I get the pain, am I going to get another one? The pain and the locking of the jaw and burning — there's a lot of nervousness about what the pain will amount to, or what do I have to face down the road?*

Similar comments were made by nurses:

> RN #1: *I'd say there's a lot of anxiety, the unknown. Their concerns exacerbate their level of pain.*

> RN #6: *Anxiety definitely impacts the pain they feel. They don't know what [will be happening] after they arrive.*

Patients discussed their fear of death and expressed feelings of impending doom:

> Patient #1: *The pain was so bad. It seemed to be in my arms and chest. It was there for quite a while. I felt really bad . . . I didn't want to go to sleep — I was afraid if I fell asleep I wouldn't wake up again.*

> Patient #3: *There was a lot of anxiety . . . what's the next [pain] going to mean? When it [your heart] stops, you're done, and, you know, by itself the pain brings a lot of anxiety.*

The Emergency Environment

Wait time. The environment of a busy ED was perceived as influencing the experience of ACS pain and anxiety and was described as impacting the treatment provided to patients. In this environment, the waiting period consisted of multiple delays. Patients described their time in the ED as constantly waiting for something to happen — waiting for pain relief, waiting for confirmation of their diagnosis or for the results of tests. They also had to wait hours or even days for transfer to a tertiary urban cardiac centre for CATH. During this waiting period, their pain continued; it was distressing for them:

> Patient #1: *I spent 3 days waiting. You wait for your angiogram because there's a time delay.*

> Patient #2: *The pain wouldn't settle down. It was constant. They gave me nitroglycerin and morphine. They were putting morphine through the IV. They gave me oxygen, of course. It [the pain] started at a 12 . . . went down to a 10 . . . worked its way down over the hours. They had me on morphine right through until Monday morning. So it was days [of pain] . . . on and off, coming back. I wasn't relieved of the pain.*

High patient volumes and lack of time. The characteristics of the ED environment were perceived by the nurses as driving the ACS care processes. Nurses indicated that the fluctuations in patient volume often drew their focus away from their ACS patients. For example, patient care that was designated in an acute or sub-acute area seemed to impact the level of attention that the nurses gave to pain assessment and management:

> RN #4: *I probably pay more attention to ACS patients when they're in trauma. If a patient is placed in acute [for] observation, sometimes the ACS patients can get lost in with your other acute patients. . . . then you*

> *have your second set and you think, Oh, [he's just waiting] . . . a second set of [cardiac markers], he's okay, he'll let me know [if he's having chest pain] — and you may find that he's not telling you.*

In each focus group, nurses reflected upon the fact that they were often operating at an instrumental level, depending on the influx of patients. They attempted to complete the most pressing tasks. Increased patient flow often served to restrict the amount of time they could spend with their ACS patients. Nurses expected patients to report their pain. They explained that ACS patients, once assessed, tended to get lost within the patient flow:

> RN #2: *It's a flurry of activity at the beginning. You get the pain-scale rating, give the nitro and Aspirin, get them sort of settled down, and then it's sort of coasting and . . . you rely on them to let you know how they're doing — I'm not sure they do all the time.*
>
> RN #7: *Yes, you sort of rely on them to tell you if they're having pain. They can get lost in the shuffle when the other people are more urgent.*

Barriers to Pain Management

Problematic pain knowledge and beliefs held by nurses. Some barriers to ongoing ACS pain assessment and management were related to problematic pain knowledge and beliefs. Pain assessment and management were mediated by nurses' misbeliefs regarding patients' pain. Some nurses described incongruence between their patients' self-reports of pain intensity, the presence of objective physiological signs, and their own initial perception of their patients' pain intensity:

> RN #4: *Some people say it's a [chest pain intensity of] 4 out of 10, but they're, like, white-knuckled, holding on to the stretcher, and can barely breathe. Or some will say it's a 10 out of 10 and be sipping on a drink.*
>
> RN #8: *Anxiety definitely impacts the pain they feel. If they're anxious . . . they're tense, their blood pressure's up, and so that's going to put their pain level up if they're an ACS.*

Triangulation of the data revealed that nurses confined their assessments of patients' pain to use of the numeric pain intensity rating scale (NRS-0-10). Although nurses did acknowledge that they assessed anxiety and determined that it impacted the pain experience, anxiety was not discussed as being objectively measured or treated. The treatment of patients' anxiety was not perceived as a clinical priority:

> RN #5: *I think their pain is more . . . my concern . . . from a clinical perspective anyway. But I'm certainly aware of their anxiety; that kind of*

> *goes around it too. But pain seems to be the main focus . . . if you get the pain under control, I find they do settle a bit.*
>
> RN #7: *I have to say, if they're pain-free and look comfortable, I don't really investigate how they are emotionally . . . I don't dwell on it [the anxiety]. I focus more on the clinical symptoms.*

Discussion

ACS Pain Presentation

Patients in this study described their ACS pain as moderate to severe while they waited for transfer for CATH. In some cases, the discomfort experienced was reported as unusual or atypical pain-related symptoms. Our findings support those of other qualitative studies (Arslanian-Engoreen, 2007; Gassner, Dunn, & Piller, 2002; Lockyer, 2005; MacInnes, 2006; McSweeney, 1998; McSweeney & Crane, 2000; Miklaucich, 1998) in which ACS pain was described as an admixture of typical anginal pain and angina-equivalent symptoms such as pain in the jaw and arm or heaviness in the centre chest with tightness, burning, shortness of breath, nausea, and excessive perspiration.

Patients reported that increased anxiety increased their pain. These results are consistent with those of other studies investigating cardiac pain and anxiety. For example, Moser and Dracup (1996) examined the association of pain and anxiety early on in the AMI trajectory and found that patients with higher levels of anxiety reported greater intensity of cardiac pain.

Intense feelings of impending doom were also expressed by patients — specifically, the fear of death. Whitehead et al. (2005), similarly, found that, in a sample of 184 ACS patients, increased anxiety and fear of dying were significantly associated with greater intensity of chest pain (≥ 8/10 NRS, OR 5.33, 95% CI = 1.40–20.4, $p < 0.001$). This finding is not surprising when one views the experience of myocardial ischemia from a neurobiological perspective. Pain is only one component that patients experience in the overall spectrum with the onset of myocardial ischemia. The affective experience, the anxiety that patients report, is typically associated with cardiac pain. It is described as a sense of impending death (angor animi) that has long been associated with angina (Rosen, 2012).

The Emergency Environment

The context of a busy ED was repeatedly discussed as problematic with regard to timely ACS assessment and treatment. The individual experience of pain depends not only on the nature of the stimulus, but also on the memories, emotions, and *context* in which the stimulus is experienced (Basbaum, Bushnell, & Devor, 2005). Pain is a subjective experience; the quality and quantity of pain experienced is dynamic and variable for each person. Melzack and Wall's (1965) seminal Gate Control Theory has led clinicians to understand that myocardial injury related to ischemia, for example, produces neural signals that enter an active nervous system — that is, the cumulative combination of past experience, culture, context, and emotion (Melzack & Wall, 1965, 1973, 1982).

The ED environment was reported as impacting patients' level of pain and anxiety. Although patients did not specifically say that living in a rural area had affected their ACS pain experience directly, they did imply that waiting for advanced cardiac interventions, specifically CATH, was anxiety-provoking, even though the wait was expected. Similar sentiments were expressed in a qualitative study examining the lives of rural women after myocardial infarction (Caldwell, Arthur, & Rideout, 2005). In that study, participants viewed the health care they received with a degree of reluctant acceptance that they did not live near cardiac services and believed they were were fortunate to have survived their cardiac event; they regarded distance as an unalterable fact of rural life and did not question it.

The patients in our study described feeling anxious waiting for analgesics, diagnostic tests, and transfer to an urban cardiac care centre for CATH. In keeping with our results, in an older study (Bengtson, Herlitz, Karlsson, & Hjalmarson, 1996) with 831 ACS patients, 465 (56%) reported that anxiety, fear, and uncertainty were the most disturbing symptoms while they awaited transfer for cardiac care.

Nurses also attributed inconsistent pain management practices to the busy context of the ED. They explained that high patient acuity demanded inordinate amounts of their time and thus precluded prompt analgesic administration. In a qualitative study with 30 patients diagnosed as having ACS, Nakano et al. (2008) found that, during the acute phase of ACS admission, patients discussed inconsistent pain management for their chest pain and reported unrelieved pain even when analgesics were administered.

Consistent with reports from other studies, our sample of nurses identified lack of patients' self-report of pain as preventing effective pain assessment and management. Clarke et al. (1996) surveyed 120 nurses for their knowledge and beliefs regarding pain management. The top nurse-ranked barrier to pain management was patient reluctance to report pain. RNs often express the expectation that patients will tell their nurse when they are in pain. This indicates problematic misbeliefs about pain that could prevent nurses from administering timely pain medication.

Barriers to Pain Management

Pain misbeliefs are attitudes and beliefs that are held about pain and pain management despite current evidence to the contrary (Watt-Watson, 1992). In our study, nurses focused more on the clinical pain presentation and tended to disregard patients' anxiety, which was not perceived as a clinical priority. Similar research conducted by O'Brien et al. (2001) found that documentation of anxiety assessment was minimal for 45% of AMI patients (n = 101); of 45 AMI patients, 58% (n = 28) were described as anxious, and nurses did not routinely assess anxiety even though close to half the sample self-reported moderate to severe anxiety. This knowledge gap in clinical practice is problematic, as nurses may not recognize anxiety as a treatable component of the ACS presentation or the potentially negative impact of anxiety on CAD patients if left untreated (De Jong et al., 2004; Moser, 2007; O'Brien et al., 2001).

Pain assessments that were discussed typically included use of the NRS. According to the Canadian Pain Society (2005), pain assessment should be routine and minimally requires the use of a multidimensional approach wherein pain intensity, quality, location, interference with activities of daily living and role function, alleviating and contributing factors, satisfaction, temporal aspects, and the effectiveness of therapy and medications are recorded. Nurses need to conduct comprehensive pain assessments with reliable and valid tools that reflect the sensory-discriminative, motivational-affective, and cognitive-evaluative dimensions of the patient's pain experience; the McGill Pain Questionnaire-Short Form is an example (Melzack, 1987).

Strengths and Limitations

Several steps were taken to ensure trustworthiness of the findings: (1) appropriate and well-recognized research methods were used; (2) analyst and participant triangulation were employed to reduce bias and ensure credibility of the data (Creswell, 1998; Shenton, 2004); (3) transparency in the informed consent process ensured participant honesty when contributing data, ensuring that they were genuinely willing to take part and prepared to offer data freely (Shenton, 2004); (4) data credibility was enhanced through the use of the same set of questions for patient and nurse focus groups with iterative questioning and use of probes in each session; (5) all participants were asked to verify the data through member checks, throughout and at the end of the focus group sessions. According to Guba and Lincoln, this is the singular most important strategy for bolstering a study's credibility (Guba, 1981; Lincoln, 1995). Moreover, purposive sampling yielded information-rich descriptions of patients' ACS pain and anxiety experiences and RNs' current pain assessment and management practices, which further enhanced the descriptive credibility of the data (Morgan, 1997). In addition, our study included a diverse nurse sample. Both expert and novice nurses participated, allowing for an in-depth exploration of clinical ACS pain management practices.

There are some limitations in the transferability of the findings. Only one hospital site was used. Further, women were not represented among the patients in the study, and neither male RNs nor physicians were represented in the nurse sample.

Implications for Research and Practice

Two important issues emerged from this study. Ongoing assessment and management of acute cardiac pain seemed to lose focus throughout the ACS trajectory while rural patients waited long hours in the ED. There are few studies providing detailed descriptions of ACS pain management patterns that reflect current clinical practice in rural settings; this warrants future consideration. Second, the assessment of ACS pain was limited to the use of one tool to measure pain (NRS), and anxiety was not assessed, measured, or treated. It is unknown whether current knowledge regarding ACS-related pain and pain management by rural nurses influence patients' cardiac pain intensity and/or anxiety levels; this also requires further investigation. Unrecognized and untreated anxiety may potentiate cardiac pain intensity. To date, however, no studies have examined this complex interrelationship in the context of pain management for ACS patients awaiting diagnostic CATH in rural EDs.

Patients described their ACS pain as moderate to severe with overwhelming feelings of anxiety and fear of death. Routine and ongoing assessments of ACS pain need to incorporate the subjectivity of the individual in pain and pain management needs to be based on patients' self-report of both pain and anxiety. Anxiety as a symptom is easy to assess, treat, and manage and ought to be included in the treatment plan for individuals with ACS. More importantly, it is critical that clinicians and patients be aware that cardiac pain and anxiety may manifest as a mixture of typical and atypical ACS-related symptoms. Moreover, this group or cluster of symptoms may be directly related to myocardial ischemia. Anxiety and non-traditional cardiac pain symptoms should not be separated out from the differential diagnosis of ACS.

Conclusion

Acute coronary syndrome is a painful condition that often includes overwhelming anxiety. The immediate treatment for myocardial ischemia is reperfusion with percutaneous coronary intervention within 90 minutes of ACS onset. ACS patients in rural areas can experience long wait times for diagnostic cardiac CATH, and adequate cardiac pain and anxiety assessment and management should be provided for these patients in order to preserve vulnerable myocardial muscle. Results from this study suggest that rural ACS patients are at risk for unrelieved cardiac pain and ongoing and unrecognized anxiety. We need research examining the interrelationships of current pain management practices in rural areas and patients' report of cardiac pain and anxiety while they wait long hours for transfer for cardiac reperfusion interventions. This qualitative focus group study provides important information and new knowledge about the ACS patient experience of cardiac pain and its related anxiety in the rural context. These results could provide unique discussion points that extend the dialogue and discourse to include the rural ACS patient experience in decisions that determine Canadian wait times for interventional cardiovascular care.

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Sheila O'Keefe-McCarthy, RN, PhD, is Ontario Research Chair, Canadian Council of Cardiovascular Nurses, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Ontario, Canada. Michael McGillion, RN, PhD, is Heart and Stroke Foundation/Michael G. DeGroote Endowed Chair in Cardiovascular Nursing Research, School of Nursing, McMaster University, Hamilton, Ontario. Sioban Nelson, RN, PhD, is Professor and Vice-Provost, Academic Programs, University of Toronto. Sean P. Clarke, RN, PhD, FAAN, is Professor and Susan E. French Chair in Nursing Research and Innovative Practice, Ingram School of Nursing, McGill University, Montreal, Quebec, Canada. Jeremy Jones, MD, FRCPC, is Internal Medicine Specialist, Ross Memorial Hospital, Lindsay, Ontario. Sheila Rizza, RN-EC, MN, is Adult-NP, Heart Failure Clinic, Humber Regional Health Centre, Toronto. Judith McFetridge-Durdle, RN, PhD, is Dean, College of Nursing, Florida State University, Tallahassee, United States.

Appendix 1 *Questions and Probes Contained in Semi-structured Interview Guide*

Broad Questions	**Probes**
Patients	
1. Can you tell us what it was like to have chest pain? What was that experience like while you were admitted to the emergency department?	Were there any other symptoms you experienced besides your chest pain?
2. Would you describe yourself as anxious at all when you were having chest pain?	Can you tell me whether your pain and anxiety affected the pain you were feeling?
3. Can you tell us what it was like while you waited in the emergency when you were having pain?	Were you able to talk to your doctor and nurse about your pain or your anxiety? How did the nurses and doctors manage your pain? As time progressed, what were the things that most concerned you about your chest pain or your anxiety? Can you tell me more about that?
4. Is there anything else that you would like to tell us that you think is important for nurses and doctors to know about what it is like to have chest pain and anxiety?	

Continued on next page

Appendix 1 *(cont'd)*	
Nurses	
1. Based on your experience, how would you describe patients presenting to your ED with acute coronary syndrome?	What are the most common symptoms you see in the ACS population? Do you find that most patients self-report the typical mid-sternal chest pain type of symptom?
2. What would you consider important in your assessment and management of a person with ACS?	Do you use any standardized pain measurement tools in your practice? When you consider cardiac pain, are there other symptoms that are of concern for patients? You identified anxiety as impacting the patients' pain experience; can you give me an example of what you mean?
3. What do you think are the challenges that nurses face related to pain assessment and management of ACS patients in the emergency on a daily basis?	What do you feel that nurses do well in the treatment of ACS pain? Within your current practice, what would you identify as barriers to pain management? Is there anything else that you would like to add at this time?