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EDITORIAL

What Have We Learned From the H1N1 Crisis?

Several years ago we used this space to write about the 2002–03 SARS (severe acute respiratory syndrome) pandemic. Slightly over 8,000 cases were confirmed, with an overall fatality rate of almost 10% (much higher among the elderly). In that editorial we discussed the tragedy of the pandemic both in Hong Kong and in Canada, the impact of global travel on the spread of infectious diseases, and the long-term and downstream consequences of the casualization of the nursing workforce in Canada.

The SARS crisis was a bleak time in Canadian hospitals. As cases accumulated in the province of Ontario, fear mounted. A number of health-care providers fell ill and some died. This raised public concerns internationally. Hospitals scrambled to fit workers with protective equipment as the crisis unfolded. Families were abruptly denied access to their hospitalized loved ones.

Other impacts were seen as well. Throughout the 1990s in Canada, a common human resource management strategy in the health-care field was to hire many workers, including nurses, on a part-time basis. This meant that nurses who held positions at multiple institutions in order to make a full salary could no longer work across these institutions when control measures were introduced or if they fell ill. Staffing, already tight, became tighter.

The H1N1 influenza pandemic of 2009 was a very different crisis. With perhaps 700,000 cases confirmed through laboratory testing (although laboratory confirmation was abandoned quickly in most communities), and perhaps 10,000 deaths worldwide (more than 400 in Canada), H1N1 appears to have made less of an impact than even “regular” seasonal flu. In vulnerable patients, however, H1N1 struck quickly and dramatically. The fatalities were widely reported. Emergency rooms in some cities rapidly became crowded with the “worried well” and those who were infected but were in no immediate danger. Staff in intensive care units treated small numbers of patients in respiratory failure; they were able to save many.

What was different this time, more than 5 years after the SARS pandemic? To state the obvious, H1N1 was a different illness. (We use the past tense because, as of this writing, many consider the crisis over, although experts and authorities have not ruled out the possibility of

another wave of infections in the coming months.) It spread less aggressively than SARS and was less often fatal. On a superficial level, virtually all health-care workers and trainees — in Canada, at least — were fitted with protective masks by the time the pandemic was in full swing. The nurse shortage had perhaps eased slightly, and casualization (and employment at multiple health-care facilities) was probably less widespread, but nurse employment participation is now at an all-time high, due to the global financial crisis more than to policy initiatives.

So did we really learn from SARS? More importantly, what lessons can we take from H1N1?

With SARS fresh in the minds of many, and with officials and policy-makers attempting to ready communities for H1N1 by insisting on immunization and preparing to redeploy health-care personnel, the tension mounted. Around dinner tables, in hospital cafeterias, and elsewhere, health-care workers talked through their choices — first about immunization and then about whether they would agree to work with afflicted patients in the event of a true crisis. Questions surfaced as regulatory bodies and health-care employers sought to clarify obligations and duties. With SARS, there was no vaccine available. With H1N1, a vaccine had been developed, but, as with seasonal flu vaccines, doubts were raised about its effectiveness (and not only by malcontents, apparently). Health-care managers and executives attempted to combat scepticism about the effectiveness and safety of vaccination by strongly recommending it, and even, in some cases, issuing dire warnings about the consequences of refusing it. In the end, perhaps because of effective infection control, perhaps because of a fortuitous lower-than-expected rate of transmission, or perhaps because of aggressive immunization campaigns, the spread of H1N1 never hit crisis levels or strained the limits of the health-care workforce. Still, it is now clear that we have a generation of health-care workers who are unaccustomed to isolation procedures and who practise on a daily basis with virtually no concern for their own safety. The H1N1 pandemic of 2009 may have foreshadowed a crisis that will bring us face to face with thorny questions around the risks and obligations confronting health professionals in a modern society.

The H1N1 pandemic of 2009 also highlighted new challenges in evidence-based practice and policy. Officials in a number of provinces attempted to use data from vaccine field tests to decide how to deploy staff in immunizing against H1N1 versus seasonal flu. Ontario, for instance, delayed H1N1 vaccination for the elderly and put off seasonal flu vaccination for younger individuals based on such data. Other provinces pursued different approaches, and as the media reported the differences many Canadians became perplexed. Scientific controversies about the risks and benefits of influenza vaccination and about the use of

antiviral medications were reported in the media but not always fully explained. Thus, the decisions facing policy-makers around mass vaccination were excruciatingly difficult; choices had to be made when evidence and ongoing surveillance data were suboptimal, slow to arrive, and unclear in their implications. Although H1N1 highlighted these challenges, many walked away with a sense of cynicism rather than empathy for the leaders involved.

The H1N1 crisis also offered a glimpse into the difficult resource-allocation decisions that lie ahead when a “real” pandemic strikes. Vaccine supply was limited, apparently because of production issues; this, in turn, forced officials to draw up priority lists and raised the spectre of vaccine rationing. (Interestingly, while all of this was going on the sceptics were spreading anti-vaccine messages and loudly announcing their refusal to be vaccinated.) In response to the delays, many panicked and many expressed anger at the authorities. There were reports of community leaders and celebrities receiving the vaccine by “jumping the queue.” Ironically, by the end of the crisis millions of doses of vaccine sat unused, while the pharmaceutical companies involved in their manufacture marked record profits. Vaccines turned out to be the only resource in short supply during the crisis. But early on, hospitals and physician groups raised the possibility that, should the pandemic widen, there might be a need to limit access to ventilator support for those who developed respiratory failure. Fortunately, that point was never reached. But should our health-care system ever be confronted with a true catastrophic pandemic, resource-allocation decisions will be numerous — and very tough.

For the moment, at least, the lasting impact of H1N1 is surely its object lesson with respect to the new age of health information. With the instantaneous flow of information on the Internet (not only “good,” verifiable information but also false rumours) and the reluctance of politicians and bureaucrats to make “bad calls,” mixed messages flooded the airwaves and the bandwidth. Word of suspicious deaths, limited vaccine availability, adverse effects of vaccines, and government proclamations spread like wildfire, and public officials struggled to stay informed, let alone reach policy decisions and articulate them in the media. In many communities across the country, the public and health professionals alike were confused, and often very angry.

By December, the public had reached media saturation. Many commentators opined that the national and international public health response likely represented “overkill” and that public education efforts verged on panic-mongering. However, these comments were made squarely in hindsight — and about an apparently benign pandemic. The impact of H1N1 was nowhere near what had been feared. Again, perhaps

this is partly because many health-care workers and leaders worked tirelessly and infection control efforts were successful, but luck was on our side on many fronts (this was not “the one,” the killer pandemic flu that some public health experts say we’re due for). In the end, was H1N1 a pandemic or a “panic-emic”? Did the sharing of information through the media genuinely help with prevention efforts?

Some caution is in order before we conclude that public health officials and the authorities “cried wolf.” The H1N1 crisis was fraught with many of the same uncertainties and challenges that have always marked public health policy, but with a new element: near instantaneous reporting (and critique) of every judgement call. When reviewing the choices of public health officials, we should bear in mind that public health departments in many communities in Canada and around the world have faced funding cuts and understaffing for years. In many Canadian communities, the response to H1N1 and the attempt to staff vaccination clinics virtually shut down all other public health activities. In Toronto, for instance, a municipal workers’ strike grounded planning efforts at the public health unit in the months leading up to the crisis. Other communities had equally limited methods for coordinating access to information and delivery of supplies. Despite progress in many areas of health care, the management of public health crises is becoming more complex and challenging, and it is clear that we are ill-equipped to deal with the worst of infectious disease pandemics.

The SARS and H1N1 episodes highlight both the best and the worst in our health-care system. It is incumbent on health professionals, leaders, and researchers to take lessons from these experiences. While we learned much from SARS, the “test” was not a full one. We must continue to invest in human resource capacity, as well as in education and research, to deal with the health crises — infectious and otherwise — that are surely coming.

Sean P. Clarke
Associate Editor

GUEST EDITORIAL

Rural Health Research in Canada: Assessing Our Progress

Julith C. Kulig

Five years ago I was the guest editor for the inaugural issue on Rural Health Research. Preparing for this issue on the same topic calls for reflection about our current state of rural health research and what, if anything, has changed over the past half decade.

What are our current understandings of rural? The debate about the meaning of “rural” continues, but most researchers have adopted the rural and small town (RST) definition of rural dwellers (i.e., those who live outside the commuting zones of urban centres of 10,000 or more; duPlessis, Beshiri, & Bollman, 2001). Based on this definition, there are 6 million Canadians who could be considered rural. This figure has held steady for the last 25 years, but the *share* of the RST population within the overall national population is decreasing (22% in 1996 and 19% in 2006) (Bollman & Clemenson, 2008). The number of rural individuals in geographic locations varies across the country, but increasingly the two most populous provinces (Ontario and Quebec) are the least rural. In addition, the rural areas that are increasing in size are largely more adjacent to urban centres. The bottom line is that the proportion of rural residents (regardless of the definition used) is shrinking in our increasingly urban country.

What do we know about the health of rural residents? In 2006 the Canadian Institute for Health Information released the report *How Healthy Are Rural Canadians?* (Canadian Institute for Health Information [CIHI], 2006). This landmark document (the first ever to report on a pan-Canadian examination of rural health) acknowledges that place does indeed matter when it comes to health. Rather than examining health issues by province and territory, the analysis focused on the health of rural dwellers according to their residence within Metropolitan Influenced Zone (MIZ) classifications formulated by Statistics Canada. This enabled comparison of different types of rural (i.e., based on variables such as the percentage of residents who commute, with larger percentages indicating that the area is closer to an urban centre) and urban (i.e., the actual size of the community reflected in Census Metropolitan

Areas and Census Agglomerations). The report paints a comprehensive picture of rural health status that was previously not available in Canada. For example, we now know that life expectancy is lower for both women and men in rural areas, that the incidence of respiratory diseases is significantly higher in rural areas than in all other MIZ categories, and that rural residents engage in less healthy behaviours and have higher overall mortality rates, particularly those related to circulatory diseases, injuries, and suicide. Rural residents have to travel greater distances to receive all services, including health services, and have higher rates of mortality due to motor vehicle collisions. We also know that there are larger proportions of rural people with low incomes and without secondary education but with a greater sense of belonging to their community compared to their urban counterparts (CIHI, 2006).

What is happening in the rural health research arena? By and large, rural health researchers in Canada tend to be individual investigators (MacLeod, Dosman, Kulig, & Medves, 2007) who work virtually with others across the country (and sometimes across the globe) or in place-specific rural research centres in mostly rural and northern locales. The Canadian Rural Health Research Society (CRHRS; www.crhrrs-scrsr.usask.ca/), established in 2003, hosts an annual scientific meeting that brings rural researchers together to discuss issues such as capacity-building for the next generation of rural health researchers, funding opportunities, and the need for a political voice to ensure the implementation of rural-focused policies and services. In all of these areas, however, challenges remain. There are few training opportunities for rural researchers in Canada. The Public Health and the Agricultural Rural Ecosystem (PHARE) training program at the University of Saskatchewan, with partners across Canada (www.cchsa-ccssma.usask.ca/trainingprograms/phare.php), provides funding for graduate students and postgraduate fellows. It offers the scholars numerous opportunities to engage with each other and with experienced rural researchers in developing research expertise in their chosen discipline as well as to enhance related scholarly skills such as publishing and presenting. Researchers can become prepared through programs such as PHARE, but will they have opportunities to obtain funding as rural researchers? Attempts to develop a rural peer-review committee within the Canadian Institutes of Health Research (CIHR) have been unsuccessful, despite the best efforts of the CRHRS and CIHR staff. Rural researchers, often with limited infrastructure, have to go up against all other researchers in a field that is already competitive — particularly so with the removal of health funding from the Social Science and Humanities Research Council. According to statistics compiled by CIHR, in 2008 this agency committed \$8.1 million and \$11.2 million to rural and northern research, respectively, which represents just 0.24% of its 2008

budget. Finally, where will rural researchers publish? In May 2008 the journal *Rural and Remote Health* launched its online North American section (www.rrh.org.au/nthamer/defaultnew.asp). That publication and others, such as this focus issue of *CJNR*, are becoming vital to the highlighting of ongoing rural research that can be used by decision-makers and clinicians in their everyday work.

Unlike the Journal's inaugural issue on Rural Health Research, this issue did not attract submissions focused primarily on health human workforce matters (i.e., the availability of rural nurses and description of their role). The majority of the articles address clinical issues (i.e., knowledge held by rural nurses) and the perspectives of rural residents (i.e., beliefs and experiences). Zibrik, MacLeod, and Zimmer concentrate on professionalism in rural nursing, drawing from a sample of rural acute-care nurses in British Columbia and Alberta. Their findings show that professionalism has both a workplace and a community perspective; nurses were always expected to act in a particular way, whether in the workplace or in the community. Findings such as these have implications for job satisfaction and potentially for the retention of nurses in rural environments. MacKinnon addresses the experiences of rural nurses in learning about maternity care. This is an ever-increasing challenge given the limited exposure to maternity cases in many rural hospitals across the country. Also, rural nurses are responsible for ensuring their own professional competence, yet they do not always have the workplace supports or the workplace opportunities needed to hone their skills in maternity nursing. The question remains: How can rural nurses provide safe maternity care? In the final article in this category, Andrews, Morgan, and Stewart discuss dementia care in northern practice. Like MacKinnon, these authors point to a lack of exposure. Andrews et al. demonstrate that northern nurses have neither the professional exposure to patients with dementia nor the educational background necessary to assess for this condition. In their study, these shortcomings were exacerbated by communication barriers (i.e., inability to speak Aboriginal languages). In general, the nurses felt professionally isolated and lacking in educational resources suitable for their northern location.

The final two focus articles in this issue consider the perspectives of rural residents themselves. Lockie, Bottorff, Robinson, and Pesut address the experiences of rural family caregivers in commuting for cancer care. The rural setting provides the context for why commuting is necessary and how it affects the entire experience, including weather conditions and the need to deal with the patient's symptoms while on the road. Finally, Dabrowska and Bates report on the well-being of Old Order Mennonite women who live in an area known for its environmental hazards. The women's attachment to place plays a large role in their belief

that their health is protected from the hazards that surround them. The findings demonstrate the need to follow sound ethical principles but also to exercise great care when working with this closed religious group.

The invited pieces in this issue of the Journal deepen our understanding of rural research. In his Discourse contribution, Worley identifies similar challenges experienced in Australia regarding the conduct of rural health research. Examples of these challenges include a lack of information on the health status of rural residents and the need for capacity-building for the next generation of rural health researchers. The recommendations offered by Worley should inspire all of us to continue striving towards our goals in working with rural residents and communities. In their Knowledge Translation piece, Jardine and Furgal discuss their experiences with knowledge translation among Dene and Inuit communities in Canada's north. The examples they provide of attempting to engage successfully with these communities throughout the research process and their lessons learned will be useful for all investigators who undertake similar research. Finally, the Happenings section by Wallace clearly shows that the clinical care of rural clients has to be based on relevant evidence. Help-seeking and care options in the case of clients with head and neck cancers are two examples that need to be considered within the context of the rural environment. All of the invited pieces emphasize the fact that place matters!

What are the goals for rural health research over the next 5 years? In the last focus issue on this topic, there was speculation that rural residents would be more involved in conducting the research that is crucial to their everyday lives. Including rural residents as active participants in research is an essential step, complementing their self-reliance while helping them to achieve improved health status. As the demographics of our country change and as immigration trends impact at least some rural areas (Beshiri & He, 2006), we need research that encourages examination of the health status of new immigrants and the experiences of new immigrants with our rural health-care delivery systems. Continual changes to health-care delivery systems (for example, the change in Alberta to a single health-care region) mean that we need to monitor and evaluate the *delivery* of rural health services, identify intervention models that positively impact rural health status and client and community satisfaction. We need to continue investigating *practice issues* in rural settings, such as the perennial issues of recruitment and retention and developing and nurturing professional competence. Finally, we need to further examine the impact of place on health, to identify the links between physical and social spaces and individual and community health status.

It appears that rural health research is making progress. We have reasonable definitions of the term, health information is available, capacity-

building resources are in place, and funding, although limited and hard won, is being accessed by rural investigators. Importantly, the rural research being conducted continues to demonstrate that place matters, and this in turn suggests that rural will always be important — as well it should be!

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Discourse

Rural Clinicians as Research Collaborators: Keeping the “Care” in Our Career

Paul Worley

Rural clinicians are a courageous lot, pioneering new approaches to health-service delivery because we believe our small communities deserve the best, hammering at politicians to revise health policies that make sense in the cities but leave rural people out in the cold, and challenging universities and colleges to create training programs that are accessible to rural applicants and that encourage graduates to see rural practice as a high-profile career option. Yet so often, when we look for research to inform our vision, we are bitterly disappointed by the dearth of data developed, dissected, and disseminated in and for rural communities.

Close to 50% of the world's inhabitants live in rural communities, yet only 24% of the world's physicians and 38% of the world's nurses work in rural regions (World Health Organization [WHO], 2009). Health outcomes, particularly in relation to infant, child, and maternal mortality, are also clearly correlated with these inequities (WHO, 2009). Why, then, is there so little research specifically informing and promoting the health care of these groups? In this Discourse I will outline some of the hurdles currently being faced in rural health research, particularly those faced by rural clinicians, and offer solutions based on experiences around the globe.

My own interest in research was initiated by frustrations in delivering clinical care to my patients. My clinical load was substantial and, in the absence of a sufficient workforce, sometimes overwhelming. There wasn't time for me to create my own evidence. I didn't have a medical library in my town, and when I did find an article related to rural practice often it was based in a setting that didn't seem applicable to mine. Nor had I been given the skills in either undergraduate or postgraduate training to accumulate and analyze rigorous evidence while I worked. I had no

research colleague down the corridor to whom I could turn for advice. And my family were relying on this same rural clinical care, creating an intensely personal motivation for me to improve health-service quality. These issues — lack of local research infrastructure and support, inadequate research training for clinicians, lack of access to appropriate evidence, methodological difficulties in rural health research, and personal motivation — confront rural health research globally.

Building Dedicated Rural Research Capacity

Some gains have been made in Australia in this regard through investment in rural health research infrastructure and rural health-workforce strategies (Wakerman & McLean, 2005). These strategies are aimed at redressing the lack of the academic critical mass in rural centres that is so crucial for the broad multidisciplinary skills needed to conduct research on the complexity of rural health. In most instances, this has resulted in established city-based academics moving to rural centres and then setting about developing research capacity among local clinicians. These respected academics can then attract research students from the multiple disciplines required for rural health research, including geography, sociology, anthropology, education, psychology, management, biostatistics, and the medical sciences, as well as from the traditional health professions. An analysis of country of authorship of research articles published in the international journal *Rural and Remote Health* suggests that this strategy is having some success (Table 1), as Australian authors are disproportionately over-represented relative to their population.

My first recommendation, therefore, is that governments and philanthropic agencies be targeted for capacity-building funding, to encourage established city-based academics and their research students to reorient their careers towards rural health research.

Table 1 <i>Analysis of Articles Published in Rural and Remote Health in 2008</i>	
Article Category	Number (%)
Total number of research articles	89 (100)
Practising clinician identified as an author	48 (54)
Australian author	37 (42)
Australian practising clinician identified as an author	30 (81)

Research Training for Rural Clinicians

Are rural health researchers asking the right questions? Rural research will only be as useful as the questions it seeks to answer. The best questions come from those at the coalface. Therefore, even when there is investment in dedicated rural health research infrastructure, there must be clear mechanisms to link rural research experts with those who are at the practice and community interface. Further analysis of the authorship of articles published in *Rural and Remote Health* suggests that only half of published rural and remote health research is characterized by the strong involvement of practising clinicians, except in Australia, where specific funding has been provided for this purpose (Table 1).

Even in Australia, most rural clinicians who become active researchers do so after many years of clinical practice. Whilst this experience perspective can be an analytical advantage, these clinicians face the prospect of starting their research career, often by undertaking a PhD, whilst also confronting the demands of parenthood and the financial responsibility of supporting a family. Standard PhD scholarships do not provide sufficient support, thus discouraging many who would otherwise make a wonderful contribution to rural health research.

Most other disciplines identify and train their researchers much earlier in their careers when these conflicting social and financial demands are more manageable. Universities and colleges have been slow to ensure adequate research skills for graduates intending to practise in isolated areas, instead focusing on the procedural, public health, and cross-cultural skills — if they have a rural focus at all. Whilst these skills are important, they need to be informed by continuing research that is relevant to rural practice and rural communities, not reliant on the potentially erroneous adaptation of urban-focused evidence. Perhaps this is a hangover from the deficit model of rural practice, which assumed that the brightest and best would choose not to go there and hence research training was directed towards, and only available to, those training for specialties in tertiary academic centres in the city. Those who take up these research opportunities are, then, significantly advantaged in being selected for specialty training programs and subsequent appointment to senior clinical positions. Recent evidence suggests that this deficit model of rural practice does not now apply to undergraduate medical education (Worley, Esterman, & Prideaux, 2004). However, a quantum leap in the number of health-professional students, especially in developed nations, will be needed to create a situation where obtaining a place in rural practice training is sufficiently competitive to provide an incentive for the development of early-career rural clinician researchers.

My second recommendation is that health-professional student numbers be increased significantly and that education programs in both vocational and professional development be required to provide the research training that is essential for clinicians working in rural communities.

Rural Research Accessibility

Once created, is the research accessible? To access the knowledge we need, rural clinicians have had to confront the tyranny of distance from the centres of learning. Now we can be there at the click of a mouse. Or some of us can. Much of the scientific literature, even if it is available on the Web, is still locked behind commercial firewalls that require payment for access. For those with access to university or certain hospital privileges, this hurdle may be easily overcome, and for some rural clinicians it is a significant benefit of academic affiliation with a university teaching program.

But many of the world's rural health professionals have neither of these benefits. In fact, authors publishing in open-access journals such as *Rural and Remote Health*, rather than in subscription-based journals, have greater opportunities to see their ideas incorporated into international practice and policy. However, this does not necessarily correlate with the highest "impact factor" — a consideration for those looking for academic careers. This situation is compounded by the fact that the journals that publish most of the relevant rural health content cannot compete with the impact factors of the focused biomedical journals. The controlled incremental, step-wise approach to research and multiple journals within a small field facilitate high citation rates. Rural health research, on the other hand, is characterized by a small number of dedicated journals and by complex and often context-specific social, educational, or policy interventions.

My third recommendation is that more dedicated open-access journals be developed, to build the impact of rural health research for both investigators and those who use their research findings.

Methodological Issues in Rural Health Research

The context specificity and implicit lack of generalizability of much of rural health research are arguably the major issues bedevilling both the users of the research and the ability of authors to get their studies published in major journals. These factors, along with the small number of rural health researchers, could be why one might think there was a publication bias against rural research in the major journals. For example, an

analysis of the articles published in 2008 in the *Canadian Medical Association Journal* and the *Canadian Journal of Nursing Research* reveals that only 7 (0.5%) of 1,244 and 5 (11%) of 45 articles, respectively, had “rural” either in their title or in their abstract.

My fourth recommendation is that strategic collaboration by rural health researchers in multiple locations be developed, both within countries and across nations, to increase the power and generalizability of both descriptive and intervention studies. Such collaboration will improve all measures of “impact” and help us all to provide the best care to our patients.

Personal Motivations for Rural Health Research

For most of us, our life’s work is motivated by and mediated through close relationships. As I look around the world of rural health research, this is evident. One doesn’t take up rural health research because one is curious about it. We take it up because we are passionate about it! And this passion is inevitably born of personal experiences, often of injustices that need remediation, that have touched our lives or the lives of those we love. Research rewards those who are capable of delayed personal gratification. Remember doing your PhD? In contrast, life rewards those who resist the temptation to delay gratification with those closest to them.

My final recommendation, then, is that we remember why we are involved in the struggle and remember to spend time with those who are our principal motivation.

Rural health research is crucial to the health and well-being of the 50% of our world who live outside major cities. By paying attention to personal motivation, professional education, government facilitation, journal circulation, and international collaboration, we can together build an evidence base that informs the care of the communities we are committed to and sustains the individuals and their families who are at the frontline.

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Conflicts Identified

The author is a rural doctor, the Editor in Chief of *Rural and Remote Health*, the captivated husband of Liz, and the proud father of Jess and Brendan, Mike, Sarah, and Alexa.

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Le professionnalisme en matière de soins actifs en région rurale

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Le thème du professionnalisme revient souvent en sciences infirmières, mais on sait peu de choses sur la place qu'il occupe dans l'exercice quotidien des soins infirmiers. Cette étude porte sur l'expérience des infirmières à cet égard et tente d'explicitier la nature du professionnalisme dans le milieu des soins actifs en région rurale. On a analysé au moyen d'une description interprétative des données d'entrevue recueillies auprès de huit infirmières travaillant dans ce secteur en Colombie-Britannique et en Alberta, au Canada. Il en ressort que le professionnalisme est un phénomène dynamique et durable chez les infirmières exerçant la profession en région rurale. Il est associé à la place qu'elles occupent dans la communauté et aux réalités qu'elles côtoient dans leur milieu de travail. Ces conclusions comportent des implications importantes pour l'étude et la valorisation des sources de satisfaction au travail et la création de milieux professionnels adaptés au contexte rural.

Mots clés : soins actifs en région rurale

Professionalism in Rural Acute-Care Nursing

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Professionalism is commonly discussed in nursing but little is known about how it is experienced in everyday nursing practice. This study examines rural nurses' experiences of professionalism and articulates the nature of professionalism in rural acute-care settings. Interview data from 8 nurses in rural acute-care facilities in British Columbia and Alberta, Canada, were analyzed using an interpretive description approach. The findings indicate that professionalism among rural nurses is a dynamic, enduring phenomenon that exists in workplace and community contexts. To experience professionalism in rural nursing means being visible in the community while embracing reality in the workplace. Understanding professionalism in a rural context has significant implications in terms of affirming and identifying sources of job satisfaction among rural nurses and creating professional practice environments in rural areas.

Keywords: acute care, health services, nurse relationships/professional issues, rural and remote health care

Introduction

The concept of professionalism is frequently discussed in nursing. However, the experience of professionalism in everyday practice is not well understood. This is particularly the case for nurses who live and work in small, rural communities, where resources are limited and demands are many. There is growing evidence suggesting that professionalism is an important factor in nurses' job satisfaction and may play a role in recruitment and retention. Through the exploration of the experiences of rural acute-care nurses, the important facets of professionalism as it is lived in everyday practice can be understood and articulated.

Rural nursing has been characterized as fundamentally different from nursing in urban areas due to factors such as geographic and professional isolation, limited access to resources, social connections in the community, and a varied and often extended scope of practice (Bigbee, 1993; Bushy, 2005; Lee, 1991; Long & Weinert, 1989; MacLeod, 1998; MacLeod, Martin Misener, Banks, Morton, & Bentham, 2008; Thompson & Chambers, 1993). In Canada, hospital-based, acute-care registered nurses (RNs) make up the largest cohort (39%) of rural nurses (Stewart et al., 2005). Understanding the experiences of professionalism among rural acute-care nurses may lead to contexts where nurses achieve greater

job satisfaction and where the recruitment and retention of nurses meet with greater success.

Professional practice environments (PPEs) — settings where nurses function within the scope of their professional roles and experience a sense of professionalism — are frequently cited as a strong predictor of job satisfaction (Blegen, 1993; College of Registered Nurses of British Columbia, 2005; Laschinger, 2008; Manojlovich & Laschinger, 2007; McNeese-Smith, 1999). Similarly, nurses who work in environments that are conducive to the exercise of professional roles or attributes such as autonomy, specialized knowledge, collegiality, and teamwork generally enjoy greater overall job satisfaction (Baumann et al., 2001; Manojlovich, 2005; Miller, Adams, & Beck, 1993; Wynd, 2003). To date, nearly all studies linking PPEs to workplace satisfaction have been conducted in urban settings. In the one exception, Laschinger, Almost, and Tuer-Hodes (2003) included data from rural hospitals that provided tertiary services. In addition, these studies of PPEs focus on within-workplace factors. They fail to address the influence of the community on nurses' experience of their workplace, a factor that is increasingly acknowledged as important in rural nurses' work and job satisfaction (Kulig et al., 2009; Penz, Stewart, D'Arcy, & Morgan, 2008).

Although the concept of professionalism is cited as an important measure of nursing job satisfaction (e.g., Blegen, 1993; Cowin, 2002), the nature and elements of professionalism remain ambiguous and elusive. Broadly speaking, professionalism refers to the "conduct, goals or qualities" (Schwirian, 1998, p. 8) that are indicative of a profession or that designate someone as a professional. A best practice guideline (BPG) developed by the Registered Nurses Association of Ontario (RNAO) titled *Professionalism in Nursing* describes eight key attributes (Knowledge, Spirit of Inquiry, Accountability, Autonomy, Advocacy, Innovation and Visionary, Collegiality and Collaboration, Ethics and Values) that "signify professionalism of the nurse" (Registered Nurses Association of Ontario [RNAO], 2007, p. 23). The *Professionalism in Nursing* BPG was developed through a systematic review of the literature combined with input from an expert panel of Canadian nurses. Its authors suggest that incorporating the attributes of professionalism into the workplace will help to create a healthy work environment for nurses. Even though this BPG represents the best available evidence describing professionalism, it does not fully address issues of context. The rural context inevitably affects the ways in which rural nurses experience and fulfil their professional roles.

The purpose of this study was to understand the nature of professionalism and professional practice as experienced by nurses in rural acute-care settings. The study was guided by two research questions: *How do acute-care nurses in rural areas of British Columbia and Alberta describe their experiences of*

professionalism and professional practice? What are the characteristics of professionalism and professional practice environments in rural health-care settings?

Method

Interpretive description was selected as the approach for this study, as it is theoretically aligned with the tenets of naturalistic inquiry and can be used to generate knowledge relevant to clinical nursing contexts (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). This approach generally incorporates small, purposively selected research samples comprising people whose experiences are similar to some degree (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997) and uses data-collection techniques that facilitate the documentation of meaningful accounts of experience, such as interviewing, participant observation, and documentary analysis (Thorne et al., 1997, 2004).

The data for this study were generated as part of a 3-year multi-method national research project, *The Nature of Nursing Practice in Rural and Remote Canada* (MacLeod, Kulig, Stewart, & Pitblado, 2004). One avenue of inquiry was a narrative study in which 151 nurses from across Canada, in all practice areas, were interviewed in depth about their everyday practice (MacLeod et al., 2004, 2008).

A purposive sample of eight interviews was selected from the interviews conducted for the national narrative study, as this number would allow for an in-depth understanding of experience. The sample comprised the full pool of interviews with acute-care nurses in British Columbia and Alberta. Interviews were selected for logistical purposes relating to data management and analysis in the qualitative tradition and on the basis of participants' self-identified practice focus in rural acute-care nursing. The participants were all female. Five resided in British Columbia and three in Alberta. The participants had been employed as RNs for an average of 20 years (*range* = 10–30 years), with an average of 16.5 years' experience in rural acute-care settings (*range* = 8–25 years).

Participants were recruited through advertisements placed in the newsletters of provincial professional associations and through word of mouth. Participation was voluntary, no financial remuneration was offered, and written consent was obtained prior to interviewing. The second and third authors and research assistants collected data through telephone interviews using a semi-structured, phenomenological interview format, with interviews lasting an average of 75 minutes. Interviews were guided by questions such as "Could you describe what a typical day/week is like for you?" and "Could you tell me about: A situation that went unusually well? A situation that is very ordinary and typical? A situation that was particularly demanding?" Responses were followed up with interview

probes designed to elicit full and detailed descriptions of nurses' practice experiences. Interviews were audiorecorded and transcribed verbatim. Confidentiality and anonymity were ensured through the disguising of specific community characteristics or events and through the use of pseudonyms. Ethics approval for the narrative study was obtained from the Ethics Committee of the University of Northern British Columbia.

Data for the study were analyzed using Lincoln and Guba's (1985) unitizing and categorizing strategy. Units of data were extracted from the text and transferred onto index cards. Provisional categories were created, with the aim of bringing together cards with similar content and devising rules for the inclusion or exclusion of cards within a category (Lincoln & Guba, 1985). Data saturation, the point at which the researcher is not hearing or seeing any new information, was achieved after approximately six interviews had been reviewed. Rigour was addressed in three ways. First, thick and rich descriptions of the data were provided, along with the consideration of alternative interpretations. Second, the findings were reviewed with a group of acute-care RNs from a rural community in northern British Columbia, who confirmed that the descriptions and interpretations resonated with their own experiences. Third, a reflective journal of the analytic decisions was kept, codes and categories were reviewed through peer evaluation, and interview transcriptions were compared with the audiorecordings for technical accuracy.

Findings

The overarching day-to-day experience of professionalism for rural acute-care nurses can be best conceptualized and described in terms of nurses' interactions in two contexts: the community, and the workplace. In the narratives, nurses' descriptions of being a professional were contextually situated in reference to their experiences and interactions in community and workplace environments.

Interview questions focused on nurses' experience of their everyday practice. Therefore, nurses' experiences of professionalism in the context of the workplace make up the largest proportion of the findings. However, within the interpretation of the data, there is an appreciably strong notion that being a professional nurse in a rural acute-care setting extends beyond the physical boundaries of the workplace. When nurses were asked to describe their day-to-day work, their responses frequently contained descriptions of interactions and experiences occurring external to the workplace. There is an apparent degree of permeability between the rural workplace and the community setting, and this seems to enhance the lives and professional practice experiences of rural nurses.

The Community Context: Being Visible

Rural nurses are socially embedded in their community, which means that their voices and actions are under constant observation by the public. The overarching theme of *being visible* emerged from the narratives. It describes physical and social elements of how nurses experience being a professional within a rural community environment. Rural nurses are subject to a high degree of visibility in the community, and many of the participants related the feeling of being constantly watched. “As a nurse, you’re kind of in a fish bowl,” explained Catherine. “People do know who the nurses are, and you’ll be approached in various places for advice and information.” Rebecca commented on how visibility within the community made it difficult for nurses to escape from work:

The bad thing is [that] sometimes you just can’t get away from work. You know, you walk down the street . . . that’s what my husband says to me all the time, if we walk down the street together . . . everybody’s like, “Hi, how are you? Do you remember me?”

Managing obligations and expectations. Aside from not being able to escape the permanent identity of being a nurse, many participants perceived visibility as an inherent benefit, as it made them feel like a professional. Knowing that people would approach them for advice or ask them questions outside of work helped affirm their position as a respected and trusted member of the community. Many nurses said that community members had expectations of how nurses ought to act and that they were obliged to maintain a professional disposition at all times. Sara said, “You want to do your best because you know that people look up to you and everybody knows everybody.”

It was evident that rural nurses felt pressure to behave professionally and always interact with community members in a courteous, helpful, and friendly manner. The issue of knowing members of the community on a personal level as neighbours or family friends increased the need to always behave in a professional manner and be personable. Many nurses expressed the sentiment that they felt obligated to be extra accommodating to clients from the community, as public perceptions could destroy their reputation in the community:

Sara: It’s important to you to do your best for them.

Interviewer: And why do you feel that?

Sara: Why do I feel it’s important? Like I say, you live in this community. I mean, you know how word of mouth . . . if so and so went into the hospital and I treated her [badly] . . . you know that’s going to get around the whole town. I mean . . . you want to be respected, to a degree.

The participants not only experienced high visibility as nurses, but also spoke of being seen as leaders within their communities, and many expressed the view that they were expected to set a good example for the community. Catherine explained that there was “no place to hide.” She felt that her actions were observed, and perhaps emulated, by members of the community:

I try to lead or provide a healthy example. I'm not someone who goes to the bar or that kind of thing. We do — my husband and I — go for walks frequently, so they see us out walking and trying to lead a healthy lifestyle, which I think is trying to present a good example for everyone, really. Because I think . . . a lot of times the nurses are watched as to what they're doing, and maybe people try to follow what they're doing.

Maintaining confidentiality. Visibility in the community also meant that nurses were sometimes approached by people and questioned or even pressed to provide personal information about patients. Nurses in rural settings must have access to strictly professional knowledge that is known only by members of the staff and is not shared with the public. A part of nurses' professional role is to ensure client anonymity and confidentiality and to safeguard private information. Navigating this issue without appearing rude can be especially challenging in smaller communities when there has been a previous nurse–client relationship or when family connections or friendships are involved. “You have to be careful,” explained Heather, “because people will stop and ask you if somebody is in the hospital or how they are or whatever, so with the confidentiality thing you have to not say what's going on.” Sara added that “confidentiality is super important, really important in a rural community.”

The Workplace Context: Embracing Reality

As with the community context, the workplace context was mediated by interactions between the nurse and the physical environment (i.e., hospital equipment and resources) as well as people in the social environment (i.e., other members of the health–care team). Part of the professional role of rural nurses is recognizing the need to be flexible and being prepared to manage unrehearsed events. This requires not only quick thinking but a considerable amount of teamwork and collaboration among the nursing staff. *Embracing reality* was interpreted as a significant, recurring theme in the workplace context, relating to the casual yet professional, darkly humorous, dynamic attitude that rural nurses adopted as part of their professional demeanour and professional practice.

Being versatile: “Jack of all trades, master of none.” Many participants described their role as rural nurses as akin to being a specialist in general

nursing. Rebecca and Sara used the same expression, “jack of all trades, master of none,” to characterize the work of rural nurses. This expression was used in the context of describing the variety of tasks, knowledge, and roles required of the rural nurse during the course of a given day. It illustrates how these nurses felt they were expected to change roles as the situation demanded, drawing on their wealth of knowledge. Several other participants also alluded to this idea in their narratives: “I feel that I know a little bit about everything” (Heather); “You need to know a little bit about everything” (Shannon).

Though there were many examples of challenging workplace situations requiring versatility, participants’ descriptions rarely included expressions of complaint or frustration. Nurses realized that in most cases there was no one to fall back on or to take over for them, and they assumed an “it’s up to us” mentality. In some instances it was apparent that nurses derived a sense of satisfaction, importance, and pride in knowing that there was no one else around to do their job. For these nurses, being versatile was just another facet of how they embraced the realities of the workplace and shared their experience of being a professional.

Being prepared: “The Boy Scout school of nursing.” It was clear in the narratives that in this line of work one has to expect the unexpected and that being prepared for anything is the best course of action. Catherine described the challenges of caring for a variety of patients and not knowing what might happen over the course of a day. She stressed the importance of being prepared:

The variety of patients that come in the doorway is challenging. Sometimes we have warning of what’s coming and sometimes we don’t. The ambulance people are very good about giving us as much information as they can and as much warning of what they are bringing in. So trying to get prepared for what they are bringing us — I always say that I went to the Boy Scout school of nursing, and so I tend to have everything ready that I’m going to need. On my recovery room days I don’t leave until the room is absolutely set up for the next morning, so that if something happens and I get called in during the night I know where things are and . . . everything is ready to go.

The notion of being prepared was also highlighted by Heather, who took advantage of any free time to familiarize herself with each area, in the event that she would be called to work there:

Whenever there’s a slack spot, I like to go down to Emergency and I like to go through the crash carts. Because I’m casual, I’m not as familiar as the other girls. So I go through it and go through it and go through it, and

I go through the cupboards to see what's there, what's not there, what's expired, in case I have an emergency, so that I'm familiar again where everything is and the protocols, if I find protocols that I'm not familiar with. I go through the labour and delivery room. I go through the nursery again, just to see where everything is . . . to make sure that I remember where everything is. Now, if I get a chance in the night, I'll do a kind of little mock resuscitation on their little practice babies, to practise neonatal resuscitation so that I'm prepared.

The repeated emphasis on being familiar with protocols and equipment captured another facet of this nurse's understanding of her responsibilities as a professional. Heather's narrative reveals the voluntary and relatively routine way she went about refining her skills and knowledge. This suggests that being prepared is an accepted part of the reality of being a professional nurse in a rural setting.

Teamwork. One of the most talked about aspects of being a rural acute-care nurse was strong teamwork and the notion of nurses working together. Every interview contained positive comments about colleagues and frequent mention of helping each other out as an integral and enjoyable part of rural acute-care nursing. Staff cohesiveness was often referenced as a highlight of the workplace environment, and teamwork was frequently cited as a key reason why emergency situations resulted in good outcomes. "Teamwork is so essential," explained Sara, "where there is true teamwork, it is . . . so fulfilling . . . it's wonderful." Sara went on to note that the essence of teamwork was "helping each other accomplish the work that needs to be done in a time frame" and "anticipating the needs . . . going here and picking up where I left off because I can't get to it" as well as "supporting each other . . . and looking out for each other."

The equating of adequate equipment, education, and staffing with professionalism. In addition to having to be prepared for anything, the rural nurses often lacked access to the most up-to-date equipment and resources. Access to equipment, specialized education, and adequate staffing resources not only reinforced a nurse's self-perception as a professional, but also supported the image of rural nurses as professionals in the minds of the public and other health-care providers.

Emilia said that because rural nurses often lack access to continuing education or new equipment and supplies, "sometimes you sort of feel looked down upon by girls who work in the intensive care unit or critical care in the big hospitals." Heather noted that rural nurses "sort of get put down by the referring hospital in the bigger place because we haven't done it quite the way they do." Catherine expressed the view that urban nurses perceive rural work as less sophisticated: "My line lately

[to urban nurses] has been, ‘Come play with us and see what you have to work with’ . . . They don’t understand that we’ve done the best we can with what we have.”

Six of the eight participants made explicit reference to the fact that their practice was constrained by the lack of modern or properly functioning equipment. The nurses indicated that having the latest in terms of supplies and equipment allowed them to do the physical aspects of their job better and also made them feel more like professionals. As nurses told their stories about their equipment, their voices revealed an unmistakable blend of sarcasm and embarrassment. The nurses seemed to lament (often humorously) the fact that they had to use outdated physical resources.

Many of the participants also said that they did not receive enough educational support from their employer and that continuing education was not treated as a priority. Amanda explained that “we’ve sort of been at a standstill as far as education is concerned for quite a few years.” Rebecca shared her experience in applying for continuing education funding: “Now there’s a freeze on education, so you can apply . . . to go to a course, but you won’t get the money for it.”

Many of the nurses indicated that having available relief staff and adequate staffing levels was another dimension of being professional. When there were persistent staff shortages, rural nurses felt less like professionals because their lack of physical resources served to quickly drain their energies and their satisfaction with work. Catherine and Shannon spoke frankly and repeatedly about the realities of “limited staff members” and “short staffing” in a rural hospital environment, which put pressure on all nursing staff to be available to help, even on their days off. “There was no point calling for extra staff,” explained Sara in speaking about a particular situation, “because there was nobody else around. There was nobody around to work extra. Nobody.” Urban nurses also commonly cite the challenges associated with inadequate relief staff. However, the situation is different in rural settings, where two nurses staff an entire hospital and relief staff pools are often nonexistent.

Discussion

It is clear from the findings of this study that rural nurses in British Columbia and Alberta experience a strong sense of professionalism on a day-to-day basis, as evidenced by the emergence of two prominent themes: *visibility* in the community context, and *embracing reality* in the workplace context. Being a professional nurse in a rural setting appears to be an enduring experience that does not lapse when nurses are away from the workplace.

An examination by Kulig et al. (2009) of data from the Canada-wide survey of rural and remote nurses supports the idea that rural communities play an important role in nurses' sense of personal and professional satisfaction in and attachment to the community. The literature offers few suggestions as to how rural nurses' interactions within the community environment can be beneficial in terms of mediating their self-perceptions and experiences of being professional. Rural nursing is known to be characterized by a "lack of anonymity" (Long & Weinert, 1989, p. 120), a catch-all phrase that is often carelessly and negatively applied to rural nurses' interactions and experiences within the community (Davis & Droles, 1993; Shellian, 2002). Unlike most of the findings reported in the literature, the findings of the present study suggest that rural nurses derive a great deal of professional pride and reinforcement of professional values from their interactions with community members, and that this can in turn positively affect nurses' conceptions of their professional status.

The significance of the *visibility* finding is that visibility represents many of the positive professional reinforcing elements, as opposed to the negative connotations that seem to be firmly entrenched in lack of anonymity. Visibility speaks to the rural nurses' own sense of being viewed as professionals, which in turn influences their actions in the rural community. In the community context, nurses' narratives revealed striking similarities and patterns related to the ideas of being seen and being approached because of their public status as a nurse. The predominant theme of visibility was apparent in nurses' rich descriptions of interactions within the community, and it surfaced repeatedly in the narratives of all eight nurses. The extent to which nurses expressed professionalism as occurring within the community context, and the strength with which they did so, is of particular interest, as the interviews were intended to capture typical workaday experiences.

The literature contains very little evidence that directly supports the notion that community members play a role in rural nurses' sense of being a professional, and no studies that examine how the community might support nurses' sense of being a professional. Given the results of this study, it seems entirely reasonable to suggest that community members play an active and important role in reinforcing rural nurses' experiences of being professional.

In the data, the subthemes of *obligations and expectations* and *confidentiality* fell under the overarching notion of visibility. The literature does not have much to report on how rural nurses' sense of community obligations and expectations (in terms of what they say or do) affects their experience of being a professional. However, it is known that nurses derive a sense of satisfaction from their work when they are able to apply

professional principles and enact the philosophies of the nursing profession (Baumann et al., 2001; Biton & Tabak, 2003). Nurses' desire to be regarded favourably by members of their community might also be their motivation for being positive role models who lead by courteous, healthy example. Positive role modelling in turn is likely to affirm nurses' professional experience.

The visibility of nurses in rural communities was often the basis for participants being approached by members of the community. These encounters frequently led to a situation in which the nurse had to exercise her professional duty to maintain confidentiality. All participants spoke of the importance of maintaining confidentiality about clients' illnesses or hospitalizations and safeguarding clients' personal health information during encounters outside the workplace. Interestingly, nurses' discussions about confidentiality were almost entirely based on interactions away from the workplace. This stands in contrast to the notion that confidentiality in nursing is a professional ideal that generally applies in the context of professional, workplace relationships (Canadian Nurses Association, 2008). Owing to the need for confidentiality, rural nurses seem to be constantly engaged in a professional relationship with members of the community, even though the basis for a particular interaction may be personal.

The need for teamwork was highlighted for participants when the hospital became especially busy and nurses had to collaborate and communicate with each other in order to keep up with care demands. The "fulfilling" aspect of being a team member suggests that teamwork contributes to nurses' sense of satisfaction with and happiness in their job. Nurses said that knowing they could rely on their colleagues to come in during particularly busy periods helped them to feel like professionals and contributed to good patient outcomes, which in turn reinforced their sense of professional satisfaction. The participants' emphasis on teamwork is echoed in the literature with regard to professionalism and job satisfaction (e.g., Apker, Propp, Zabava Ford, & Hofmeister, 2006; Leveck & Jones, 1996).

In the rural nursing literature, specific reference to the importance of teamwork and job satisfaction is scarce (Hegney, McCarthy, Rogers-Clark, & Gorman, 2002), but urban studies of the positive relationship between teamwork, job satisfaction, and professionalism are plentiful (Day, Minichiello, & Madison, 2007; Dunn, Wilson, & Esterman, 2005; Hegney, Eley, Plank, Buikstra, & Parker, 2006). The RNAO's (2007) *Professionalism in Nursing* BPG uses the phrase "collegiality and collaboration" to describe collaborative partnerships, mentorship, and interdependence between care providers in professional workplace environments; it suggests that professionalism, in terms of collegiality and collaboration,

includes nurses “developing collaborative partnerships within a professional context” (p. 27) as well as “acknowledging and recognizing interdependence between health care providers” (p. 27). Participants in the present study repeatedly affirmed that teamwork was a critical element in their experience of being a professional and ultimately helped to foster their own perceptions of a satisfying workplace.

The participants expressed many concerns about the lack of functional or modern equipment and the poor aesthetics of existing equipment. These concerns detracted from the nurses’ view of themselves as professionals and their work as professional. A recent analysis of national survey data from the Nature of Nursing Practice in Rural and Remote Canada study by Penz et al. (2008) found that “having available, maintained, up-to-date equipment and supplies was highly related to rural [acute-care] RNs’ job satisfaction” (p. 795). While there has been little rural research on how equipment and supplies affect nurses’ job satisfaction, the results of several urban-based studies do support the connection (e.g., Hegney et al., 2006; Khowaja, Merchant, & Hirani, 2005; Petzäll, Berglund, & Lundberg, 2001; West, Barron, & Reeves, 2005).

The experiences of the rural nurses in the present study overlapped with, but could not be readily categorized into, all the attributes of professionalism identified in the RNAO’s (2007) BPG (Knowledge, Spirit of Inquiry, Accountability, Autonomy, Advocacy, Innovation and Visionary, Collegiality and Collaboration, Ethics and Values). The goal of the present study was to articulate rural nurses’ experiences of professionalism in practice rather than to substantiate a predetermined framework for professionalism in nursing. While many of the RNAO attributes were evident in the nurses’ descriptions, the experiences of the nurses suggest a more nuanced and multi-faceted understanding of what it means to embody the qualities of nursing professionalism within the context of rural acute-care practice.

Limitations

The limitations of the study centre on its small number of participants and the analysis of interview data, which did not specifically aim to elicit the nature of professionalism or professional practice. The rich, detailed description of nurses’ experiences provided in the interviews offsets this limitation. All of the nurses who volunteered for the study were residents of western Canada, were female, and had 8 or more years of rural acute-care nursing experience. The findings could be different in other geographic locations in Canada, among male nurses, and among rural nurses with less than 8 years of acute-care experience.

Conclusions and Implications

In this study, rural acute-care nurses in British Columbia and Alberta experienced professionalism in the contexts of the community and the workplace. The findings show that nurses' experiences of visibility in the community are significant in terms of affirming their perceptions of professionalism and job satisfaction. This phenomenon has not been attended to in detail in previous studies. It is clear that accurate representations of professionalism in a rural setting must reflect the important role played by nurses' interactions with community members.

Researchers have studied the various concepts of professionalism and job satisfaction. However, we need to achieve a firmer grasp on how professionalism can ultimately translate into improved recruitment and retention of Canadian nurses. The findings of this study suggest that nurses who perceive themselves as professionals are satisfied with their work. There are potential benefits associated with nurses' community visibility, and further exploration of the impact of visibility in the community context is warranted. Research on key components of professional practice environments in rural settings is also needed. The present results confirm that professionalism in rural nursing remains multidimensional and dynamic, traits that are frequently characterized by the presence of teamwork, communication, collaboration, and adequate equipment and staffing, as well as access to continuing education. These characteristics are also commonly associated with the positive assessment of job satisfaction, workplace commitment, recruitment, and retention.

With regard to nursing practice, the findings confirm the need for nurses to be aware of core nursing values when interacting in the community. Ensuring nurses' access to continuing education and quality equipment can enhance nursing practice and reinforce nurses' sense of professionalism. The findings suggest that, in order to more fully represent professionalism in rural practice, the RNAO's (2007) BPG would benefit from a reconsideration of the role of the community, engagement in teamwork, and collaborative practice, as well as the availability of equipment, human resources, and continuing education.

Education and policy supports for professional practice in rural nursing can help to create rural workplace and community environments that attract and retain nurses. Discussion in undergraduate nursing programs of professionalism as it is manifested in everyday rural nursing practice will help nurses to appreciate the significance and the dynamics of being a professional in a small community. Practical training in the management of multiple relationships and role conflict in the community could help nurses to prevent situations that compromise ethical practice. Acknowledgement of the important role of the community in nurses'

experience of professionalism can contribute to new ways of engaging rural communities in the recruitment and retention of nurses. Lastly, opening up a broader dialogue on professionalism and rural nursing could help to correct misperceptions about rural nursing and its development in Canada.

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Résumé

**L'apprentissage des soins de maternité :
l'expérience du personnel infirmier
en milieu rural**

Karen MacKinnon

Deux monographies examinent l'expérience du personnel infirmier prodiguant des soins de maternité dans les milieux ruraux de la Colombie-Britannique, au Canada. Les auteurs de ces études ont d'une part réalisé des entrevues auprès d'infirmières et infirmiers de première ligne, de gestionnaires et de prestataires de soins de santé, et d'autre part observé les pratiques de ceux-ci. L'une des principales difficultés cernées par les infirmières et infirmiers en milieu rural est de veiller à ce que du personnel infirmier compétent et averti dans le domaine des soins périnataux ou de maternité soit disponible en permanence dans les hôpitaux régionaux. Il est aujourd'hui difficile pour le personnel infirmier travaillant dans de petits hôpitaux en milieu rural d'acquérir les compétences nécessaires pour offrir des soins de soutien et de maternité sécuritaires en raison de la baisse des taux de natalité, de l'augmentation des charges de travail et de la diminution des possibilités de mentorat. Les décisions d'allouer au personnel infirmier en milieu rural des congés autorisés et des ressources pour de la formation professionnelle continue (FPC) s'articulaient autour de discours mettant de l'avant la responsabilité personnelle des infirmières et infirmiers à l'égard de la « compétence continue ». Ces méthodes de travail institutionnelles contribuent à accroître le fardeau du personnel infirmier en milieu rural, et ont de ce fait une influence négative sur l'accès des infirmières et infirmiers à de la FPC et sur l'expérience que celles-ci et ceux-ci vivent lors de la prestation de soins de maternité, ce qui a des répercussions tant sur la santé des bénéficiaires des soins que sur la conservation du personnel infirmier.

Mot clé : formation professionnelle continue

Learning Maternity: The Experiences of Rural Nurses

Karen MacKinnon

Two research studies explored rural nurses' experience with the provision of maternity care in rural British Columbia, Canada. Frontline nurses, managers, and health-care providers were interviewed and their practices observed. One of the main challenges identified by rural nurses was ensuring that a knowledgeable/skilled maternity or perinatal nurse was always available at the local hospital. Learning how to provide safe and supportive maternity care is difficult for nurses working in small rural hospitals today due to declining birth rates, increased workloads, and a decrease in opportunities for mentoring. Decisions about the allocation of time off and resources for rural nurses' continuing professional education (CPE) were structured by discourses of personal responsibility for "continuing competence." These institutional work processes increase the burden on rural nurses, negatively affecting their opportunities for CPE and their experiences of providing maternity care, with implications for both patient safety and nurse retention.

Keywords: rural nursing, nursing education, continuing professional education, maternity nursing, institutional ethnography

Over a 4-year period, two research studies guided by institutional ethnography (IE) were conducted to explore rural nurses' experiences with the provision of maternity care in the Canadian province of British Columbia. Registered nurses (RNs), managers, and other health-care providers working in nine rural communities participated. Findings from these studies indicated that rural nurses practise autonomously and demonstrate a deep sense of commitment to and responsibility for the people living in their communities. The RNs described caring for childbearing women and their families while at the same time being responsible for the safety of all of the patients in the rural hospital (MacKinnon, 2008). The purpose of this article is to report on an additional analysis of the data exploring one important aspect of rural nursing work: how rural nurses learn to provide maternity care and the social organization of their learning experiences.

Background

Lack of access to maternity services in rural settings increases the stress and vulnerability of childbearing women (Kornelsen & Grzybowski, 2005a). Recent trends reflect an impending crisis in the provision of

maternity care for Canadian women (Kornelsen & Grzybowski, 2005b). In rural Canada there is a shortage of health-care providers, including nurses (Canadian Nurses Association [CNA], 2002). Addressing this workforce shortage will require not only new models of collaborative practice (Minore & Boone, 2002) but also better ways to support the readiness of health-care providers, including nurses, to provide maternity care (Rogers, 2003).

Literature Review

Global nursing shortages and the aging nursing workforce have created a crisis situation for the staffing of many rural hospitals in Canada (Stewart et al., 2005). Researchers have identified the provision of affordable and accessible education programs as an important strategy for recruiting and retaining rural nurses (Hegney, McCarthy, Rogers-Clark, & Gorman, 2002). MacLeod et al. (2004) found that targeted funding is needed for education programs that prepare nurses for the realities of rural and remote nursing practice. There are descriptive accounts of such programs (MacLeod, Lindsey, Ulrich, Fulton, & John, 2008; Smith, Emmett, & Woods, 2008). In Canada, most nurses receive their entry-level education in larger centres, but regional programs in smaller cities are rapidly developing. Some nursing education programs have included the option of rural clinical placements to help rural communities recruit new RNs (Neill & Taylor, 2002; Van Hofwegen, Kirkham, & Harwood, 2005; Yonge, Ferguson, & Myrick, 2006).

A Canadian study of nurses' migration patterns determined that the majority of RNs who migrate to a big city to go to school do not return to their original community (Pitblado, Medves, & Stewart, 2005). Partnerships between urban and regional education programs and rural communities have been proposed (McCoy, 2009) and preceptorship programs and/or internships for rural nurses have been recommended to help new graduates make the transition to assuming responsibility for complex and varied rural nursing work (Lea & Cruikshank, 2007).

Jukkala, Henly, and Lindeke (2008) report that rural nurses want educational opportunities that are relevant to rural practice and accessible in rural settings. Challenges to continuing professional education (CPE) include physical isolation, heavy workloads, small professional networks, and financial constraints. Other barriers to CPE access include poor technologic and communications infrastructure and lack of funding to support travel and registration fees (Curran, Flett, & Kirby, 2006). Penz et al. (2007) found that removing the barriers to participation improved job satisfaction, with implications for retention of rural nurses.

Rural Nurses' Experiences With the Provision of Maternity Care

Our research team conducted two projects exploring the social organization of nursing work and seeking to identify possibilities for changes in health policy, nursing education, and nursing practice environments (MacKinnon, 2009). In the first study we interviewed and observed the practice of 16 RNs working in hospital settings and 21 public health nurses serving as expert informants. In the second study we interviewed 42 hospital and 9 public health nurses, resulting in a total of 88 interviews with RNs. In addition, 10 other health-care providers (including physicians, midwives, a physiotherapist, and two Licensed Practical Nurses) and 10 frontline service managers were interviewed about their experiences working with rural nurses. The initial findings of these interviews have been analyzed and are reported elsewhere (MacKinnon, 2008, 2009).¹ The current research explores additional “threads” or areas that emerged from the second study and that warrant further investigation.

Methodology

Institutional ethnography, which was developed by the Canadian sociologist Dorothy Smith (1987, 2005), focuses attention on the *socially organized* character of everyday life. The goal of IE is not to explain people's behaviour but to be “able to explain to them/ourselves the socially organized powers in which their/our lives are embedded and to which their/our activities contribute” (Smith, 1999, p. 8). Beginning from the standpoint of rural nurses provides an entry point into the institutional relations that organize their experiences. In an IE study, researchers identify “threads” or traces of social organization that warrant further investigation. This article is the result of a thread that was identified; something important was going on related to nurses' experiences of learning to provide maternity care in rural settings.

Context for Rural Maternity Nursing Work

Both studies used a working definition of a rural community as less than 10,000 people living beyond commuting distance of an urban setting (duPlessis, Beshiri, Bollman, & Clemenson, 2001). The second study (reported on here) included five communities that fit this definition. The study took place in a mountainous interior region of British Columbia near the Rocky Mountains where high mountain passes, snow and ice in the winter months, and deer on the highways make travel treacherous.

¹ See MacKinnon (2008) for more details on the research methods.

In one of these communities the hospital had recently closed, forcing women to travel to a neighbouring community to receive hospital care during labour and childbirth.

The four remaining hospitals ranged in size from eight acute-care beds (two hospitals with residential or long-term care provided in an adjoining building) to 20 acute-care beds (also two hospitals). Over the last 5 years the average number of births in these hospitals has ranged from 26 to 94 per year (see Table 1). Day surgeries were provided in all but one of these small community hospitals. The hospital with the lowest number of births was struggling to maintain “low risk” obstetrical services (no oxytocin inductions were initiated and few women gave birth to their first baby in this hospital). The other three hospitals had experienced periodic operating room closures when it was not possible to guarantee the availability of the skilled health-care providers (physicians and nurses) needed to ensure a safe emergency Caesarean delivery.

Table 1 *Number of Births per Year, by Hospital, for the Years 2003–04 to 2007–08*

	2003–04	2004–05	2005–06	2006–07	2007–08	Average
Creston (20 acute-care beds)	85	65	75	56	75	71.2
Elk Valley (20 acute-care beds)	94	104	88	81	103	94
Golden (8 acute-care and 26 residential beds)	63	65	74	77	60	67.8
Invermere (8 acute-care and 35 residential beds)	20	30	28	31	21	26

Source: www.bcphp.ca/Deliveries%20by%20Maternal%20Residence%20Tables.htm
(retrieved November 15, 2009).

Investigative Methods

In an IE study, participants do not constitute a sample but rather serve as a panel of expert informants. This study began from the standpoint of rural nurses, with the goal of exploring how nurses’ experiences of providing maternity care are influenced by institutional practices. Data-collection methods for both studies included observations of/interviews with nurses, textual analysis, and follow-up interviews with informants. In the current analysis, we reviewed the nurses’ experiences of learning

to provide maternity care in a hospital setting and investigated how those experiences were organized such that they are repeated across time and place.

Institutional Analysis as an Analytic Approach

In IE, the goal of analysis is to make visible the complex practices that coordinate the actions of women, nurses, and other health-care providers (Campbell & Gregor, 2002). Analysis of the nurses' interview transcripts included describing the complexity of the nurses' work, listening for traces of social organization in their talk, and mapping out how their experiences intersected with those of the managers and the other health-care providers. Participant observation in the hospital setting helped to identify the key texts that mediated the interactions between the women, the nurses, and the other health-care providers. Further analysis of these transcripts and texts was guided by the work of McCoy (2006).

Ethical Considerations

Ethical approval for the study was obtained from the research ethics boards of the university and all three health regions involved. The integrity of the study (Koch & Harrington, 1998) was addressed by making the decision-making process as transparent as possible through the use of field notes and reflective journals. We also sought confirmation of the findings by asking for feedback from the nurses/other participants in response to Community Information Sheets that summarized the key findings developed from the preliminary analysis.

Limitations

The findings of this study are necessarily limited to the particular historical and social context explored in one western Canadian province. However, the social relations identified may be of interest to other researchers concerned with investigating the social organization of rural nurses' work and nurses' experiences of CPE.

Findings

The analysis that follows, which has not been previously reported on, focuses on the experiences and concerns of nurses who work in a rural hospital setting. These rural nurses experienced difficulty learning how to provide safe and supportive maternity care. Nurses' learning was found to be particularly difficult in communities with low birth rates. In many of these communities the birth rate was considerably higher in the past and many of the older nurses had learned "how to do" maternity nursing

“on the job” and from each other (sometimes with support from a British-trained nurse midwife).

Experiences of New Nurses

Nurses were asked to describe their experiences of providing maternity care. Almost without exception, new nurses (which we defined as nurses with less than 5 years of nursing experience) said that initially they were scared (“scared to death”). One new nurse described a recent experience:

It was a night shift, and right when we came out of report at 8 [o'clock] at night I already had 11 patients. And then a maternity walked in . . . We were so busy . . . and understaffed, it was crazy . . . and then we had this maternity that walked in. And she said, “I’m in active labour!” So I called the doctor and I went . . . I’ve only done a vag exam once, so I don’t even know what I’m feeling.

. . . I think the doctors are upset that we don’t have enough staff, or qualified staff, to look after the maternity. They get a little upset that not all of us have the same background. And there are things that they’ve been doing for years and they get quite upset — “Well, everyone knows you’re supposed to do that!” And it’s like, “Well . . . I’m new, I don’t know what I’m doing. So, you know what? You have to spell it out for me, because I don’t know.” And, you know, it’s just not safe. Well, it’s turning me off of maternity, really.

This new nurse was learning to provide maternity care in an environment that did not support her learning. She was also concerned about the physician seeing her as an “incompetent nurse” so had become reluctant to provide maternity care for women in her rural community.

Learning Experiences

New nurses told us that their nursing education programs had little content on maternity care. New RNs said that that they may have had one “theory” course but it was often “integrated” with other specialty areas, including mental health and pediatrics. Participants described learning to assess and provide care for postpartum women and their newborns but said that they had very little exposure to childbearing women during labour and birth. The following comment illustrates new nurses’ educational preparation:

P1: As for our schooling, we did 4 weeks practicum, so really, nothing. . . . I’m not comfortable with maternity at all.

P2: Four weeks, but 2 days a week . . . so 8 total days of maybe 6 hours a day. And the first week was, like, seek and find.

These nurses had spent a total of 48 hours learning to provide maternity care in a hospital setting. When asked specifically about opportunities to provide nursing care during labour and birth, most new nurses told us that they had observed one or two births, and frequently one or both of these was a Caesarean.

Learning Maternity Nursing “On the Job”

Many experienced nurses told us that they learned maternity care “on the job” under the watchful eye of an experienced maternity nurse or a British-trained nurse midwife. They stressed that in the past the number of births was higher and childbirth seemed less complicated and required less technology. Some of the more experienced nurses stressed that they had learned that birth is a healthy life process for most women, although some also shared their experiences of having to deal with difficult situations.

New nurses explained that it is difficult to learn maternity in small rural hospitals today, in an environment where few staff members are available and little education is provided. When speaking of her early experiences, one new nurse said:

I graduated and went to [northern hospital] . . . and talk about throwing me in! . . . I had six orientation shifts and during those six orientation shifts there were no babies.

When we asked specifically about orientation provided for maternity nursing, we learned that practices varied considerably. One new RN described her orientation as follows:

It was all of about 45 minutes . . . And I was given a book to read. And we went over the infant warmer that we have . . . But it's not really . . . I mean, you can't just do things once and then expect to know it. That's just not the way it is. And that's not the way I learn, especially things that are brand, brand new to me.

This nurse stressed that she had informed her employers that she had no maternity experience, although she did have experience in medical/surgical and intensive care nursing. Another new nurse told us that in the 6 months she had been working at the rural hospital she provided maternity care five times and in three of these cases she was the only RN available, and therefore was not mentored or supported by a more experienced nurse. Some new nurses learn maternity by being “thrown in,” without the benefit of mentoring by a more experienced nurse and in an environment where safe maternity care is almost impossible, thus contributing to nurses being “turned off” providing maternity care.

Other new RNs were supported in obtaining additional education before being “allowed” to provide care for women in labour. The following nurse received funding to take part in a Perinatal Nursing Certificate program. As part of the program she went to a regional centre to gain some maternity experience 1 year before the interview. She also assisted at a birth the morning of the interview:

We did a practicum at the end. I went to [regional centre] for a . . . whole month and got really good experiences. I actually got to deliver a few babies. And when I came back here I delivered a baby in the toilet one day. It was a good experience.

I'm a new nurse and it's a bit scary only because you don't see [a sufficient] volume of maternity patients to stay experienced. It'll be a few months, and the anxiety goes up. And this morning it was like that in a sense, but it was nice because it wasn't her first baby. She was relaxed and everything was good for her. And you just have to feel like you know things . . . the baby's healthy, the mom's healthy . . . It can be a little bit nerve-racking . . . I'd like to have more courses, for sure. I'd like to have the whole program. But I think with experience it will be better . . . I'll take any [maternity] courses that are available.

This nurse's account contrasts sharply with that of the previous speaker. Her experiences were “a bit scary” and her concern was more about staying “experienced,” or retaining her newly acquired skills. This new nurse also worked in a setting in which an experienced maternity nurse was always available as a mentor. Some of the hospitals we visited had established a requirement whereby a nurse had to have “education plus experience” *before* being expected to provide maternal care during labour and birth (unless an experienced nurse was working somewhere in the hospital and was available in case an unusual situation should arise).

Experienced nurses acknowledged that they had been mentored to “learn maternity” by an experienced maternity nurse and that they had *never been left alone until they knew what they were doing*. They said that birth rates and staffing levels have changed and expressed concern that such practices as mentorship were no longer available for new RNs:

I think for a lot of new nurses they get so [few] deliveries. We had an RN here we were training for nursing, and she's been involved in one delivery. That's all she's had in her whole training. One. And so what kind of training is that? You stick this person . . . in a labour room without much help, because the rest of the floor has gone crazy — whatever else [is] happening in a rural setting — this person is lost.

Experienced nurses did not believe that one birth was enough for a nurse to learn how to provide safe and supportive care during childbirth. They

were also concerned about “keeping their own skills up” and described the provision of maternity care as “hit or miss.” One nurse spoke of low birth numbers and her “comfort level”:

We only have about 35 deliveries a year. You dilute that down between — how many nurses? There’s probably 20 RNs . . . So even if you like maternity and you think you know your stuff, sometimes I go through a dry spell and I won’t have a maternity for 4 months.

Experienced nurses working in small rural hospitals wanted an opportunity to “refresh” their skills by working a few shifts in a slightly larger regional centre. Most of them also told us that it would be difficult for them to get away for more than a week because of family commitments. Experienced RNs also told us that they valued opportunities to hone infrequently used skills (such as handling a breech birth, shoulder dystocia, or a newborn in distress), preferably within interprofessional teams, since “we all have to work together.” Programs such as ACoRN, MORE,^{OB} and ALARM² were identified as exciting opportunities for team learning.

The Social Organization of Continuing Professional Education

Rural acute-care nursing has been described as “multi-specialty” practice (MacLeod et al., 2008), and nurses in our studies described the difficulties they encountered in maintaining all the required “certifications,” particularly in this era of “evidence-based practice” and professional responsibility for “continued competence.” The rural nurses told us that their greatest challenges in terms of care were emergency, acute mental illness/substance use, and maternity, and that all but maternity could be learned in the rural setting. We also learned that, since the operating room is intimately tied to the ability to perform a Caesarean section, peri-operative nursing is similar to “maternity nursing” in that it calls for experience gained at a larger, regional hospital. Our participants were also adamant that going to a big city to learn maternity nursing “does not work,” because a rural hospital nurse is not able to access all the “fancy teams” available to RNs working in the city and childbirth at a rural hospital is “low tech” and “more normal.”

One younger nurse described how fortunate she was to be able to take a perinatal nursing course that was funded by her employer, but she was concerned because funding had recently been cut, affecting one of her colleagues:

² Information about ACoRN can be obtained from the BC Perinatal Health Program Web site at www.bcphp.ca/ACoRN.htm. Information about ALARM and MORE^{OB} can be found at www.sogc.org/index_e.asp.

Another girl took the same course I did, but that funding has been cut so she still hasn't done the practicum . . . She said she would go do it if there was money . . . you're spending your own time . . . you're learning and you're improving your nursing knowledge and experience. . . it's hard to go take those courses away from your job . . . you'd have to take a leave and use your holidays or something.

Another new nurse told us that she was frustrated at being unable to attend the required neonatal resuscitation program (NRP):

I know they provide courses, but they're not always convenient . . . the NRP [course] was offered but I couldn't take it . . . I was a full-time employee . . . all the casuals took the course and I couldn't get time off to take it . . . It's crazy, because I'm there all the time. So now I just say, "Well, I'm not doing the baby." You know, I'll go in, and I'll do mom, but I'm not . . . going to do the baby, because they set themselves up for it.

She clearly understood that to be the "baby nurse" at a delivery one needs to have NRP certification. Since she was not given an opportunity to take this course, she felt that she should decline to care for the newborn.

The following nurses were part of a small focus group and are talking about how local staffing rules influenced their ability to participate in continuing education:

P1: *If I decide to take 4 hours off for something [CPE], it's really difficult . . . they don't like that because they don't . . . it has to be the full shift—*

P2: *—and we're not able to give away a shift either. Sometimes there are casuals who are looking for shifts . . . When I worked in Alberta as a casual nurse, they [full-time RNs] would say, "Can you work this shift for me, and this?" And I'd say, "Yeah." And they'd fill it in and they'd take the days off as LOAs [leaves of absence] or vacation. Here, you can't give up a shift; you have to repay.*

These comments suggest that decisions about the allocation of time off and resources for rural nurses' CPE are structured by something other than the learning needs of the nurses involved. Rural nurses also described having family commitments that made it difficult for them to leave their community for CPE. Nurses who worked full time told us that it was difficult for them to leave because there was no nurse available to replace them at the hospital. Having skilled nurses available to provide maternity care in hospitals during labour and birth is therefore becoming increasingly difficult.

Although there are few registered midwives (RMs) working in rural British Columbia, we spoke with some RNs and RMs who had been working together. We learned that nurses who had worked alongside RMs had collaborative relationships with them and the two professionals were open to learning together. In British Columbia, and in most of Canada, midwifery and nursing have separate regulatory bodies. Since midwives have been recognized as the “experts” in normal childbearing, they can play an important role in educating and supporting rural nurses. Canadian educators, regulators, and health-service planners could look to international models where nurses and midwives work closely and learn together.

Discussion

Nurses have revealed that the skills required for managing normal labour and birth (and for resuscitating/stabilizing the woman/newborn) are the most difficult for them to acquire/maintain. Applying IE methods, we can evaluate how discourse — the organizer of experience — affects the work of these rural nurses. Discourse can be understood as the circulation of ideas or concepts through talk, text, and media or other images. Two discourses stand out in this study: tensions between generalist and specialist work, and issues of professional responsibility.

Exploring Generalist and Specialist Tensions

Nurses clearly identified maternity nursing as a form of specialized practice, and it was the care of women during labour and birth that caused them the most concern. Nurses described their work as the “intensive care” of the perinatal period and indicated that things could “go south” very quickly, with devastating results. Perinatal loss has been shown to be traumatic for both nurses and physicians, affecting their willingness to continue providing maternity care and/or to remain in their rural community (Grzybowski, Kornelsen, & Cooper, 2007).

In Canada, perinatal nursing is a recognized specialty and is understood as providing nursing care for childbearing women from conception through the postpartum period. The specialty discourse reflects the range of settings (including the woman’s home) where nurses provide care for childbearing women and their families (CNA, 2009). Although generalist nurses working in small rural hospitals described having benefited from education around the entire childbearing period, most hospital nurses needed to focus their *initial learning* on a narrower range of competencies, particularly those required for the intrapartum and immediate postpartum periods.

Because of health-care reforms over the last decade, employers have had their education budgets severely reduced so that they can no longer provide a sufficient variety of continuing education programs. Nurses working in different specialty areas now have to compete for continuing education funding or pay for the education themselves.

Discourses on Professional Responsibility

Recent changes to the scope and regulation of nursing work have resulted in the assigning of responsibility for “continuing competence” to individual nurses:

Registered nurses (includes licensed graduate nurses) are lifelong learners who continually assess and improve their practice. To be eligible to renew practising registration in British Columbia, CRNBC registrants must meet two continuing competence requirements: practice hours, and personal practice review. When registered nurses meet CRNBC’s annual continuing competence requirements, they indicate to the public that they take their professional development obligation seriously and that they are maintaining their competence to practise. Meeting the obligations of continuing competence is one way registrants maintain the public’s trust. (College of Registered Nurses of British Columbia [CRNBC], 2009a)

This text provides a concrete example of how continuing competence is being constructed as the responsibility of the *individual* RN. This ongoing competence discourse can have a negative impact on rural nurses’ opportunities for CPE. Nelson and Purkis (2004) show how self-surveillance procedures shift responsibility for professional development from the employer to the individual nurse.

Also, in the past nursing associations played an important role in helping nurses to acquire/maintain the knowledge and skills needed for professional nursing practice. In British Columbia the introduction of the *Health Professions Act* in 2005 meant that the professional nursing association was replaced by the College of Registered Nurses, which has a regulatory mission. The primary role of the CRNBC moved towards protecting the public through “quality assurance.” In a recent paper on “working within limited resources,” the CRNBC described employer responsibilities as follows:

Employers are responsible for ensuring that there is a sufficient number of competent staff. Employers must also ensure that registered nurses are supported to work within their own level of competence. (CRNBC, 2009b, p. 16)

This document is silent on any employer responsibility to support nurses’ CPE.

Collective bargaining agreements can also provide a means to interpret the issue of professional competence and personal responsibility. We found that bursaries are available to members of the British Columbia Nurses Union, depending on the “member’s job classification and collective agreement” (British Columbia Nurses Union [BCNU], 2009b). However, the institutional structure of the unions rewards seniority and disadvantages younger nurses and those who do not have a full-time position. Rewarding seniority without regard to work setting can serve to obscure differences in the knowledge and skills needed for nursing work.

We learned that if the employer “requires” or “approves” the education program, the employer is responsible for the RN’s expenses:

An employee shall be granted leave with pay to take courses at the request of the Employer. The Employer shall bear the full cost of the course including tuition fees and course required books, necessary traveling and subsistence expenses. Courses identified by the joint OH&S Committee to promote a safe and healthy workplace and approved by the Employer, shall be treated like Employer requested leave. (BCNU, 2009a)

However, when a nurse requests CPE, the employer is obliged to grant only 1 education day and to reimburse the nurse for expenses. Analysis of the collective bargaining agreement reveals why CPE for nurses has become “contested ground,” particularly in this era of health-care reform and budget cuts. Since RNs are the largest group of employees working in acute-care hospitals, support for nursing CPE can be an expensive budget item, requiring justification and close scrutiny. The experiences of rural nurses have also been influenced by management discourses of scarcity, cost-effectiveness, and practices grounded in decentralized cost accounting (Rankin & Campbell, 2006), which can have far-reaching effects on health care and many other sectors that receive public funding.

Researchers have demonstrated that investment in CPE for nurses can result in cost savings due to lower turnover rates and improved retention (Levett-Jones, 2005). In our study, local managers were shown to be very creative in finding money for “their” nurses. However, increased funding and more transparency would permit better cost-benefit analysis. More flexible staffing processes might also enable local solutions and informal arrangements between nurses. Rural nurses need to be recognized for their contributions to maternity care and for their complex and multi-specialist work in hospital settings. Further research is needed on how to support a culture of lifelong learning among acute-care and rural nurses.

Conclusion

We have shown that rural nurses' experiences of "learning maternity" are influenced by declining birth rates, increased workloads, and a dearth of mentoring opportunities. Current discourses locate responsibility for CPE with the individual nurse, while the need for education in multiple "specialties" adds to the burden of rural nurses. Employers and nursing leaders need to recognize the unfair burden placed on rural nurses. Nursing unions could play a role in addressing the issues entailed in recognizing differences in the knowledge and skills required for nursing work in different settings.

"Specialty" discourses and the social construction of responsibility for continuing competence displace local knowledge about the needs of rural nurses. Nursing regulatory bodies need to focus their efforts on supporting nurses' learning/maintaining the complex knowledge and skills required for rural nursing as a strategy for ensuring patient safety and fulfilling their mandate to protect the public. We need to break down the professional barriers to interprofessional collaboration and learning now, to avert the "crisis" in rural maternity care in Canada. Collaboration with the College of Midwives could be explored. At stake are the future of some of our most vulnerable citizens and the viability of our rural communities.

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La connaissance des troubles de démence dans le cadre de la pratique infirmière en région nordique

**Mary Ellen Andrews, Debra G. Morgan,
Norma J. Stewart**

Cette étude a pour objectif de cerner les concepts clés en matière de soins aux personnes souffrant de démence, selon le point de vue des infirmières autorisées œuvrant dans le Nord canadien. Des entrevues ont été réalisées auprès d'IA en poste dans de petites communautés nordiques isolées, portant sur leurs expériences de dépistage de la démence, la prestation de soins liée à cette maladie et leurs perceptions concernant les ressources disponibles. La méthode de théorisation ancrée utilisée dans l'analyse des données d'entrevues a mené à l'élaboration d'une théorie portant sur la connaissance des troubles de démence dans le cadre de la pratique infirmière en région nordique. Les auteures de l'étude ont cerné trois points qui influencent les connaissances des IA œuvrant en région nordique relativement à la démence : *les soins aux personnes atteintes de démence et la prestation de soins communautaires*; *les caractéristiques de l'IA œuvrant en région nordique*; et *la vie professionnelle des infirmières en milieu nordique*. Les résultats indiquent un besoin de mettre en place des programmes et des politiques de santé qui sensibilisent le personnel infirmier nordique aux troubles de démence, une mesure qui permettrait d'améliorer les soins prodigués aux populations nordiques.

Mots clés : démence, théorie

Dementia Awareness in Northern Nursing Practice

Mary Ellen Andrews, Debra G. Morgan,
Norma J. Stewart

The purpose of this study was to identify key concepts in dementia care from the perspective of registered nurses working in the Canadian north. Interviews were conducted with RNs employed in small, remote northern communities about their experiences with dementia assessment and caregiving and their perceptions about dementia care resources. The grounded theory method used in analyzing the interview data led to the development of a theory about dementia awareness in northern nursing practice. The study identified 3 categories of conditions that influence northern RNs' awareness of dementia: *dementia care and community caregiving*, *characteristics of the northern RN*, and *northern nursing worklife*. The findings suggest the need for educational programs and health-care policies that increase awareness of dementia in northern nursing practice and thereby improve the care provided to northern people.

Keywords: Aboriginal health, dementia, primary health care, rural and remote health care, theory, underserved populations

Northern nursing is commonly associated with expanded “generalist” practice roles and functions. Little is known about dementia assessment and caregiving as perceived by northern registered nurses (RNs) in Canada. Most of the literature on dementia caregiving is presented from the perspective of southern rural and urban practice settings (Morgan, Semchuk, Stewart, & D’Arcy, 2002). Although some studies have explored caregivers’ perceptions of support services for dementia care in northern locations (Loos & Bowd, 1997) and the prevalence of dementia in two northern Manitoba communities (Hendrie et al., 1993), population demographics have changed since these studies were carried out.

The present study aimed to add to the knowledge base on northern nursing by exploring a clinical area of practice, dementia assessment and caregiving, from the perspective of RNs working in northern health-care facilities. The intent was to provide insight into the exposure of northern RNs to dementia assessment and caregiving and the views of these nurses on the key issues associated with care of older adults with dementia. The intended outcome was the development of a theory on how northern RNs might develop an awareness of dementia in their practice.

Background

Dementia epidemiology, assessment, and caregiving in northern Canada is a largely unstudied area. The dearth of information on dementia assessment and caregiving in northern regions is a concern because global estimates of the prevalence of dementia diagnoses are pointing to a 100% increase between 2001 and 2040 (Ferri et al., 2005). Estimates by the Canadian Study of Health and Aging indicate that Canada will have 778,000 people with dementia by 2031 (Canadian Study of Health and Aging Working Group, 2000). A limitation of the Canadian Study of Health and Aging was exclusion of rural areas, First Nations reserves, and the northern territories: Yukon, Northwest Territories, and Nunavut. As a large portion of the northern population is Aboriginal, and the Aboriginal elderly population is projected to double by 2017 (Statistics Canada, 2005), knowledge about assessment and caregiving in northern locations is sorely needed.

Challenges in Diagnosing Dementia

Sternberg, Wolfson, and Baumgarten (2000) performed a secondary analysis of the data from the Canadian Study of Health and Aging and report that cognition was not a standard part of the assessment of older adults. Other authors have suggested that a lack of knowledge about dementia and the lack of local resources to support older adults with dementia have served to minimize the recognition of cognitive decline (Iliffe et al., 2005). A study of community nurses' perceptions about the identification of cognitive impairment in older adults (Manthorpe, Iliffe, & Eden, 2003) found that nurses specializing in community mental health were more apt to assess cognition in older adults than nurses with a focus on public health or nurses in other specialties practising in community settings.

A recent Canadian study by Pimlott et al. (2009) on the assessment of dementia by physicians in family practice found that the complex nature of dementia caused uncertainty in diagnosis; other challenges were pressures that put limits on the amount of time spent with a client, the need to be familiar with the client, and the importance of family involvement. Pimlott et al. propose the development of primary care teams, referral systems, and ongoing education as ways to support family practitioners in assessing and diagnosing dementia.

Because health services are population-based, small rural and northern communities have relatively few health-care resources (Romanow, 2002). In many small rural and northern communities, nurses function as the only health-care providers, responsible for delivering acute, chronic, and public health services — sometimes simultaneously. The challenge

for dementia assessment and care in these settings is the immediacy of acute health issues and relegation of non-life-threatening concerns to secondary status (Roberts & Gerber, 2003; Vukic & Keddy, 2002). In a comparison of nursing procedures in southern rural and northern remote communities (Krieg, Martz, & McCallum, 2007), the role of the northern RN was found to entail more expanded-practice skills (e.g., ability to perform minor surgical procedures) and limited continuity of care due to high turnover of health-care personnel.

Dementia Care

Care for older adults with dementia is commonly provided by family, close social contacts, and health professionals in the community. In a study on access to health services by older women in a northern Saskatchewan community, 28.5% of community members over the age of 15 reported having assisted in the care of an older adult (Krieg et al., 2007). In rural and remote communities, most caregivers are reported to be women (Parrack & Joseph, 2007) and many caregivers experience detrimental health effects associated with caregiving (Bedard, Koivuranata, & Stuckey, 2004).

One of the priorities of the National Aboriginal Health Organization has been to explore the health issues of older adults (National Aboriginal Health Organization, First Nations Centre, 2006). In the Organization's report on First Nations older adults, 48.8% of those over the age of 55 reported having a disability and 85.2% reported having one or more chronic conditions. Policy initiatives have included the expansion of home care services in the north due to the desire of northerners to be cared for in their communities by their families (van Liempt, 2006).

The Study

This study used a sequential exploratory (QUAL → quan) mixed-method approach (Morse, 2003) to explore RNs' perceptions of dementia care in remote northern communities in Saskatchewan (Andrews, 2008). The qualitative method of grounded theory (Glaser & Strauss, 1967) was chosen as the lead methodology for this exploratory study because so little is known about dementia care in the Canadian north and about the practice of northern RNs who work with cognitively impaired older adults. The use of a sequential design allowed for the concepts from the grounded theory to inform the selection of variables in the quantitative secondary analysis of survey data (Stewart et al., 2005) from a national study, *The Nature of Nursing Practice in Rural and Remote Canada* (MacLeod, Kulig, Stewart, Pitblado, & Knock, 2004). The qualitative study focused specifically on RNs working in one of

three northern Saskatchewan health regions (north of the 55th parallel), while the quantitative analyses were complementary and provided a national context and north-south comparisons for selected variables related to the theory. This article reports the findings from the qualitative grounded theory analysis (Andrews, 2008). The primary research question for the study was *What do RNs in northern Saskatchewan perceive as key issues and concerns with respect to the care of older adults with dementia?* Related questions concerned northern RNs' degree of exposure to older adults with dementia, caregiving for dementia in the north, and adequacy of services for dementia assessment, diagnosis, and care.

Method

Grounded theory provides a systematic and rigorous method for developing theory using qualitative data (Glaser & Strauss, 1967). Because the theory is generated inductively from the data, it is termed "grounded," or found in a particular set of data. The constructivist perspective on grounded theory (Charmaz, 2006) guided this research. Charmaz contends that the researcher is a co-participant in constructing the theory, as opposed to "discovering" it. The theory is developed through interactions with participants and is influenced by the perspectives and experiences of the researcher. In this study, the first author's experience as a northern RN was recognized and accepted as affecting and contributing to the study outcomes. The focus was on developing a substantive theory: a parsimonious understanding of the situation surrounding dementia care in a northern Canadian province through the identification of a core concept that accounted for a large portion of the variation in the data.

The grounded theory method is especially useful for making suggestions and hypotheses about common or everyday problems (Glaser & Strauss, 1967). The theory must be meaningful for and relevant to the research area; theories about northern nursing practice and dementia care may not entirely fit dementia care in urban nursing practice settings. A theory must be able to explain what has happened, predict what will happen, and interpret what is happening in the substantive area of inquiry (i.e., the process by which RNs in northern Saskatchewan develop an awareness of dementia). Finally, grounded theories are conceptual and become broader than the data, a characteristic that renders them modifiable and applicable to other social problems.

Recruitment

Theoretical sampling is a method of data collection used in grounded theory whereby sampling is aimed at seeking and collecting pertinent data to develop and refine categories in the emerging theory (Charmaz, 2006). Theoretical sampling was carried out on two levels: the commu-

nity, and the individual RN. Participants were recruited initially from four northern communities that had long-term-care facilities or home care services. It was theorized that RNs who were working in these communities would have more opportunity for interaction with older adults with dementia than RNs working in communities without these services. Theoretical sampling at the level of the participant included RNs from many areas of practice, to explore whether perspectives on dementia are influenced by type of nursing position. Finally, data were collected in a community without long-term-care or formal home care services provided by an RN, to determine whether dementia concerns are more prominent in communities that have long-term-care or formal home care services.

Seven health-care administrative bodies, from the three northern Saskatchewan health regions, were contacted and subsequently administrators consented to having their RNs approached to participate. Posters were sent to the administrators for display in the facilities, along with brochures to be distributed to the RNs. On-site visits were organized to facilitate data collection, and these proved to be more effective than the posters and brochures in recruiting RNs. Recruitment challenges included the small number of RNs in the target communities, low staffing levels during the on-site visits, and vacation leaves during the summer months.

Participants

The final sample of northern RNs for this qualitative study comprised 14 RNs who were employed in six health-care facilities in the northern half of Saskatchewan at the time of the study. The facilities were located in communities varying in size from approximately 300 to 3,000 people. One of the communities was accessible only by air; the others were accessible by road.

Only one of the participants interviewed was male. Participants ranged in age from 28 to 60 years ($M = 49.2$ years; $median = 54$ years). Three were of Aboriginal, Métis, or Inuit ancestry. Eight held a nursing degree and six held a nursing diploma. Two of the participants were registered nurse practitioners (RN-NPs). All of the participants held full-time permanent positions: two worked in administration and three in community/public health, two were NPs, one was an acute-care staff nurse, two were community health nurses (staff nurse in a nursing station/health centre), two held the position of nurse-in-charge of a nursing station/health centre, one was a home care RN, and one was a program coordinator. Nine of the nurses had 6 or more years of northern nursing experience.

The study was approved by the University of Saskatchewan Advisory Committee on Ethics in Behavioural Science Research. Nurses who volunteered to participate signed a consent form that outlined the purpose of the study, the time commitment, ethical considerations, and proposed use of the findings.

Data Collection and Analysis

The aim of data collection was to capture a wide range of experiences from which to explore perceptions of dementia and dementia caregiving. Data collection took place over the course of 1 year during the period 2006–07. Of the 14 interviews, 12 were audiorecorded and transcribed; two participants did not agree to be recorded but allowed note-taking. Two of the recorded interviews were conducted via telehealth video link, one was conducted face-to-face in an urban community, and 11 entailed travel to the northern community. The interviews were guided by a list of open-ended questions. Field notes were used to describe the interview setting as well as the interaction between participant and researcher.

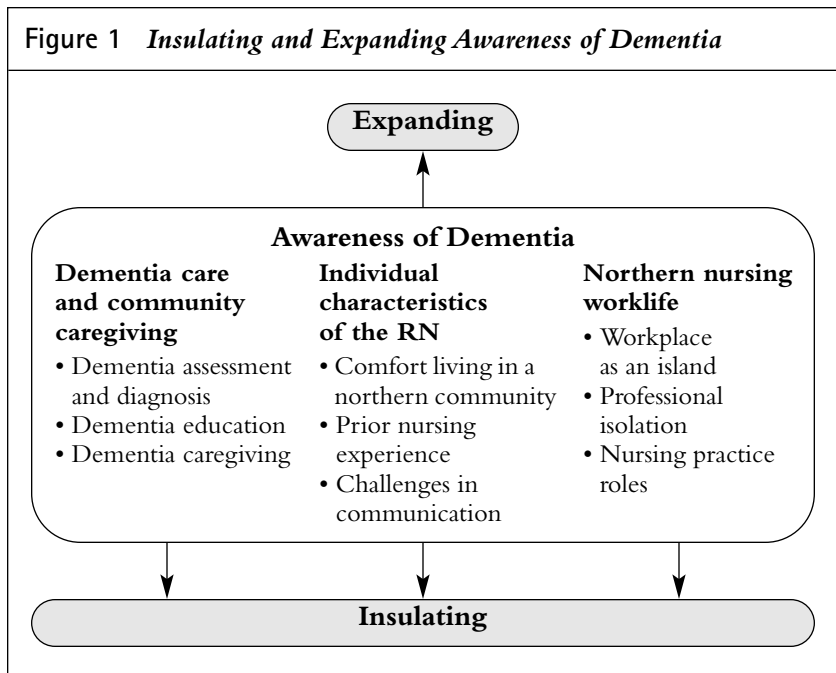
Interview transcripts and field notes were used as the data set for the analysis. The goal of data analysis was to maximize the variation in conceptual elements that emerged from the data (Charmaz, 2006). Constant comparative analysis, whereby all new data are compared to data already collected, was used to identify patterns (Glaser & Strauss, 1967). Data analysis began with initial coding (coding all instances until a pattern of differences and similarities appears), focused coding (to develop categories), and theoretical sampling (to fill gaps in categories and patterns in the data) (Charmaz, 2006). Memos were used to describe and document the ongoing analysis and theorizing about categories. Data collection and analysis were continued throughout the project until patterns reappeared in the coding, indicating that theoretical saturation (maximization) of the concepts had been reached. Strategies used to ensure credibility and rigour included an audit trail of interview data, field notes, and analytical memos; verbatim transcripts of interviews; first and second author review of all transcripts; and analytical discussions with members of the research team. NVivo software was used to facilitate data management.

Findings

The context of this study, or the main concern that centred the analysis (Glaser & Strauss, 1967), was that dementia assessment and caregiving were not perceived as prominent issues in the practice of northern RNs. Reasons for this perspective included the small number of older adults seen in the practice settings and communities of northern RNs and a perception that northern RNs' knowledge about dementia was limited

and outdated. On reflection, participants characterized older adults as an “overshadowed” or “forgotten” population in northern health services, which are more focused on meeting the acute and preventative health-care needs of the large younger demographic.

The grounded theory analysis resulted in the theory “insulating and expanding the awareness of dementia in northern nursing,” which explains the conditions under which northern RNs do or do not develop an awareness of dementia in their practice community (Figure 1) (Andrews, 2008). These conditions were conceptualized as insulating (decreasing the RN’s ability to form an awareness of dementia) or expanding (increasing the RN’s ability to form an awareness of dementia), clustered into three categories: *dementia care and community caregiving*, *individual characteristics of the RN*, and *northern nursing worklife*. The identified conditions tended to be more in the direction of insulating awareness than expanding awareness of dementia. The word “insulating” is used as a metaphor. Insulation is a barrier that prevents the transfer of heat or energy to the outside of a building. In this context, insulating was used to conceptualize the conditions (e.g., the demands of acute and emergency care, inability to speak the local language) that collectively became a barrier to the development of an awareness of dementia as a health concern for older adults in northern communities.



Dementia Care and Community Caregiving

Awareness of dementia was influenced by personal and professional exposure to older adults with dementia. This awareness included perceptions of dementia assessment and diagnosis, education about dementia, and caregiving in the community. None of the participants reported caring for an older adult with dementia in their role as a northern RN.

Dementia assessment and diagnosis. Participants believed that responsibility for diagnosing dementia was within a physician's role and not the role of an RN. Family members were most often cited as the source of information about behavioural concerns, because most of the older adults did not speak English and were not often seen in clinics. The participants had conflicting perceptions about whether family members would voice their concerns or conceal troubling behaviours out of respect for the older adult.

Participants noted that recognition of dementia may have been hampered by physicians and nurses viewing memory loss as normal in older adults and by the dearth of provincial resources for geriatric referrals. Few of the RNs were aware of or used geriatric resources. Resources for assessment in the community included psychologists, but participants reported that psychologists were "overloaded" with acute issues. When questioned about diagnosis and assessment, one RN stated, "I'm trying to think how many patients in the north that I actually knew had dementia, never mind having it documented. . . . I don't think I ever saw any documented." Another participant, who spoke Cree, explained that language and cultural differences only added to the assessment challenges: "There's no such word that I know of that refers to dementia."

Dementia education. All of the participants expressed a need for professional, caregiver, and community education on dementia. They identified challenges to the dissemination of information on dementia, such as the regional distribution of specialized services in the north versus the training of community members to function in an outreach capacity. Additionally, in communities with long-term-care facilities, participants reported difficulty obtaining expert assistance with the management of behavioural symptoms and the lack of secure units when needed. RNs reported that their successful efforts at managing behavioural issues created the impression that additional resources were not required. Further, the participants stated that available continuing education programs were not presented from a northern perspective: "They always try to lump northern and rural together . . . but what goes on in [a southern town] is pretty different from what goes on in [a northern community] . . . having more northern content would be beneficial."

Participants also expressed the view that education and training in assessment skills ought to be extended to Licensed Practice Nurses

(LPNs) and Community Health Representatives (CHRs) employed by northern health-care agencies, since LPNs and CHRs have more contact with older adults in the community than RNs. When discussing LPNs and CHRs, the participants said, “[they are] community people,” “they know the community,” “they’re in the homes,” and “they see it first.” One RN said, “The nurses traditionally are stuck in the station [nursing station or health centre].” Another added, “To my knowledge, there have been no educational opportunities for families to learn how to deal with people at home, but often, because of the number of beds and things, that is how people are dealing with it.”

Dementia caregiving. Participants saw the challenges in providing care for older adults as related to the remoteness of northern communities, limited caregiving resources, limited financial resources, and the respect for older adults that is inherent in northern cultural values. They described the dependence on family members to serve as caregivers for older adults as similar to situations they had encountered in the south. The support system for older adults was viewed as larger in northern communities. However, there were concerns that the increasing mobility of the younger generation would serve to reduce the number of family members available to provide care in the future.

The participants explained that when institutional care was required, even if the community had a long-term-care facility the limited number of beds available often meant that older adults had to leave the community for care. They expressed the view that when such facilities were not available in the community, nurses’ knowledge about older adults in the community was limited by the relocation of individuals to facilities outside the community. The high turnover of nurses in the north also served to reduce RNs’ familiarity with older members of the community and thus their ability to detect changes in cognitive and physical functioning. In communities with long-term-care facilities, LPNs commonly provided direct care, further distancing RNs from knowledge about dementia and dementia care.

Individual Characteristics of the RN

Personal and professional characteristics of the participants influenced their awareness of dementia. These individual characteristics were as follows: comfort living in a northern community, prior nursing experience, and challenges in communication.

Comfort living in a northern community. Community integration and social isolation were found to influence the nurses’ awareness of dementia. Community integration can be described as the nurses’ level of comfort with their social interactions in the community. Nurses who had grown up in a small community were more comfortable working in a

small community and interacting with older adults. Professional status and the lack of anonymity created a sense of separateness from the community, as the RNs felt that community members identified them as “the nurse” in all social situations. This separateness inhibited the nurses’ ability to develop relationships within the community and hence their knowledge of the community and its older members. Other factors that contributed to the participants’ sense of social isolation were lack of experience living in a northern community in a non-professional role and not having family members residing in the community.

Prior nursing experience. Participants described nursing experience in acute care as a requirement for northern nursing practice. The chances of being recruited for a northern nursing position with only long-term-care experience were described as “pretty slim.” This focus on experience in acute or emergency care when hiring northern nurses contributed to a lack of comfort and skills needed when working with older populations, including those with dementia. The development of home care positions in the north was seen as expanding the knowledge base on dementia and promoting the integration of RNs into the community. Home care was viewed as increasing the potential for the monitoring of cognitive function and behavioural changes in older adults. However, the benefits of home care services were tempered by the belief that “not everybody is totally receptive to home care.” One of the participants used the following rationale to describe the need for expanded resources and services for older adults:

The lifestyle in the north is changing and people are living longer, and so we’ll see the trend change in the north as it has in the south. We’ll actually see more people living longer but more of the same health issues that we’ve had in the past, because as they grow older we’re going to get a lot more heart failure, we’re going to get a lot more cases of hypertension, and we’re certainly seeing an increase in diabetes. It continues to evolve as they grow older. So I think we’ll actually see more dementia in the north.

Challenges in communication. The inability of most of the participants to speak the community language had the largest influence on insulating the nurses’ awareness of dementia. The participants explained that “a nurse with the language is going to be able to take care of that person 100% better than I am.” They stated that the language barrier affected their ability to assess cognitive function because it limited their social interaction with older adults. Nurses who had considerable experience interacting with patients through interpreters had developed a level of comfort with this type of communication and reported less difficulty due to language differences.

Northern Nursing Worklife

The work setting was described as having a significant influence on the RNs' awareness of dementia. Conditions related to nursing worklife included the perception of the workplace as an island, perspectives on professional isolation, and characteristics of nursing practice roles. The overall view was that health services offered in small northern communities do not address the needs of older adults.

Workplace as an island. Nursing work settings were conceptualized as islands within the community. Participants believed that their perspective of the community was a function of "what's coming through the door." They saw their work as demanding and driven by the "trauma and drama" of acute care. However, one RN admitted that the phrase "we're too busy" was often used to avoid developing health promotion programs. Further, although the "trauma and drama" were perceived as demanding, this work also appeared to provide a great deal of job satisfaction. One nurse described the best parts of her job as "watching them [clients] get well" and the "autonomy."

Since the participants perceived that very few older adults were attending the clinics, and community services specific to older adults were scarce, the nurses placed a low priority on improving their skills related to dementia care. All of the communities offered a chronic disease management clinic (e.g., diabetes, hypertension, cardiovascular disease) that monitored individuals with chronic disease across all age groups. Participants believed that these programs let medically stable or well older adults with cognitive deficits "slip through the cracks" and that available programs did not have a focus on mental health, including cognitive assessment.

Perspectives on professional isolation. Isolation from other health professionals influenced the participants' awareness of dementia. The demands of northern nursing practice limited their ability to attend educational events and to collaborate with other health professionals. For example, one participant said that telehealth was a useful tool for continuing education but that most sessions had to be videotaped as few RNs were able to attend the live presentations.

Although professional isolation was a concern for them, the participants did identify avenues for expanding their knowledge and decreasing their isolation. One of their suggestions was to expand the use of communication technologies. A few of the participants found these technologies very useful in their practice:

It's still remote, because we're still a distance away, and we still have to wait for a plane to come in to get emergency health care, so that makes us remote. But in terms of being isolated, we're not. You and I are sitting here,

you in _____ and I'm living in _____ [yet] we're looking at each other right now and talking to each other, so we're not isolated. Our technology is the same in the north as it is in the south. We use satellite phones, we use two-way radios around the town, but . . . we don't have cell service, so in that way we're a little bit isolated, but we have cable . . . Our physicians are only a phone call away as well, and we do have telehealth with our physicians if we need to, and digital cameras. We can actually take a really good picture and send it off, and have somebody down south tell us exactly what they think . . . with the technology we're not really isolated.

However, resistance to learning about new communication methods and integrating technology into practice routines were perceived as barriers to expanding the use of technology in the north.

Characteristics of nursing practice roles. Nursing practice roles in the north were seen as unstructured in that nurses need to be available to attend to a variety of issues. At the same time, however, nursing roles were seen as structured, with a set of mandated functions or tasks that each nursing position is responsible for fulfilling or carrying out. Participants noted that one of the challenges in developing a program to increase awareness of dementia would be nurses' opposition to restructuring their roles, as restructuring roles might result in increased workloads without additional personnel or formal training. They felt that there might be interest in developing general services for older adults but that interest in dementia-specific information would be minimal unless there were a number of residents affected by dementia: "They [the community] have to buy into it or it won't work."

A few of the RNs had broadened their practice and created new programs. One participant had developed a seniors' foot-care program. This program became a gathering place for older adults that included food and entertainment while also providing the nurses with a means to monitor the health status of the community's older population.

Discussion

The findings of this study offer a perspective from which to view the development of dementia awareness in northern nursing practice. In keeping with the fundamentals of grounded theory (Charmaz, 2006), the purpose was to provide an understanding of the present situation, make predictions about the future, and explore the consequences of dementia as a concern in northern health care.

The participants were older, in terms of average age (49.2 years), than rural and small-town nurses in Canada generally, as reported in a national database (42.9 years) (Canadian Institute of Health Information, 2002). Other differences between this sample and the characteristics reported in

the national database include the proportion reporting a university degree as their highest level of education (8 of the 14 in the present study, vs. 18% nationally). However, the length of time the RNs had been practising in northern communities and their experience and knowledge in varied nursing practice settings contribute to the strength of the findings.

The study identified conditions that had the effect of *insulating* or *expanding* northern nurses' awareness of dementia. These terms were chosen as metaphors because they appear to fit and have relevance for northern nursing. The central theme of the study was that a number of conditions influence the ability of RNs working in remote northern settings to recognize, assess, and care for older adults with dementia. More insulating conditions were found than expanding ones. Insulating conditions that are similar to those reported by other studies are as follows: the language barrier and the need for interpreters, which were seen as reducing nurses' ability to assess cognition (Cattarinich, Gibson, & Cave, 2001); lack of familiarity with the client and the client's family (Pimlott et al., 2009); lack of availability and acceptance of home care (Forbes et al., 2008); and limited community education and resources for older adults (Iliffe et al., 2005). A condition that expanded awareness of dementia — also reported in the literature — was the development of assessment and caregiving resources in the community.

A condition not addressed in this study is the perception of aging and cognitive loss from the perspective of community members. An understanding of the cultural meanings associated with dementia and aging in the north would be useful for the development of culturally appropriate dementia-assessment protocols and caregiving supports. Family and community education about dementia might serve to highlight memory concerns and could lead to earlier identification and treatment of cognitive problems.

The literature documents concern about a projected increase in the number of older adults diagnosed with dementia in the coming years (Canadian Study of Health and Aging Working Group, 2000). Similarly, some of the participants in the present study were concerned about the potential for dementia to become more prevalent in northern communities. The high hospitalization rates reported for northern areas (Irvine & Stockdale, 2004) and the increasing prevalence of diabetes and chronic diseases warrant the availability and accessibility of a wider scope of health services. In a retrospective study, Whitmer, Sidney, Selby, Claiborne Johnston, and Yaffe (2005) found that the presence of risk factors for cardiovascular disease (e.g., diabetes) at midlife had a 20% to 40% increased associated risk for the development of vascular dementia with advancing age.

Improving links to urban health care and specialized services has the potential to reduce the professional isolation experienced by northern RNs. The challenge, in terms of insulating or expanding awareness of dementia, is that nurses were not aware of the existence of services in urban settings. The development of clinical pathways to disseminate knowledge about dementia services to northern RNs would benefit both the nurses themselves and the recipients of care in northern communities. Increasing access to communication technologies and helping northern RNs to integrate the use of these technologies into their practice could facilitate access to services for dementia assessment, diagnosis, and management.

Social isolation has long been a characteristic of northern nursing practice (Vukic & Keddy, 2002). Although nurses who relocate to a northern community have made a personal choice to do so, it appears that the social isolation reported by RNs in this study was conferred by their professional status, which served to limit their participation in the community and affected their self-perception as community members. Physical isolation within the clinic, as a function of the acute-care focus of most nursing positions, also had the result of limiting their awareness of dementia.

It is important that the development of educational resources to improve dementia awareness among northern RNs be carried out from the standpoint of their work in the north. The needs and health issues addressed by health services in the north are perceived as different from those addressed in southern rural communities. The development of education programs with content specific to northern health-care settings, and delivered in the north, may result in increased access to and interest in continuing education that is focused on dementia.

The findings of this study suggest that older adults with dementia in northern Canada could be considered vulnerable given their location in isolated communities and the limited resources available locally to diagnose, treat, and support family caregivers. Historically, northern health care has focused on acute-care needs, which were the impetus for the development of northern outpost nursing stations (Waldram, Herring, & Young, 2006). The perception persists that a handful of RNs can address acute health-care concerns in addition to the ever-widening range of services needed by a community. The practice of hiring RNs based on their skills in acute and emergency care serves to isolate the nurses within acute-care settings and to hinder the development of their clinical knowledge with regard to dementia, dementia caregiving, and dementia resources.

Limitations

The goal of theory development is to describe patterns and relationships in the data and to conceptualize the conditions under which these patterns and relationships develop. A caution in theory development is to view the resulting theory as representing only one understanding of a situation. Therefore, the present findings may not be transferable to nurses practising in other remote northern communities. Research into nursing care in remote northern locations in Canada can be challenging with respect to sample size, given the small number of RNs working in northern communities, the time demands on the clinical work of RNs, and the difficulties inherent in the retention of RNs.

Conclusion

This exploration of dementia care in northern nursing practice and in northern communities has identified the complexity entailed in developing an awareness of dementia. Suggestions for northern policy development with respect to dementia assessment and care include the provision of resources to address the health concerns of older adults living in the north and the inclusion of northern health-care concerns in continuing education programs for RNs practising in the north. Future studies on dementia care in the north might focus on developing an understanding of dementia from the perspective of northern residents and the challenges encountered in assessing older adults from the perspective of translators.

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Résumé

**L'expérience des soignants familiaux
en région rurale en matière de
transport des patients en soins palliatifs**

**Sharon J. Lockie, Joan L. Bottorff,
Carole A. Robinson, Barbara Pesut**

Le transport est une question importante pour les patients des régions rurales qui sont atteints de cancer avancé et reçoivent des soins palliatifs. Cette étude qualitative de nature descriptive visait à explorer les expériences des soignantes et soignants familiaux qui s'occupent d'un proche recevant des soins palliatifs avancés dans un centre de traitement régional. On a mené des entrevues auprès de 15 soignantes et soignants (âgés de 27 à 73 ans) qui accompagnent un proche à ses rendez-vous. La vie en région, les multiples responsabilités en matière de soins, la présence d'un réseau social et la culture du centre régional de traitement constituent des facteurs contextuels pertinents. Un grand thème se dégage des entrevues : le souci de faire en sorte que les déplacements soient les plus agréables possibles pour les patients. Parmi les sous-thèmes, soulignons : *la planification requise pour parer à toute éventualité; les expériences sur la route; le fardeau des déplacements pour les soignantes et soignants; la volonté de tirer le meilleur parti de la situation*. Les auteures formulent des recommandations en matière de soins auto-administrés, de prestation des soins infirmiers et de recherche.

Mots clés : cancer, prestation des soins, soins palliatifs, régions rurales

Experiences of Rural Family Caregivers Who Assist With Commuting for Palliative Care

Sharon J. Lockie, Joan L. Bortorff,
Carole A. Robinson, Barbara Pesut

Commuting for advanced cancer care is an important option for rural patients who require palliative treatment. The purpose of this qualitative descriptive study was to investigate the experiences of rural family palliative caregivers (FPCs) who supported advanced cancer patients receiving palliative treatment at a regional cancer centre. Semi-structured interviews were conducted with 15 FPCs (27–73 years of age) who commuted with family members. Rural life, the multiple responsibilities borne by FPCs, the availability of support networks, and the culture of the regional cancer centre were all relevant contextual factors. The dedication of FPCs to making the commuting experience as positive as possible for the patient was the central theme. Subthemes were *planning ahead to prepare for all possibilities*, *experiences on the road*, *the toll of commuting on FPCs*, and *making the best of it*. The authors offer recommendations for self-care, nursing practice, and future research.

Keywords: cancer, caregiving, environment and health, family health care, palliative care, rural and remote health care

Studies have been conducted to describe caregivers' perspectives on travelling for cancer care (Longo, Fitch, Deber, & Williams, 2006; McRae, Caty, Nelder, & Picard, 2000). However, the commuting experiences of family palliative caregivers (FPCs) who accompany advanced cancer patients from rural and remote locales for palliative care (PC) is largely uncharted. Palliative caregivers are known to be at risk for physical and psychosocial morbidity and to face economic challenges (Aoun, Kristjanson, Currow, & Hudson, 2005; McRae et al., 2000). Little is known about the effects on FPCs when they take on responsibilities for commuting in addition to other caregiving tasks. This knowledge could be used by nurses and other health professionals to enhance supportive PC for families travelling to access services for their loved ones. In the absence of information on FPC commuting experiences, health-care interventions and supportive measures may fail to address key family needs. The aim of this study was to examine the experiences of FPCs who commute from rural and remote locales with a family member receiving advanced cancer care and to broaden our knowledge about the demands of family caregiving in that context.

Literature Review

Despite attempts to define rurality and take into account relative levels of remoteness, there is a lack of consensus on how rural communities should be classified. For example, the Canadian Rural Information Service defines rural as areas with fewer than 150 people per square kilometre (www.rural.gc.ca/cris/fac/def_e.phtml) and Statistics Canada defines rural and small towns as communities with populations of under 10,000 (duPlessis, Beshiri, Bollman, & Clemenson, 2002). Nevertheless, the urbanization of Canadian society, with almost 80% of the population living in small or large cities (Statistics Canada, 2008), is a significant factor influencing health services in rural and remote areas. Although PC services in Canada are increasing, as specialist services they tend to be situated in urban centres while in rural and remote communities they are provided by local generalist health-care providers, including community nurses, family doctors, and volunteers. This trend is not likely to change.

In the province of British Columbia, evidence suggests that the majority of those who could benefit from hospice PC services do not have direct access to such services (BC Hospice Palliative Care Association, 2005). Access is particularly limited for residents of rural and remote areas. Out of necessity, patients and their families living in rural parts of the province often travel to larger centres in order to access PC services. At present, there is a dearth of research on PC in rural and remote settings (Robinson et al., 2009). In particular, the influence of rurality and the family perspective is underrepresented. Yet family-centred care is one of the foundations of hospice PC (Canadian Hospice Palliative Care Association, 2003), and FPCs are a critical element in PC services in both urban and rural settings because of the role they play in home-based care. Literature reviews on the topic conclude that as caregivers take on more complex care, their ability to meet all demands is challenged (Andershed, 2006; McCorkle & Pasacreta, 2001).

Researchers have described the needs of family caregivers in rural contexts (MacLean & Kelley, 1997; McGrath, 2006; McGrath et al., 2006; McGrath, Ogilvie, Rayner, Holewa, & Patton, 2005; McRae et al., 2000; Wilkes, White, & O'Riordan, 2000; Wilson et al., 2006). In the only two applicable Canadian studies located (MacLean & Kelley, 1997; McRae et al., 2000), accessibility and quality of services are reported to be primary considerations for caregivers. What is poorly understood is the impact of travel on rural FPCs who transport and accompany family members to palliative cancer services in urban centres. There is also a lack of information on how commuting influences the caregiving capacity and well-being of FPCs.

Palliative care studies conducted in rural settings have not always accounted for geography and the influence of other factors related to the place where people reside (Robinson et al., 2009). There is growing acknowledgement that the characteristics of where people live, including geography, climate, the built environment, and socio-economic characteristics, are all factors that have the potential to influence health and that need to be better understood (Solberg & Way, 2007). Understanding the influence of place becomes particularly important when geographical location provides the context for health-related experiences and nursing practice (Bender, Clune, & Guruge, 2007).

As part of a larger study focusing on the needs of rural PC patients and their caregivers served by a regional cancer centre in British Columbia, we interviewed both PC patients and family caregivers who had experience with commuting for PC. We found that commuting presented patients with challenges, including the time and energy needed to prepare for travel (e.g., pain management), to maintain significant relationships, and to deal with anxiety related to the trip (Pesut, Robinson, Bottorff, Fyles, & Broughton, in press). Although commuting was costly, it had significant benefits for patients in terms of supportive relationships and quality of life. In this article, we describe FPCs' perspectives on supporting family members in commuting for advanced cancer care.

Method

A qualitative descriptive design was used for this study (Sandelowski, 2000). The study was conducted in the south central region of British Columbia served by a regional cancer centre adjacent to a tertiary-care facility in a small city. The cancer centre served a health region of approximately 215,000 square kilometres, including many rural communities. Advanced cancer treatment provided at the centre included radiation therapy, chemotherapy, and pain and symptom management as well as support services. A nearby lodge offered affordable accommodation and meals. Ethical approval for human subject research was obtained from the university and the health authority.

Sample

Purposive sampling was used to recruit 15 FPCs who were (a) actively involved in providing care to a family member with advanced cancer, currently or within the previous 2 years; (b) commuting from a rural or remote area for the purpose of accompanying a patient who was receiving advanced cancer care at the regional cancer centre and who had been identified by the centre as palliative; and (c) English-speaking. For the purposes of this study, rural/remote was defined as outside the commut-

ing zone of a “major urban centre” — a community of 10,000 or more people. In the study region, nine centres met the criteria for major urban centre at the time of data collection. Those FPCs who did not reside in one of those nine places were considered to be living in a rural locale. During scheduled clinic visits at the cancer centre, potential participants were flagged by rural or remote postal code. These people were approached by a specially trained cancer centre volunteer, who gave them a pamphlet about the study and invited them to complete a consent-to-contact form. Those who agreed to receive further information were contacted by one of the authors (SL), who provided more information, obtained informed consent, and set a time for an interview.

An overview of the sample is provided in Table 1. The average commuting distance was 177 kilometres each way. Although the majority of FPCs returned to their own homes on the same day, some stayed in town because of the time required to travel long distances, frequency of appointments, illness of the patient, or weather conditions. Four participants made use of the nearby lodge for overnight stays and meals.

Table 1 Characteristics of Sample (n = 15)¹	
Gender	
Male	6
Female	9
Age (years)	Average = 55 (range = 27–73)
Education	
High school diploma	3
Technical/trade diploma	7
University degree	4
Marital status	
Married or living with a partner	11
Not married or living with a partner	3
Residency status with regard to patient	
Living in same household	12
Living in same community	1
Living in different community	1
Income	
\$11,000–24,000	2
\$25,000–49,000	4
\$50,000 or higher	6
Don't know/prefer not to answer	2
¹ Demographic data missing for one participant.	

Data Collection

A demographic questionnaire, together with an in-depth semi-structured interview, was the primary means of data collection. The majority of interviews were conducted face-to-face in participants' homes or at the cancer centre. At their own request, one third of FPCs were interviewed by telephone. Interviews were digitally audiorecorded and ranged in length from 30 minutes to almost 3 hours. Open-ended questions were used to invite participants to share the experiences and concerns they deemed most important. Field notes were recorded (Morse & Field, 1995); these included information on locale and the interviewer's initial impressions of the interview. An honorarium of \$20 was provided to FPCs in acknowledgement of their contribution to the research.

Five FPCs were interviewed following their first commute for advanced cancer care. Among the remaining participants, commuting experiences ranged from three visits to numerous visits over an extended period. Several participants accompanied family members who were in a fragile state; increased pain and unpleasant symptoms made travel even more difficult towards the end-stage of the illness.

Data Analysis

The initial transcripts were read several times and open-coded independently by the authors. At team meetings, observations of the data were discussed and a preliminary coding framework was developed to capture salient ideas and themes. Coding then proceeded using NVivo data-management software. As additional transcripts were reviewed, new categories were added to the coding framework and some codes and their definitions were revised. Additional questions that surfaced during data analysis were incorporated into subsequent interviews. Once coding of the interviews was completed, data for each category were retrieved and constant comparison was used to identify and refine themes and sub-themes.

Methodological rigour was strengthened through verification strategies, clarification of the disclosures, identification of experiences common to all families or unique to particular families, the gathering of additional details to enrich descriptions, and analysis concurrent with data collection. An ongoing process of discussion and revision of coding served as one component of the internal audit. An electronic audit trail of procedures, decisions, possible thematic development, and sources of bias was initiated at the beginning of the study and continued until the study was complete.

Findings

Context of Commuting for Care

The commuting experiences of FPCs were influenced by four contextual factors. The first was rural life. Although rural living was highly valued by participants, it came with a price. Experience had taught FPCs to expect challenges in commuting long distances, whether related to weather, road conditions, traffic problems, accidents, road construction, or vehicle breakdowns. Goods and services are more expensive in rural communities than in larger towns and there are costs associated with travel (e.g., gas, meals, and accommodation). For the group as a whole, the weighing and consideration of expenses was a preoccupation. Commuting added to the financial strain, particularly for those with fixed incomes or reduced employment incomes as a result of caregiving. One FPC knew she could fall back on family members to help out if she found herself “completely tapped for cash,” but at the same time she worried about “taking away” their financial resources:

It's a lot more stress, you know, because . . . I'm on [employment] leave so my income isn't high, and when you're paying 60 bucks in gas to go out, it gets pricey.

The second contextual factor influencing commuting was the busyness of FPCs' lives and the added burden associated with commuting. Participants fulfilled a range of roles and responsibilities at home and in their communities, as parents, employees, volunteers, and community members. Layered upon these was their role as a palliative caregiver and their responsibilities related to commuting. The burden of commuting was heavier because of these multiple commitments.

The third contextual factor related to the strong social networks that are characteristic of some rural communities. Commuting experiences were therefore influenced by the availability of support in rural settings, as well as whether FPCs accepted the support that was offered to them, as evident in a comment provided by one FPC:

Early on, we felt it was something the two of us could do with no help. [laughs] . . . you're married 43 years, you figure, well, okay, you can do this.

The majority of FPCs did not have close relatives living nearby and thus relied primarily on friends or neighbours. When family members did live nearby, they were usually involved in the commuting experience.

Finally, the regional cancer centre and services represented an important contextual influence. Participants spoke of the staff, including volunteers and receptionists, as providing compassionate care. They noted in

particular that the friendly and encouraging manner of the staff serve to create a community of support. The majority of participants described visits that included good humour, smiles, and a sense of being remembered between appointments by staff and volunteers at the cancer centre and the lodge. In summary, the nature of rural life, the multiple responsibilities borne by FPCs, the availability of social networks, and the culture of the regional cancer centre all provided context for how FPCs experienced commuting.

Family Palliative Caregivers' Experiences of Commuting

Family caregivers took their responsibility to support commuting seriously and were committed to doing everything in their power to ensure that their family members received the treatments they needed. A 36-year-old FPC who drove his mother in for care stated, "Whatever you have to do, you make . . . it happen . . . with work or anything . . . family is everything." Four themes capture important aspects of FPCs' experiences of commuting: *planning ahead to prepare for all possibilities*, *experiences on the road*, *the toll of commuting*, and *making the best of it*.

Planning ahead to prepare for all possibilities. Planning and preparation were key to ensuring that the commute went as smoothly as possible and that appointments were not missed and that they were flexible for rescheduling. Family palliative caregivers had to attend to every detail. Preparations included a number of strategies. The first involved attention to a range of practical issues: getting time off work; making sure the car was in excellent running order; packing clothes, medications, and equipment for the trip; occasionally arranging for a second driver; and monitoring weather and highway conditions. The participants not only needed to consider the possibility of traffic delays or poor road or weather conditions, but also had to plan for contingencies in case of breakdowns or other problems:

If you go off the road or hit a deer, then you've got to be prepared . . . because then you have to take into consideration the person with you is [in a] compromised [condition] . . . in general, so they get cold faster . . . they need their medicine . . . they're just not able to do the hike or walk that far, or stand for 3 hours hitchhiking, or whatever the case may be . . . So you always want to make sure that if that happened, . . . one person was able to stay in the vehicle and stay warm, then the other person could go for help or gas or whatever.

Anticipating the needs of the family member was the second major planning strategy used by FPCs, to be sure the person was as comfortable as possible during commutes. They had to ensure that even when the patient was not well they would both be prepared to take the trip. One

FPC observed, “That’s not really conducive to cancer treatment at all . . . you know, he’s throwing up on the road or whatever, you still have to go.” The potential for changes in level of debility over the course of the treatment challenged FPCs to engage in monitoring before each trip. They watched over family members to assess their sleep, activity and energy levels, changes in appetite and associated changes in weight, and adherence to medication regimes. Assessing pain was one of the more difficult monitoring tasks that FPCs took on to guide their planning: “It’s tough . . . [the] physical . . . also mental [pain] . . . [and] taking inventory as to where the pains are.” One caregiver described pain control as “big” and said that it was important to “take lots of breakthrough doses” for the trip. Packing analgesics and other supplies in a “just in case” bag was common practice, to be prepared for any unexpected changes or events during the trip.

Managing time was the third strategy used by FPCs. A high degree of flexibility and planning was needed to be sure that there was sufficient time to make all arrangements and get to appointments on time. Participants reported that they always planned to leave early in order to build a cushion of time into each trip. They also found that they needed to anticipate changes in appointment times and the possibility of unexpected wait times. The participants needed to plan for “an all-day affair” as well as very short radiation treatments. In the case of brief appointments, the FPC barely had time for a hot drink before heading out on the road again. Unlike paid caregivers, FPCs did not get breaks from the responsibilities associated with commuting. The concepts of time and time management as discrete knowable entities were replaced by the idea of time as a fluid commodity. In summary, planning ahead required considerable effort on the part of FPCs.

Experiences on the road. For FPCs, the demands of commuting were most clearly reflected in their experiences on the road, where they not only took responsibility for driving and getting their family member to appointments safely and on time, but also managed other caregiving responsibilities. Their experiences are captured in three subthemes: *doing double duty*, *getting into a routine*, and *dealing with unfamiliar territory*.

The multiple roles that FPCs took on while travelling can be described as doing double duty. Caregivers needed to be particularly cautious with their driving, especially when patients found it difficult to sit in the car for long intervals due to pain or when their discomfort was aggravated by rough roads. Assessing the person’s physical tolerance for the trip was an important part of commuting — a part of the job that became more difficult as the disease progressed and the patient suffered increasing pain and fatigue as well as other effects of the disease or side effects of the treatments. Some caregivers found it hard to motivate the

person to make the trip in for more treatment when he or she was experiencing nausea and vomiting that might be made worse by a long car ride. Managing the range of emotions experienced by the ill person in relation to commuting for cancer care was also a challenge. While driving, FPCs responded to the person's anxieties related to upcoming appointments, reluctance to travel, disappointment at having to return for additional treatments, and loss of independence associated with the advancing disease. The range of support provided by FPCs is illustrated in the account of a participant who found himself coaching his wife during the commute on how to manage her claustrophobia during radiation treatments. He suggested she use images to distract herself:

Trying to imagine what it was going to feel like lying there. You know, when you can't move your head, right? And what sort of things can you see that are going to help you deal with that? So we talked about what she would try and imagine. Like her garden . . . or, on a particularly nice day in the fall, walking the dog . . . and it's nice and the colours are out and it's cool and sunny.

Getting into a routine, the second subtheme capturing FPCs' experiences on the road, was a common experience among those who commuted frequently. These participants began to feel as though they were "on autopilot." One man commented, "There [were] days . . . holy cats, here we go again! . . . Pretty soon the truck would go by itself." Although being "on autopilot" helped FPCs manage the additional responsibilities associated with frequent commuting, over time the trips became tiring. In addition, routines were disrupted sometimes, such as when appointments were unexpectedly changed.

Dealing with unfamiliar territory was the third subtheme identified in the FPCs' commuting experiences. The additional stress and numerous arrangements required when accompanying a palliative patient took commuting outside the realm of customary travel. A few FPCs were unaccustomed to long-distance driving and city traffic. The role reversal from secondary to primary driver created a stressful trip to the city for one wife, who had never driven such a long distance before. She opted to leave home a day early to avoid heavy traffic.

The toll of commuting. For most of the FPCs, commuting for advanced cancer care had implications for their own health. As their family member's disease progressed, seven of the FPCs experienced a range of health impacts related to commuting, including the stress of driving, increased worry, anxiety and tearfulness, fatigue, exacerbation of chronic health conditions leading to physical discomfort, and altered sleep and eating patterns. A few FPCs who could not remain in town during treatments because of commitments at home found that they

were unhappy being home alone and worried about the ill person. Anxiety about what would occur at the cancer centre and concern about the patient's well-being often obscured their own health issues. In one case, an FPC omitted her regular prescribed medications because she was concerned they would make her an unsafe driver. Some FPCs admitted that they would forget to take their pills and would put themselves "on hold" or "on the back burner" during the commuting period. Two FPCs reported that pre-existing chronic conditions worsened and caused them physical discomfort during the commute. Despite these health issues, FPCs never wavered in their commitment to supporting family members on their commute for care.

Making the best of it. Practical-minded FPCs took advantage of the travel to a larger centre to do errands and shop for items that were not available in their own community. Participants also focused on making the commute as pleasurable as possible. There was a strong consensus that commuting for advanced cancer care should be combined with enjoyable pursuits. The overall commuting time was valued by many as an opportunity for meaningful conversation. Discussions about goals, asset protection, or relationships, or just enjoyable private chats, seem to have been facilitated by the close quarters of the car, motel, lodge, or airplane. One FPC noted:

I think people just find it easier to talk in a small space . . . you have that extra time that's just there, just for you . . . that few hours that you're taking to drive in or out. I think it becomes important.

The idea of the car as an intimate space played out for other families as well. Married couples sometimes became closer because of the commuting experience. One FPC explained, "We're near the end of where we need to — where we are — and so every time for us together is important . . . we need the time together."

There were also examples of taking advantage of the travel to renew connections with relatives and friends and to do something different or special (e.g., have a meal at a new restaurant) or to fit in some shopping. Some FPCs found it difficult to find a balance between supporting the family members' engagement in these activities and preventing them from doing too much.

Family Palliative Caregivers' Recommendations for Commuting

Participants had a number of recommendations for families in similar circumstances and for health-care providers. Their recommendations centred on various strategies for maintaining overall health and building endurance for travelling in these particular circumstances. One spouse

used sombre tones in describing what he thought other FPCs should be told:

Take what you think [is] the worst thing [that could] happen to your partner and double it, triple it, in terms of how they're going to feel. Because it really is quite scary, in terms of how physically beat up individuals get. . . . And they can say, "Yeah, you're doing fine" . . . and you look at this individual who is just hardly anything there. And there's no energy . . . It's just . . . it's an eye opener. . . . Take the good stuff [out of the situation] that you can. Certainly, don't dwell on the down side of it. Enjoy the time with your partner.

Being well organized, getting ready well in advance, and being prepared for unexpected events were reiterated by the FPCs as important strategies. In addition, participants emphasized the importance of asking for driving assistance. Self-care suggestions were what most FPCs wanted to pass along to others who might need to commute with a family member in the future. The most endorsed recommendation was that FPCs and patients arrange to stay over in the city or town during treatment, to reduce the strains associated with travel.

The participants stressed the link between how cancer care is provided and positive commuting experiences. Their expectations of health-care providers included good communication, clear information, acknowledgement of the prognosis, appreciation of the demands of commuting, permission for FPCs to observe treatment whenever possible, weekend support by volunteers, caregiver support groups, and a social services liaison. One FPC was returning to the cancer centre with his mother after 2 years away:

I think the most important thing is that when you arrive, you have a good experience from the doctors . . . no matter what's happening with . . . the cancer. Like, you don't want to drive all that way and go away . . . disappointed.

To address the financial implications of commuting, FPCs advocated for "compassionate pricing," rebates for travel costs associated with commuting, and ready sources of funding to cover basic commuting costs that ought to be available right at the cancer centre.

Discussion

This study is one of the few to describe in detail FPCs' commuting experiences for advanced cancer care and the investment of time and energy entailed in taking on this responsibility. For FPCs, the commute involved much more than simply driving. Their dedication to making the

commuting experience as positive as possible for the family member underpinned their extensive preparations for the trips, precautions taken to ensure safe travel regardless of weather and road conditions, efforts to continuously monitor the impact of travel, and provision of comfort and support during commutes. These activities demonstrate the extra work that FPCs put in on a regular basis to support commutes — work that sometimes pushed them beyond their limits of endurance. Moreover, the financial burden of commuting was a significant worry for some. Despite these challenges, FPCs discovered unexpected benefits to commuting.

The study's findings are influenced by the particular characteristics of the setting and how cancer services are provided there. The experience could differ for FPCs who live in very remote settings, have greater responsibilities associated with rural life (e.g., farming duties), have inadequate financial resources, or have limited access to reliable transportation. The experience could also differ when the person who commutes with the patient is not a family member. This study did not capture the experiences of those FPCs who had to stop commuting because the travel could no longer be managed, by either the FPC or the ill person, or of those FPCs who chose not to commute at all. The relatively small sample may not have captured the full range of FPC experiences. Despite these limitations, the interviews produced a rich data set that provides important insights into FPCs' experiences of commuting and that extends our understanding of an important dimension of PC in rural settings.

Although other studies describe the needs of family caregivers in rural contexts (McGrath, 2006; McGrath et al., 2006; McGrath, Ogilvie, Rayner, Holewa, & Patton, 2005; McRae et al., 2000; Wilkes et al., 2000; Wilson et al., 2006), our study included a more detailed examination of the influence of the rural environment on the experiences of FCGs. The importance of taking into consideration complex rural dimensions of health experiences has been recognized (Harvey, 2007). However, a focus on the social and economic hardships of rural life has often directed attention away from the positive aspects of rural life (Rogers-Clark, 2002) and tensions inherent in rural life (e.g., tension between social isolation and sense of belonging) (Harvey, 2007). In this study, rurality influenced family caregiver experiences in complex ways that both enabled commuting and made it particularly challenging.

Since rural environments influence the way people relate to one another and are often characterized by strong social networks, it is not surprising that FPCs benefited from local instrumental and emotional support that directly influenced the commuting experience. However, there were also many instances of FPCs declining or not asking for assistance. While the independent nature of many rural dwellers might be an

explanation, there were hints that FPCs wanted to protect their privacy and the personal time they had available to spend with their family member. It is possible that FPCs perceived that those less familiar with their family member's condition would not be able to take on the additional caregiving responsibilities they associated with commuting and that it would be too much to ask of them. Most of the FPCs chose to make the journey alone with the patient, and few asked another person to go along, either as an extra driver or as a companion. This position is illustrated in their descriptions of the intimacy afforded by the drive to and from the cancer centre as well as the complexities of managing pain and other side effects during commutes. These are features of commuting that have not been systematically described, and they point to potential drawbacks of depending on volunteer drivers. An added advantage for FPCs and patients when they travelled together was the opportunity to engage in interactions infused with meaning. This is an important observation. These types of interactions have been noted as essential for family well-being (Syren, Saveman, & Benzein, 2006).

Commuting is generally an accepted part of rural life and the familiar routines of travel prepared FPCs to assess and modify the commuting approach when palliative caregiving was needed. However, the findings highlight the additional responsibilities and stressors that result when travel is needed due to advanced cancer care for family members. In particular, the FPCs' experiences were influenced by pressures caused by their growing awareness of the family member's nearing the end of life and increasing difficulty coping with the travel. The pain, exhaustion, or other side effects experienced by ill family members were concerns that affected FPCs while commuting. The tiring and stressful effects of commuting had a direct effect on caregivers' own health. Researchers have described the psychological, occupational, and economic aspects of caregiving in this context. For example, Grunfeld et al. (2004) report substantial increases in caregiver anxiety and depression as family members enter palliative and then terminal phases of their illness. The present findings suggest that the physical, psychological, and economic impacts on FPCs are magnified when commuting responsibilities for PC are added to their already difficult caregiving roles. The challenges of pain and symptom management and provision of psychological support during commutes need to be considered as important aspects of caregiving in rural contexts.

Participants were independent, self-reliant, and dependable when it came to commuting, and were highly committed to being there at all costs for their family member. The result is that in some instances they may have encouraged patients to travel for advanced cancer care when this might not have been in their best interests. There has been a general

lack of recognition of the complexity of decisions and preparations for commuting in the context of advanced cancer care. Participants did the best they could with the information they had. The vital role played by family caregivers of those with life-limiting illness is recognized (Andershed, 2006). Extending adequate support to FPCs can serve to improve the quality of life of palliative patients.

In summary, although participants viewed the rural environment as an important resource, rural living presented significant challenges that underpinned their commuting experiences. Despite many demands related to caregiving and commuting, FPCs strove to “make the best of it” in multiple ways. Hudson (2004) notes that it is important for health professionals to help caregivers realize the benefits in their role; it appears that these FPCs were able to do so on their own. These findings add to a growing body of literature supporting the need to recognize the tensions inherent in rural life, as well as the influence of rural environment, distance, and climate (Keating, 2008).

Recommendations

The augmenting of PC services in rural communities is now under way, but it is likely that for some types of treatment (e.g., radiation therapy) commuting for advanced cancer care will continue to be a part of the experience of many patients and their families. The findings provide some direction for practice, policy, and future research. In relation to practice, nurses and other health professionals at all levels need to be aware of the potential challenges that FPCs face when they take on commuting responsibilities in addition to significant caregiving, employment, and family commitments, and the complex work that this involves. The health effects for FPCs of commuting for advanced cancer care cannot be ignored or underestimated. Efforts should be directed at providing FPCs with guidance for pain and symptom management while travelling, decision-making support related to commuting, and regular assessments of FPC well-being and support needs. Reducing the number of commuting days for rural and remote palliative families by coordinating appointments for diagnostics, treatment, and consultation should be a priority, to minimize the need for travel and associated costs. Advocating for policy changes to address the financial burden associated with commuting for PC is also clearly required.

The provision of effective support will ultimately depend on a more thorough understanding of the needs of FPCs who commute from outlying areas to regional centres. Further research is needed to deepen our understanding of the factors that influence the experiences of commuting FPCs, in order to develop effective support and respite measures that

will minimize the health risks associated with caregiving. Examining the influence of the frequency and duration of commuting on FPCs' experiences and health outcomes is also important, as well as the influence of diversity in terms of ethnocultural groups, gender, and socio-economic status as they relate to the commuting experience. Finally, through the extension of research initiatives to other rural populations who also commute for advanced cancer care, our knowledge of how rural contexts influence commuting experiences will be enhanced. The results of this research could also provide direction for improvements in the provision of PC services in these locales.

Conclusion

The findings of this study hold particular significance for those who work with patients/families from rural and remote communities, especially given the trend towards the centralization of health services and expected increases in the numbers of individuals requiring PC associated with demographic trends in Canada. The insights into the experiences of rural FPCs who commute with a relative for palliative cancer care highlight a dimension of rural PC that is in need of greater attention. The results add to our understanding of the needs, challenges, and quality-of-life issues facing FPCs and suggest ways that nurses and other health professionals can support family providers of palliative care in rural areas.

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Résumé

**Les croyances en matière de santé
des femmes du Vieil Ordre Mennonite
de l'Ontario rural au Canada**

Ewa M. Dabrowska, Judy Bates

Cette étude qualitative vise à explorer les questions de santé touchant les femmes appartenant au Vieil Ordre Mennonite, une communauté ethno-religieuse fermée établie en Ontario rural au Canada. C'est la première fois que des femmes issues de ce groupe, qui parle l'allemand pennsylvanien, un dialecte du haut allemand, participent à un projet de recherche sur la santé. Les auteures s'appuient sur un cadre d'analyse des effets du lieu sur la santé pour étudier les perceptions de ces femmes vivant dans une région où l'environnement est contaminé. Elles concluent que la socialisation religieuse a inculqué chez elles un système de croyances ainsi qu'un attachement au lieu qui les amènent à considérer ce dernier comme un espace sanctifié, qui serait protégé des effets sur la santé que peut entraîner un milieu hautement toxique. Un phénomène que les auteures décrivent comme «les effets du lieu modelés par les croyances».

Mots clés : Vieil Ordre Mennonite, allemand pennsylvanien, santé des femmes, rural, lieu

The Health Beliefs of Old Order Mennonite Women in Rural Ontario, Canada

Ewa M. Dabrowska, Judy Bates

The purpose of this qualitative study was to explore women's health issues in a closed, ethno-religious Old Order Mennonite (OOM) community in rural Ontario, Canada. This is the first time that conservative OOM women from this community, who speak Pennsylvania Deutsch, a High German dialect, have participated in health research. The theoretical framework of "place effects" on health is used to examine how OOM women perceive their health in an environmentally contaminated area. The authors conclude that the belief system and attachment to place developed through the religious socialization of these rural OOM women have created a presumed sanctified space protected from the health effects of a highly contaminated environment. They refer to this phenomenon as "belief-informed place effects."

Keywords: Old Order Mennonite, Pennsylvania Deutsch, women's health, rural, place, ethnography

Background

Marginalized ethnic groups whose culture sets them apart from contemporary Canadian society can present challenges to nurses, midwives, and other health professionals (Hall & Kulig, 2004; Kulig, Babcock, Wall, & Hill, 2009; Kulig et al., 2002). These challenges may be exacerbated when such groups live in a rural environment that has a long history of industrial environmental pollution. This article examines understandings of health among women from an Old Order Mennonite (OOM) community in a highly contaminated area of rural Ontario. Conservative religious beliefs and isolation from the outside world are central features of this OOM group, who speak Pennsylvania Deutsch, a High German dialect (Horst, 2000) often referred to as Pennsylvania Dutch.

Theoretical Framework

The theoretical framework of belief-informed place effects is applied to examine conceptions of health experienced by rural Mennonite women in Woolwich Township, Ontario. Geographical variations in conceptions of health can be accounted for using compositional, contextual, and col-

lective explanations (Macintyre, Ellaway, & Cummins, 2002). Collective explanations, such as those associated with “religious affiliation, kinship systems, domestic division of labour, gender, age” and culturally appropriate roles within the family and the community, have been shown to be important in accounting for sociocultural differences in conceptions of health in various places (Macintyre et al., 2002, p. 130). The characteristics of place can inspire spirituality and tranquillity and may alter conceptions of health within a community of believers (Gesler, 2003). The valuing of place is not something that individuals are born with, but it can be learned through a process of religious socialization (Mazumdar & Mazumdar, 2004). We propose in this article that the belief system of OOM women and their attachment to place, developed through religious socialization, have created a presumed sanctified space that protects them from the negative health effects of a contaminated environment. We refer to this phenomenon as “belief-informed place effects.”

Literature Review

Numerous scholars have developed theories concerning the environment and its impact on the health and well-being of people physically, socially, culturally, and politically at a variety of geographical scales (Day, 2006; Elliott, 1999; Krewski et al., 2008; Wakefield & McMullan, 2005). An approach grounded in health geography introduces “place and landscape” as a theoretical framework for examining how perceptions of environment may be related to place in explaining health inequalities (see Curtis, 2004, for a review). Studies of the ecological landscape or of the distribution of physical or biological environmental risk factors include investigations of environmental health disasters such as a recent outbreak of *E. coli* in Walkerton, Ontario (Harris, 2004), and an examination of environment-health links in the Canadian Farm Family Health Study (Arbuckle et al., 1999). Exposure to environmental chemicals poses significant hazards to physical health (Schettler, Solomon, Valenti, & Huddle, 2000) and may cause behavioural and lifestyle changes among residents of rural/remote areas (Leipert & George, 2008). For example, in a study with a First Nations group living on a reserve near Sarnia, Ontario, Mackenzie, Lockridge, and Keith (2005) found that the “close proximity of this community to a large aggregation of industries and potential exposures to compounds” (p. 1295) could influence the sex ratio of the Aamjiwnaang First Nation. However, examination of an ecological landscape does not provide a full understanding of how environments can influence health, particularly when health is defined as total well-being, in the cultural context of communities.

A number of scholars have argued that social dimensions, such as gender, ethnicity, and minority status, are important in the conceptualization of place, since these dimensions contribute to the experience of health (Gesler & Kearns, 2002). The construction of images and interpretation of place in the human mind occur through complex processes and, as Jackson (1989) notes, “the same physical environment has given rise to quite different cultural landscapes because of different cultural processes” (p. 13). Symbolic environments are created by human acts of giving meaning to nature in geographic locations through particular filters of beliefs and values that are grounded in culture (Greider & Garkovich, 1994). People’s spirituality, sense of place, and identification with community are critical to the shaping of their perceptions of health. For example, in rural central and eastern North Carolina, part of the so-called Bible Belt where religious beliefs are strong, scholars have identified links between health and religion and have demonstrated that strong religious beliefs and practices are related to better mental health, better physical health, and stronger immune systems, especially in older populations (Gesler, Arcury, & Koenig, 2000).

In her research with First Nations communities in Ontario, Wilson (2003) has recognized the culturally specific, spiritual links between health and place in the conceptualization of wellness by Aboriginal communities. Rural women living in poverty in Canada have limited access to medical care and their poverty precludes good nutrition and access to medical services not covered by provincial health plans (Sutherns & Bourgeault, 2008). We focus on a Canadian rural landscape where gender and ethno-religious identities among a conservative Anabaptist group have rarely (Brunt, Lindsey, & Hopkinson, 1997; Kulig et al., 2009) been the subject of studies by health professionals.

Gavin Andrews (2002) introduces the geographical concept of *place* to nursing research, noting its importance in qualitative analyses of human-environmental interactions in professional health practices. Bender, Clune, and Guruge (2009) acknowledge that among nurses and clients in community work “place matters — as geographical location and lived experience, as demarcation of space, as a site of meaning creation” (p. 129). The theoretical importance of place in health studies is growing, and health research is incorporating multidisciplinary examinations of health inequalities. Macintyre and colleagues (2002) propose three types of explanation for geographical variations in health: *compositional* (characteristics of individuals), *contextual* (local physical and social environment), and *collective* (sociocultural and historical features of communities). The collective explanation highlights the importance of an anthropological perspective (shared norms, traditions, and values) in creating area effects. The authors argue for a more comprehensive examina-

tion of variations in health, including features of non-material culture such as identity (ethnic, regional, and national), religious affiliation, political ideologies, legal systems, shared stories, kinship system, and domestic division of labour. The multiple perspectives used to conceptualize place effects should be seen as complementary, each contributing to the overall place effects.

Religion affects people's attachment to place — their emotional bonds with places — and imbues places with symbolic meaning (Low, 1992). Religious place attachments are significant in the lives of many people. Physical and social elements of the environment cause the believer and the non-believer to see a place differently and thus generate dissimilar experiences (Gesler, 1996). Religious place attachments affect people's perceptions of security in place, as demonstrated by Jewish settlers in Gaza, where individuals with strong spiritual values have developed the means to cope with extreme situations (Billing, 2006).

One's attachment to place is often developed through religious socialization. It is learned through rituals, artifacts, prayers, stories, and symbols. Children learn from parents, from educators such as priests, and from peers within the community of believers (Mazumdar & Mazumdar, 2004). Religious socialization contributes to one's identification with a particular place, which, as noted by Hummon (1989), extends across generations, thus providing a continuous sense of identity. Theoretically, religious values (Reimer Kirkham, Pesut, Myerhoff, & Sawatzky, 2004), sense of place (Andrews & Moon, 2005), and ethnicity and culture (Clarke, 2004) are important in the context of different health outcomes in communities.

Purpose

This article reports on research conducted among OOM women, members of an ethno-religious minority living in rural Ontario, to elicit their perceptions of health. Using ethnographic methodologies, we examine how rural women perceive their health in a discourse of place. The research question was *How do OOM women living in rural southern Ontario understand their health?*

Old Order Mennonites in Ontario

The Mennonite faith is a Christian denomination that traces its origins to the Swiss Anabaptists of the 16th century. Seeking to escape from persecution and to enjoy religious freedom, some four thousand members of the Swiss Mennonite group immigrated to Pennsylvania in the United States during the first half of the 17th century. Around the year 1800, descendants of these families began arriving in Ontario to establish farms

and agricultural enterprises (Fretz, 1989). In the late 1880s, groups of Mennonites founded several religious communities in rural Ontario. One of these groups established a community called the Old Order Mennonite Church, whose members followed very traditional and strict cultural practices (Snyder & Bowman, 2004). It is women from this group of OOMs who are the focus of the present study.

The OOM Church is an orthodox group whose members are constrained from using modern conveniences in their homes. Land ownership is held individually and generations of the same family work the land together. Horse-and-buggy transportation, traditional clothing, and a legacy of Mennonite quilt-making are outward symbols of their cultural identity. Since they value self-sufficiency and as pacifists have chosen not to engage in war, OOMs believe that they should not make use of federal or provincial social benefits, including the Ontario Health Insurance Program (Peters, 2003). These practices make them responsible for paying 100% of the cost of health care and other government-funded services.

Community Structure

Old Order Mennonites are members of a rural community that is organized on the basis of shared values and norms and strong emotional ties among members — in other words, a *gemeinschaft*-like community (Fretz, 1989). Fretz argues that the Mennonites' long history of religious persecution has shaped their community structures: "They had no other place to turn for help than to fellow church members. Therefore the church fellowship was always more than a worshipping community" (p. 17). Their church fellowship and religious values are combined with their culture in a process of religious socialization. Parents teach their young how to be faithful community members, an essential component in the preservation of the social system operating within the community. In their beliefs, separation from the world and avoidance of the temptations of the "world" are emphasized, since they are essential aspects of their holy way of living, their simplicity, and their obligation to *Gelassenheit* — or their willingness to yield to God's will in all matters (Horst, 2000). This religious doctrine requires acceptance of gender roles, including the submission of women to men in a patriarchal social order that demands women's *silence, obedience, and self-denial* and acceptance of a clearly defined community hierarchy (Epp, 2008). All OOM members are committed to community. Their theology reinforces moral codes and places the needs of the community above the needs of the individual. The historical, religious, social, and contextual circumstances of people united in a *gemeinschaft* community frame their sense of place (Eyles,

1985). This background provides the context within which our study of women in the OOM community is undertaken.

Study Site

Farming communities located downstream from the town of Elmira, along the Canagagigue Creek in Ontario's Woolwich Township, have been exposed to chemical contamination for more than half a century (Conestoga-Rovers & Associates, 2003). The source of the contamination is a plant that manufactures highly toxic pesticides, herbicides, and other chemicals, including 2,4-D and 2,4,5 T, commonly known as Agent Orange, which was used by the US Army as a defoliant during the Vietnam War. Following years of complaints by concerned Elmira residents, in 2003 the potential health effects of the contamination were analyzed in a Human Health Risk Assessment. The study found extensive health risks associated with the plant and noted that users of the Canagagigue Creek floodplain, downstream from Elmira, face a cancer risk estimated at 1.9 cases per million *above* the national rate (Conestoga-Rovers & Associates, 2003). Since all those living along the Creek, including farmers, face a cancer risk estimated to be above the national rate, the Ministry of the Environment (2004) recommended the adoption of measures to protect the OOMs from exposure. In 2005, residents along the Creek were advised to fence off the floodplain and Creek so as to reduce exposure to toxins accumulated in the banks.

Old Order Mennonites were selected for the present study because members of this group include farm families living in very close proximity to the highly polluted Canagagigue Creek.

Method

Using ethnographic methodologies (Hall & Kulig, 2004; Williams, 1996), semi-structured interviews were conducted with a sample of 15 OOM women to explore their perceptions of health in their place. Since the OOMs are a special minority group, three levels of ethics approval were required and received from the Research Ethics Board of Wilfrid Laurier University. During the 2-year preparatory stage of the project, the researchers conducted interviews with a group of medical and health professionals, including nurses, midwives, and family physicians, as well as with some community leaders. Our purpose was to gain a full understanding of the health problems that could arise as a result of the contamination over a prolonged period to which members of the Elmira community and OOMs in the region had been exposed (Waterloo Region Community Health Department, 2001). During a period of participant observation, the principal researcher attended multiple meetings with

representatives of the Waterloo Region Community Health Department, the local environmental organization Assuring Protection for Tomorrow's Environment, the Regional Municipality of Waterloo, and the (Uniroyal) Crompton Chemical Company through the Crompton Public Advisory Committee, as well as with community members in Elmira.

Introductory letters, consent forms, and interview guides were prepared with help from an OOM woman who had been raised in the OOM community but was no longer a member. Previously, this woman had participated in a research project and was able to guide the principal researcher with regard to potential cultural biases in the questions and interpretation of meanings. The culturally sensitive nature of the research necessitated a particular focus with respect to the preparation of the documentation. As the nature of the inquiry was intrusive for members of this religious community, the researcher followed the interview guide closely and limited the number of probing questions. In a short questionnaire, participants provided demographic information as well as information on their health status.

Access to the community was made possible through the help of two non-Mennonite community leaders who had worked in Elmira for more than 15 years and were acquainted with members of the OOM community. These community leaders introduced the researchers to an OOM family in which the adult male was a "cultural broker" (Good Gingrich & Lightman, 2004). This family agreed to seek out members of their community who might be interested in participating in the study. Because of this assistance, a total of 15 OOM women agreed to participate. Arrangements were made to interview each of these women. The sample was clearly purposive and limited, but, given the exploratory and unique nature of the study, we decided to proceed despite the conditions of access imposed on us.

The cultural traditions of OOM women prevent them from meeting outsiders alone, so in all cases wives followed the formal procedure of confirming the interview arrangements with their spouses and in several cases the spouse also attended the interview. Over a period of 3 months in 2005 and 2006, the principal researcher interviewed 15 women from OOM families. Due to patriarchal relations within the community, three male spouses were present for interviews. Over time, the researcher gained the confidence of community members and was received by the woman alone or was able to interview the woman on their own after being welcomed briefly by her husband.

Out of respect for Mennonite cultural values, the interviews were not audiorecorded. Immediately following each interview, the researcher checked her handwritten notes, observations, and reflections from the meeting as well as any memorized quotations. This method has been

used in research with the Kanadier Mennonites (Hall & Kulig, 2004). The data were subsequently typed into an electronic document. The interviews were analyzed and themes were identified and coded using qualitative data analysis software. The researchers paid close attention to ensure that the data were interpreted according to the cultural context of the ethnographic paradigm (Quinn-Patton, 2002) and undertook to ensure the rigour of the research by focusing on credibility, which refers to the “accuracy of the description of the phenomenon under investigation” (Jackson, 2003, p. 183). Four data-quality measures were introduced to ensure the rigour and trustworthiness of the research: (1) The interview questions were pilot tested with researchers who previously had conducted cross-cultural research. (2) Despite limited access, the researchers used diversity in sampling and selected OOM women of various ages, of different marital status, and living at different distances from the Creek. (3) All interviews were conducted by the principal researcher for the purpose of maintaining consistency. (4) The findings from the interview data were presented first to the family of the cultural broker for checking to ensure accuracy of the data, and later to medical professionals in Woolwich Township. Threats to rigour and trustworthiness were minimized through the use of strategic measures for ensuring excellence in qualitative methods (Baxter & Eyles, 1997). The participants were assured of anonymity and confidentiality throughout the study and were given pseudonyms to protect their identity.

Results

The sample consisted of 15 female members of the OOM Church living in separate households in Woolwich Township. The women were aged between 23 and 64 years, with an average age of 49.7 years. Twelve of the women were married and three were single or never married. Members of this OOM community are prohibited from attaining a high level of education, so participants had not gone beyond Grade 8. All but one of the participants lived on a family-owned farm and each of the married women had lived in her present home since her marriage. The length of residency on the farm varied from 11 to 36 years. The 12 women had given birth to 76 live children, or an average of 6.3. In the short questionnaire, the women all reported their health as good or very good.

Perceptions of Health Among OOM Women

In this section we provide the findings from the interviews. All of the OOM women expressed the universal understanding among members of the OOM community that *health is a great gift from God*. Members of the community believe that God gives them the blessing of good health.

The women spoke about their health in terms of accepting God's will: "We are not in control of our health" (Melinda). The women also referred to their commitment to take care of their own health.

In this highly patriarchal society, women consider their husbands' opinions more important than their own, even when it comes to determining their own health. Their husband's evaluation of their ability to undertake their predetermined role in society influences women's perception of their health and their sense of well-being:

My husband should answer the question how my health is. I had one kidney removed because of cancer 5 years ago. Now I am fine. (Viola)

My wife works hard milking cows. She is in good health. (Melinda's husband)

The description of "good health" for this ethnic community includes tending to others' needs before their own. In discussing general aspects of her health and well-being, Rhoda noted that her health was very good and linked her good health to her social role. She provided an example of her obligation to other women in her community:

A woman from Mount Forest was asking if I have any work and can I help sell her quilting because she needs money to pay for gas [for the stove]. Isn't it our role to help other people, when they need help? I will not sell my quilting but I will sell hers.

Maria, who was chronically ill with multiple sclerosis, described the help that she received on weekends from other women in the community:

I can spend a lot of time with you today. On Sunday my friend came and she cooked meals for our family for 2 days. I am always getting help during the weekend.

Despite refusing to take advantage of government-funded social programs, including the Ontario Provincial Health Insurance Plan, almost all OOM women in the sample delivered their children at the local city hospital, paying for the medical services out of their own pockets:

All my children were born in Kitchener hospital. We went there in case of complications. (Ellen)

Members of this OOM Church community are permitted to use electricity, rubber-tired tractors, and modern agricultural equipment in their farming practices. They may also install telephones, though these are rarely used. Women understood the advantages of telephone service for the health and well-being of their family members:

Now we call for help when we need it. (Barbara)

Families without access to a telephone are much more vulnerable to delays in receiving necessary health care:

All my sons had appendixes removed. They had complications because they were reported very late. (Lucinda)

These delays were also the result of the high cost of medical care for families.

The women's reproductive health was discussed, but most women showed discomfort in speaking at length about their pregnancies. Few of the women had experienced complications with childbirth, but three acknowledged having multiple spontaneous abortions. A miscarriage was understood as a "better place for a child to be. Child will be in heaven with God." (Ellen) One woman spoke of the support she received from her husband after several miscarriages. Her response illustrates her religious beliefs:

I have a loving husband and a son. Not everybody can have everything. Maybe it is better that the other children died. (Martha)

The strong social networks among Mennonite families were apparent, especially among farm families and in the workshops, where male children find work. Children from neighbouring farms play together and the girls help their mothers in the home and with farm and garden chores, while the boys are kept occupied helping their fathers. The women talked about their close relationships with their mothers, sisters, and other women in the community. Grandparents have a special responsibility for caring for young and sick children. Naomi explained:

I came from a family of 11 children. My youngest brother was a "special child." I remember that grandparents were always around his bed.

The close connections were evident not only among family members but also among other community members:

There are no secrets in our community. When we have high bills, our community helps to pay for our stay in hospital. (Anna)

These reciprocal relations, based on the religious commitment to "being your brother's keeper," help to alleviate the economic burden of health care and other costs. Networks of social relations have penetrated the lives of OOM women by constructing meaningful links among church members, neighbours, and interconnected families who live in close proximity to one another in Woolwich Township.

Understandings Among OOM Women of Environmental Links to Health

Two themes, religiosity and attachment to place, were essential to the women's understanding about their health and environment. First, the women felt they were safe on their land because they did not violate God's rules. In the past, dead fish were commonly found on the banks of the Creek. In response to a question about environmental degradation and the presence of dead fish, Hannah said:

I knew about the issues but I never worried. In our language, to worry means to lose sleep over it. It is all in the hands of God. I never worried about the environment.

Martha explained:

Grandpa can tell you stories about his problems with dying cattle in the 60s. This doesn't mean that we are not happy here at the farm. We trust God.

The second theme in the understanding of environmental links to health was attachment to place. The women viewed their land as a benign landscape that provided them with food and economic security and that would provide for their children and grandchildren:

Our children have a better life on the farm. We provide for their well-being in the future. Yes, they are better here than the children in town. (Lucinda)

The lives of women in the community are linked to their environment through manual labour on the farm. They value their simple way of life and view their homes and farms as healthy places:

I think we are healthy here at the farm. Our immune system is built up. (Minerva, supported by her husband)

We are healthy here. When I go to the city I am always thankful that I live on the farm. It is so nice to have wildlife coming and to be able to drink the water as well. (Mary Ann)

Most of the OOM women seemed to be unaware of the fact that they were living in a contaminated environment and that the pollutants posed considerable dangers to their health:

I think it was safe here. My husband swam in the Creek when he was a little boy. My children swam in the Creek since they were little. (Barbara)

Most of the OOM women were not interested in discussing the environmental contamination, as this was their "husband's department" (Marlene) and "our work is at home, with children" (Barbara). The women were

aware of bacterial water contamination, as members of the OOM community are obliged to follow provincial water-testing regulations for private wells.

Despite the preservation of conservative traditions, most OOM families have adopted modern agricultural technology in their farming practices, and they consider the use of pesticides a necessity. They do not question the scientific validity of information provided on the labels of the chemical products, and they believe that “used properly, pesticides are not dangerous” (Martha).

Two women were aware of the toxicity of these chemicals since their husbands were required to take training on the safe use of pesticides, yet they appeared to be in denial about the dangers of living alongside a polluted creek.

The OOM women spoke about their attachment to their land acquired by working on it, the strong community social and economic networks that structure their social ties, offer assistance when disaster strikes, and provide work for their children. In addition, they noted that their Sunday church rituals, visits with family, and weekly schedules (baking days, laundry days, trips to town) unite the members of the community. It was evident that these women relied on collective support from their family, friends, and community networks. Martha briefly described her understanding of her social environment:

We are the Mennonites. We need to honour the past and to safeguard our future. We pray together and we work together — that’s the most important.

Discussion

The findings of this study indicate that OOM women perceive their health to be good. The interviews provide clear evidence that OOM women conceptualize their health in a culturally unique way, in relation to their ability to serve their community. Unlike women in contemporary society who are part of “city culture,” OOM women do not appear to have developed individualistic conceptualizations of their health. They believe that God is in control of their health and well-being, that their health is in God’s hands. The OOM women spoke of their connections to their land but did not report any health concerns related to environmental risk factors.

The results confirm the importance of religious values, the significance of trusting God, and epistemic differences in the construction of knowledge and perceptions of risks (Douglas & Wildavsky, 1982). Old Order Mennonite women do not consider the linkages between physi-

cal environmental hazards and poor health — an attitude that serves as a protective barrier and separates them from modernity and the hazards of contemporary society (Beck, 1992).

To interpret the results of our research using conceptualizations of place effects on health (Macintyre et al., 2002), we offer the following explanations. First, a compositional explanation of place effects accounts for this religious community's way of constructing knowledge of health issues and problems that is based on their faith in God. Old Order Mennonite women, as members of a traditional community, construct their knowledge and manage threats to well-being based on a foundation of religious beliefs (Alaszewski & Brown, 2007). They believe that their environment is healthy for them, as God is protecting them. Their knowledge system is based on their trust in God, not on their trust in modern scientific theories. In contrast to the broader Canadian society, OOM women might not believe that their health is compromised because they do not associate environmental degradation with disease and poor health outcomes (Krewski et al., 2008).

Second, a contextual explanation reflects the social reality of their lives and their religious obligation to remain separate from mainstream society. Because of their lack of access to the media due to their separation from the general population, women in this community are not educated about current global threats. Old Order Mennonite women never listen to the radio, watch television, or read newspapers, so they are unaware that they are at risk in their environment. This might result in a positive outcome and serve as an additional protective factor (Wakefield & Elliott, 2003).

Third, a collective explanation accounts for the religious values of the community regarding obedience to God and the primacy of God's will. Old Order Mennonite women believe that human actions have little importance relative to God's will and are therefore beyond their concern. While their lack of perception about environmental risks is a part of their conception of place, their belief system might serve to protect these women from the negative health effects of a contaminated environment. The compositional, contextual, and collective explanations should be seen as complementary, each contributing to the overall effects of place (Macintyre et al., 2002).

Based on the positive effects of place on the health of OOM women observed in our study, we suggest that religious faith and trust in God are protective factors in the health of these women. The positive health effects of religion are well known; they range from physically measured lower blood pressure in religiously active adults to non-biomedical healing in a "biopsychosocialspiritual" model (see Koenig, 1999). A number of scholars have identified religion and spirituality as important

factors in the determination of health status (Kulig et al., 2009; Wengler, 2003; Wilson, 2003).

The concept of place effects on health is complex, and it incorporates more factors than discussed above. These include social cohesion, social capital, the socio-economic position of the community (in this case in Woolwich Township), the rules of *Gelassenheit*, and aspects of collective community functioning (Good Gingrich & Lightman, 2004). In their rural Ontario landscape, OOM women value their social networks and the contribution of these networks to their well-being (Leipert & George, 2008). Membership in a religious community and a high level of social support might serve as protective factors in terms of health (Miller et al., 2007). Furthermore, because of their gendered roles in the community, OOM women cannot concern themselves with environmental problems; according to their value system, only their husbands and male community leaders may make decisions on important issues such as how to deal with environmental degradation (another collective explanation of place effects).

Women's roles are viewed through their religious beliefs, which are integrated into their lives. Individuals must take care of themselves and other community members, but God has control over their lives and without His help life cannot be sustained. Because of OOMs' attachment to their land, they see their farms as an ideal place in which to live, work, and raise their children despite the industrial contamination. Attachment to place, developed through their religious beliefs, is also a significant factor in their health experiences. A failure to perceive their place as safe could be interpreted as a failure to put their trust in God, since God has placed them there and their people have lived on this land for two centuries. The religious and cultural links with place construct their experience of health. Our results are consistent with those of Fretz (1989), who observes that, for this conservative group, cultural and religious links are inseparable.

We cannot know whether the OOM women are in good health. We analyzed their responses to the interview questions and considered their self-rated health assessments. In our sample of 15 women, 12 reported no health problems, one had been diagnosed with multiple sclerosis, one had had a kidney removed due to cancer, and one had been diagnosed with diabetes (of an unknown type). While OOM communities generally do not access social services, they do make use of local doctors and health-care providers and pay the full cost of the service. The women tend to rely on self-health assessments and to seek medical care only when health concerns are serious. While we are not able to provide more information about their health or determine how our status as "outsiders" affected the data, we acknowledge that in-depth discussion of reproductive health

issues that could be related to environmental conditions was not possible owing to discomfort on the part of OOM women (see Kulig et al., 2009). It is worth noting that a community ethic valuing truthfulness in communication may have served to minimize bias in this ethnographic research.

Our findings support the research argument that understandings of environmental contamination are complex. A poor-quality environment may be experienced as either unhealthy or healthy by diverse communities through multidimensional perspectives (Day, 2006; Wakefield & McMullan, 2005). In order to determine the health status of this religious OOM community using a larger sample, further work should consider mixing qualitative and quantitative methodologies in a detailed study with conservative Mennonites in Woolwich Township.

Old Order Mennonite women are able to thrive in their separate place guided by their beliefs, strong community networks, and self-reliance. Our study was concerned with whether a particular understanding of place creates a true barrier to environmental pollution. Among this community, it appears that this is the case, but we note the existence of epistemic differences between participants and researchers. Informing these unaware women about possible environmental hazards could have consequences for the psychological well-being of the population (Pidgeon, Simmons, Sarre, Henwood, & Smith, 2008).

The role of nurses and public health officials is to examine these issues using a scientific approach, to study the health of marginalized communities, and to promote healthy environments for all, including communities that choose to be separate and that present challenges to the notion of environmental health equity.

Conclusions

This study documents the health experiences of Old Order Mennonite women in a rural community and contributes to our knowledge of health challenges faced by these women. Our findings suggest that belief-informed place effects and an attachment to place, combined with strong community identification, play a critical role in shaping the health experiences of OOM women.

People's experiences of place are essential to their well-being but cannot protect them against environmental hazards. This study has identified the need to provide health education programs on environmental hazards to OOM women without compromising their religious beliefs. Effective policies and culturally sensitive nursing practices are essential to protect ethnic minorities from health risks associated with environmental contamination in rural communities.

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Happenings

Rural Head and Neck Cancer Patients: New Clinical Perspectives

Heather Wallace

While continual progress is being made in the development of new cancer therapies, there is considerable evidence indicating that currently available treatments are not accessible to all patients who might benefit from them. In the case of head and neck cancer (HNC), rural patients reveal disparate prevalence, incidence, and mortality (Ragin, Modugno, & Gollin, 2007). We are lacking in evidence-based practice to address the care needs and treatment choices of this rural population. Many health-care policies and programs are based on policies that have been developed for urban populations. Research-based evidence that is specific to the needs of rural patients will help to ensure that care decisions are based on rural beliefs and values.

The Appalachian region of the United States, like many rural and isolated areas in Canada, is characterized by high HNC mortality and prevalence rates, a dearth of resources to prevent HNC, and dire shortages of health-care facilities, especially for the treatment of HNC (Huang, Gal, Valentino, & Wyatt, 2007; Lengerich et al., 2005). Appalachian populations show historically persistent high rates of tobacco and alcohol use, extreme poverty, and gaps in health insurance and coverage (Behringer & Friedell, 2006; Rowles & Johansson, 1993), and they often reflect the health disparities of Aboriginal populations in Canada. Furthermore, epidemiologists have suggested that HNC will increase within the general population as a result of sociocultural changes and increased life expectancy (Marur & Forastiere, 2008).

Emergent Insights and Recommendations for Practice

The health practices of rural residents often reflect their perceptions of health and illness (Bales, Winters, & Lee, 2006). By learning about the rural perceptions of HNC, clinicians may be able to better understand the specific health practices of this client group, which could translate into earlier intervention and more effective treatment outcomes. A recent

qualitative study explored and described the treatment decision-making processes of rural patients in Appalachian Kentucky newly diagnosed with head and neck squamous cell carcinomas (HNSCC).

The study documented the natural history of the HNSCC illness experience and gained rich insights into how, when, and why this specific group of rural patients act with regard to treatment selection and follow-through. Interviews were carried out with 31 rural HNSCC patients at the time of diagnosis and shortly after completion of treatment. The interviews provide rich insight and knowledge about how factors such as socio-economics, multiple health conditions, substance use, geography, culture, behaviour, and perceptions of time contribute to the timeliness and satisfaction of help-seeking and treatment decision-making among rural patients. This approach serves to capture both a range of unexplored and complex grounded perspectives and statistically validated associations. Such efforts are fundamental to improving health outcomes and reducing health disparities by producing formative data with which to develop innovative and culturally acceptable interventions (Green & Kreuter, 1999).

The study gave rise to several themes that are relevant to the care of rural HNSCC patients throughout their illness experience. These were useful in the development of three clinical recommendations.

Recommendation 1

Ensure that clinicians acknowledge the rural context and social dimensions of HNC in their understanding of help-seeking, goal-setting, and treatment decision-making within this population.

Rationale. The timing of and reasons given for help-seeking among rural HNC patients are often influenced by the misidentification of disease symptoms as side effects of tobacco use. Such symptoms include hoarseness, dry mouth, coughing, and mouth sores. A tendency for patients and, often, providers to dismiss such symptoms leads to a delay in help-seeking and diagnosis. Furthermore, rural HNC patients often delay help-seeking until symptoms become obtrusive or negatively affect their daily functioning and/or work responsibilities.

These characteristics are salient to goal-setting and treatment decision-making in that rural HNC patients may perceive the value of treatment options from a functional rather than a curative perspective. For example, a patient may opt for a less aggressive treatment based on the goal of preserving voice function as opposed to prolonging life without voice. In-depth and focused assessment of patients' goals and perspectives throughout the cancer experience allows for less stressful and more satisfying patient decision-making and strengthens the provider's ability to work collaboratively in the overall support of the patient.

Steps to take

- During each clinical consultation, include ongoing discussion of patient perceptions of health and treatment as well as goals.
- Assess clinical HNC symptoms as well as impact on family and occupational roles within the rural setting.
- Provide appropriate screening and health education related to HNC cancer risk among rural tobacco users.

Recommendation 2

Include clinical acknowledgement and acceptance of “doing nothing” as an appropriate treatment option.

Rationale. Many HNC patients expressed a desire to go home and let their cancer “take its course” in a comfortable and familiar environment with family and friends. They felt that the distinctive and considerable social, emotional, physical, and economic consequences of HNC medical treatment would greatly diminish their ability to enjoy an attenuated post-treatment life. Rural patients value the opportunity to die in the comfort of home, in a place (i.e., geographic setting) where they have many attachments and a strong sense of belonging. Patients felt they were unable to discuss “no treatment” with their provider as an appropriate option. Those patients who did discuss it, or simply elected to not engage in medical treatment, reported that they felt unsupported by their physician and less empowered to make personal health decisions. From a clinical perspective, recognizing and acknowledging “doing nothing” as a treatment choice may serve the patient-provider relationship by facilitating communication, rapport, and trust.

Steps to take

- Develop appropriate information for rural patients on all aspects of the array of treatment options available to them.
- Provide ongoing opportunities to discuss perceived treatment outcomes, including the option of no treatment.
- Discuss treatment options and their outcomes with patients in the context of their treatment goals.

Recommendation 3

Develop and implement clinically based addiction cessation and counselling services for rural HNC patients as they move through treatment and into recovery.

Rationale. Services for HNC patients should include a formal means of identifying, addressing, and supporting those who have a concurrent addiction to tobacco, alcohol, and/or other substances. This is particularly important for rural patients, who often lack access to such services. The

dearth of such programs in rural areas undermines clinical management of disease and leaves patients unsupported throughout their therapy. Patients with HNC frequently present with late-stage disease and have a history of tobacco and alcohol use, substance addiction, and mental health problems such as depression, which may negatively impact treatment compliance and efficacy. The development and implementation of clinically based cessation and addiction services would greatly facilitate the management of addiction-related health problems. Furthermore, such clinical programs could provide much-needed counselling and social networks to support patients and their families during recovery.

Steps to take

- Establish rural-based clinical guidelines for assessing substance use as part of the HNC patient consultation.
- Establish rural-based clinical protocols for providing access to substance cessation programs that complement the HNC treatment protocol.
- Establish a means for ongoing mental health counselling, cessation support, and addiction education for post-treatment rural patients.

Moving Forward

Appalachian people and other traditionally underserved rural populations in the United States and Canada represent a more pernicious version of the respective nation's health problems: poor health status, multiple morbidities, and increased cancer incidence and mortality (Lengerich et al., 2004; Wingo et al., 2008). Research should focus on this critical issue in order to improve our understanding of these problems and stimulate prevention and management efforts through innovative interventions. The present study generated information on previously unexplored issues in treatment decision-making and on health management interventions that facilitate the involvement of rural patients while respecting the unique needs of older rural patients and their treatment choices. Hofer, Zemencuk, and Hayward (2004) state the case well:

We need to understand, and in some cases modify, the priorities that providers (and patients) bring to clinical encounters so as to ensure that the most important interventions are not lost amid the blizzard of demands on patients' and providers' time and energy. (p. 646)

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Knowledge Translation

Knowledge Translation With Northern Aboriginal Communities: A Case Study

Cindy Jardine, Chris Furgal

Introduction

In recent years a new lexicon has emerged in the world of research, as terms such as “translating research,” “knowledge translation,” “knowledge exchange,” and “knowledge sharing” have become increasingly part of the language of health research planning and execution. The incorporation of these concepts into research activities represents a major step forward in the development of community/researcher partnerships and in the integration of research evidence into health policy and practice (Bowen & Martens, 2005). This is particularly true for research conducted with Aboriginal communities.

Doing research “the right way” with Aboriginal communities has received considerable attention in recent years. Several documents on conducting research in an ethical and responsible manner now guide researchers and communities embarking on research partnerships (Canadian Institutes of Health Research, 2007; Ermine, Sinclair, & Jeffery, 2004; Inuit Tapiriit Kanatami and Nunavut Research Institute, 2007; Schnarch, 2004). All espouse the need for a participatory research approach that includes reciprocal sharing of knowledge.

However, the practice of knowledge translation and knowledge exchange remains at a formative stage in all arenas, despite the abundant and growing literature in this area. Knowledge translation has been termed an “under-developed element of the research process” (Armstrong, Waters, Roberts, Oliver, & Popay, 2006, p. 384), and much remains to be learned about putting existing and emerging concepts into practice. The gap is particularly notable in participatory research conducted with Canadian Aboriginal communities, where many feel that insufficient attention has been paid to the development of knowledge translation within specific knowledge systems and ways of knowing (Estey, Kmetz, & Reading, 2008; Smylie et al., 2003). While we know

that factors such as a participatory approach and relationship-building are key to successful knowledge exchange with these communities, these are not consistently employed in research activities (usually because of insufficient time and resources).

This article discusses various processes to promote knowledge translation and exchange used in a study conducted with two sets of Aboriginal communities in the Canadian north. We sought to specifically acknowledge and utilize “best practices” for such research, while also acknowledging that every research project is a process of learning and improvement. We thus provide here an assessment of some of our successes and challenges in the hope that our experiences will contribute to knowledge and practice in this area.

Underlying Principles

Our research was guided by the concepts of knowledge translation and knowledge exchange. The Canadian Institutes of Health Research (2009) defines *knowledge translation* as “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge.” The Canadian Health Services Research Foundation (2009) defines *knowledge exchange* as “interaction between decision-makers and researchers [that] results in mutual learning through the process of planning, producing, disseminating and applying existing or new research in decision-making.” In our study, we viewed these two concepts as being the same in intent, and thus we use the terms interchangeably.

An integral component of effective knowledge translation and exchange with Aboriginal communities is acknowledgement of the concept of *ethical space* coined by Poole (1972). Ermine et al. (2004) describe ethical space in an Aboriginal context as the common space between two often disparate knowledge systems, cultures, and world views: “The ethical space . . . requires dialogue about intentions, values, and assumptions of the entities towards the research process. With an agreement to interact, the particulars of cross cultural engagement, along with all the issues of the research process are negotiated towards an amicable research agreement between researchers and Indigenous communities” (p. 20). Acknowledging the need to identify and work within this common space of knowing and understanding is critical if true knowledge sharing is to occur. Although this concept was not explicitly recognized in our initial research planning and implementation, it does aptly describe the process and principles that guided our knowledge translation and exchange activities.

A key underlying paradigm for knowledge translation and exchange in the study was the use of a participatory research approach. Participatory research is a general term for research approaches that “share a core philosophy of inclusivity and of recognizing the value of engaging in the research process (rather than including only as subjects of the research) those who are intended to be the beneficiaries, users, and stakeholders of the research” (Cargo & Mercer, 2008, p. 326). A major strength of this type of research is its inherent inclusion of knowledge translation through the integration of researchers’ theoretical and methodological expertise with non-academic participants’ real-world knowledge and experiences.

The Study

The purpose of the study was to develop new insights into the communication and understanding of various types of health risks with two sets of Aboriginal communities in northern Canada: the Dene communities of N’Dilo and Dettah in the Northwest Territories and the Inuit communities of Nain and Hopedale in the Labrador Inuit Settlement Area of Nunatsiavut, Newfoundland and Labrador. The 3-year study was conducted as a partnership between researchers at the University of Alberta and Université Laval and community members in the four locations.

Both sets of communities are relatively small (with 2006 populations of 330 in N’Dilo, 247 in Dettah, 1,034 in Nain, and 530 in Hopedale) but vary in remoteness. The communities of N’Dilo and Dettah are part of the Yellowknives Dene First Nation. While N’Dilo falls within the municipal bounds of Yellowknife (capital of the Northwest Territories), Dettah is a 6.5-kilometre drive from Yellowknife by ice road in winter or a 27-kilometre drive on an all-season road. The proximity of both communities to Yellowknife means that their residents are exposed to a greater urban influence than residents of more remote Dene communities in the Northwest Territories. This results in unique sociocultural influences that may affect knowledge, perspectives, and behaviours related to health risks and traditional activities. The Inuit communities of Nain and Hopedale are more isolated, “fly-in, fly-out” communities, accessible by boat in summer and otherwise only by air. Smaller, more isolated communities such as these require more comprehensive and engaged forms of knowledge transfer.

The study was conducted in two phases. The first consisted of a questionnaire administered by local community field workers/researchers as a structured interview. When appropriate, the interview was conducted in the local language (Dogrib in the Northwest Territories and Inuktitut in Nunatsiavut). The questions covered a broad range of community con-

cerns and public perspectives on various types of health risks (for example, lifestyle behaviours such as smoking and drinking, physical risks entailed in the pursuit of traditional activities, and risks associated with exposure to environmental contaminants).

The second phase used a qualitative research method called PhotoVoice. PhotoVoice is a participatory action research method whereby individuals are invited to take photographs on a specific subject, discuss them individually and/or collectively, and use them to create opportunities for personal and/or community change. This method has been found to be particularly effective for use with participants who relate better to visual images than to written materials, such as many Aboriginal individuals (Wang & Burris, 1997). Participants were asked to take pictures in their environment of situations they felt posed a risk to themselves, their family, and/or their community. They were then asked to discuss the pictures in an informal interview.

Knowledge Translation and Exchange

Five components were seen as fundamental to the knowledge translation and exchange process for this study: (1) establishing partnerships and trust with the communities; (2) using trained community field workers/researchers for all stages of research planning, data collection, analysis, interpretation, and dissemination; (3) holding regular workshops for all members of the research team; (4) making a commitment to return the research results to the participants and communities first, for verification and validation; and (5) translating the research results for government decision-makers so that they might be used to inform policy and practice.

Partnerships

Both formal and informal partnerships were established in N'Dilo and Dettah. Meetings were held with the Chiefs and Band Council members to outline the research. In addition, considerable time was invested in building relationships between the researchers and team members in the community to develop trust through a shared understanding of intentions, motivations, and interests. In Nain and Hopedale, these relationships had already been established through prior joint research initiatives.

Community Field Workers

In N'Dilo and Dettah, field workers were recruited and given several weeks of training in basic research and practical skills (such as transcribing). Existing, trained researchers from Nain were available. Additional youth assistant trainees from Nain and Hopedale were recruited and included in training and research activities.

Workshops

Three workshops involving all of the project team members from the two universities and the four communities were held at critical junctures in the research process to collectively make decisions on key aspects of the research. These workshops played a central role in knowledge sharing and exchange, particularly in giving team members an opportunity to get to know and understand one other.

Return of Results to Participants and Communities

In N'Dilo and Dettah, results were returned to the community in three sessions using different mechanisms. A summary report of the questionnaire results was prepared for return to participants and community members. A compilation of the PhotoVoice results was prepared in report form for return to participants and Band Council members. Posters of this information were used to return the results to other community members. Participants had been promised that they would be the first to see the results. Accordingly, a luncheon of caribou stew and bannock was held specifically for participants. The community field worker personally invited the participants to this event. Approximately 25 people attended. Results were presented to the joint N'Dilo/Dettah Band Council meeting the same evening, with time allotted for questions. A final presentation was made to the general community at a "tea and bannock" get-together. Flyers were distributed to all homes in N'Dilo and Dettah publicizing this event. Approximately 20 people attended. At both participant and community events, the sharing of local food was considered important to the facilitation of knowledge exchange.

In Nain and Hopedale, a variety of mechanisms were also used to return results to the participants and the community. On the recommendation of the community researchers and the regional Inuit government, an open house was held in Nain to present general results from the survey and PhotoVoice phases of the study to participants and other interested individuals. Attendees were provided visual (photo images), summary (posters), and synthesis (fact sheets) information on the study and its basic results. Additionally, the regional television and radio station, the OKâlakatiget Society, video interviewed the researchers and recorded events at the open house for regional broadcast. The Nunatsiavut Government Environment Division newsletter published the summary results of the study in an edition circulated to all Nunatsiavut coastal communities. A planned open house in Hopedale had to be cancelled due to poor weather but the information was disseminated to the community via the local office of the regional Inuit government using the prepared materials.

Presentation of Results to Government Decision-Makers

The results were formally presented to the First Nations and Inuit Health Branch of Health Canada in Ottawa. In attendance were policy-makers from Health Canada, Indian and Northern Affairs Canada, and the national Inuit organizations. While those present found the survey results interesting, they appeared to be more engaged by the photos and accompanying words generated during the PhotoVoice phase of the study. The presentation prompted many questions and subsequent e-mail discussions of the results and their potential policy ramifications.

Discussion

What did we learn from this extended process of research and knowledge exchange? First and foremost, we reinforced our conviction that it is essential to spend time developing relationships and trust among all research partners. This instils confidence in the researchers and in the project. It also addresses suspicions — fostered by previous, inappropriately conducted, research activities in the north — about the research agenda and the efficacy of the results. Regular face-to-face, interpersonal contact is vital to establishing this trust relationship (Bowen & Martens, 2005).

The use of community-based field workers/researchers was crucial to the success of the project. The local knowledge of these team members was critical to ensuring that the right questions were asked in the right way. Participants were far more comfortable talking to people they knew and trusted. The use of local field workers/researchers also ensured that the research was conducted in the language most comfortable for the participant. Knowledge exchange was greatly enhanced through these processes, compared to more traditional researcher-conducted interviews. Furthermore, the training of local researchers served to build research capacity within the community, which is considered an important component of knowledge translation (Bowen & Martens, 2005).

Involving all members of the research team in workshops throughout the study enabled a true two-way exchange of knowledge and a mutual learning environment, as everyone strived to acknowledge the “ethical space” between two knowledge systems and world views. On several occasions the pitfalls of failing to acknowledge this “space” became evident. For example, the university researchers initially interpreted addictive risk behaviours as constituting a “voluntary risk,” in keeping with the conventional literature on factors influencing different risk perspectives and behaviours (Slovic, 1987). However, community research partners pointed out that this was an erroneous interpretation for their communities, where addictive behaviours have ceased to be “voluntary”

for many people. This reinterpretation greatly influenced the meaning attached to the results and the implications for health policy and practice.

The PhotoVoice technique was an effective means of knowledge exchange for all parties. For the researchers, it was a way of exploring risks unbiased by their preconceived ideas about the major issues for these communities. For the community, the PhotoVoice process served as a mirror of risk situations in the community, as risks that were known but had become so commonplace that they were no longer “seen” took on new meaning. For the decision-makers, the issues experienced by the communities were made much more “real” through the use of pictures and words than if they had been described only in numbers and graphs.

There were also some challenges in the knowledge translation process. Efforts to return the results to the communities and decision-makers were less successful than expected. The community presentations were poorly attended overall, and not all decision-makers accepted the invitation to participate in the research process by attending the final team workshop. Nonetheless, it was recognized that providing an opportunity for participants to learn about the study and the results is often the most important aspect of knowledge translation. Several community members and decision-makers expressed regret at being unable to attend the formal presentation of results and acknowledged the value of the written materials. This illustrates the need for knowledge translation to take many forms so as to accommodate multiple needs.

Finally, it is difficult to measure the changes resulting from this study. The project did spur further, community-generated, studies in N'Dilo and Dettah. For instance, results showing a high prevalence of smoking and smoking adoption at a very young age led to a partnership research program on tobacco use among young people. However, while it is suspected that the research process and the results have led to many other changes (at the individual, community, and policy level), it is difficult to determine the direct impact of the knowledge generated.

In summary, knowledge translation is an evolving process within participatory research programs with Aboriginal communities. Sharing our experiences (both successes and challenges) will further our collective quest for continued learning and improvement.

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Studies such as this would not be possible without the participation of the members of the communities, and we are grateful to them for sharing their time and knowledge.

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Book Review

Rural Nursing: Aspects of Practice

Edited by Jean Ross

Dunedin, New Zealand: Rural Health Opportunities, 2008, 258 pp.

ISBN 978-0-473-13351-1

Reviewed by Mary Ellen Andrews

I was honoured to be asked to review this book by Jean Ross, who is an exceptionally well regarded supporter of rural nursing education and practice in New Zealand. The publication of this work is an example of her ongoing commitment to dissemination of knowledge about rural nursing. She has been a teacher, mentor, and colleague to many of the book's contributors, and is one of a small number of authors who endeavour to share the advancement of locally discovered rural nursing knowledge internationally.

Rural Nursing: Aspects of Practice is a collection of scholarly papers based on research conducted by master's of nursing students in New Zealand. It takes a novel approach to the dissemination of knowledge produced in graduate nursing programs and does so in a manner that is accessible, in language and content, to both practitioners and scholars. The primary theme throughout the collection is the *context of rural nursing practice*. I think most researchers would agree with Ross's assertion that rural nursing is shaped by the context of practice and that the context of practice consists of a set of diverse, interrelated elements: the people and culture, the health-care agency and nursing roles, and the geography and economy of the community.

The challenges entailed in defining the context of rural nursing practice include the debate on how to define "rural" and the economics of health-system disparities between rural and urban. The book aptly begins by discussing these issues. However, in contrast to some of the current perspectives on how to define rural, the view expressed in this book is that a consensus definition is not possible. The authors suggest that the diversity of rural settings would be negated by a generic definition and that distinguishing between rural and urban would hinder the development of collaboration for the purpose of achieving comparable health services.

Three subject areas addressed in *Rural Nursing* make it an important book for nurse researchers, health-care administrators, and nurse practitioners who focus on rural nursing practice. The first is the well-

developed presentation of a contextual framework for rural nursing practice: the Rural Framework Wheel. The value of this framework is its system approach of categorizing concepts by describing the context of rural nursing practice from ecological, health, occupational, and socio-cultural perspectives. The model integrates salient issues reported in the international rural nursing literature, such as recruitment and retention, personal and professional boundaries in nursing practice, and the need for nurses to grasp the importance of collaboration for the successful delivery of community-focused rural primary care.

Second, the book will be of interest to scholars, as it presents studies that employ a wide variety of research methods. Of interest to me was the use of storytelling as a means of reflective critical analysis of rural nursing practice. Although we often use interview methods that allow rural nurses to tell their story about rural nursing issues, the interview format does not permit in-depth critical reflection on all aspects of practice. The two chapters on storytelling as a method for sharing practice knowledge illustrate how this type of analysis can facilitate the exploration of concepts in rural nursing practice and lead to additional research questions.

Lastly, the book enhances our understanding of rural nursing practice, adding to the dialogue on rural nursing and rural health services. This collection of papers does not merely explore the dissimilarities and similarities in rural and urban nursing practice. It illustrates the potential for new and compelling nursing research, describing exciting advancements in rural nursing practice and health-care delivery and fostering a new appreciation for rural innovation. The studies described here offer a unique perspective on collaboration between researchers and practitioners through the development of programs that increase access to traditionally urban-based services within rural communities. The innovations presented include evaluation and implementation research on a mobile surgical unit, a resuscitation-education program, and a rural-based triage telephone information line that sits in contrast to the standard urban-based health information lines used for rural communities.

The book concludes with three chapters that look at the future of rural nursing practice. These chapters describe the challenges that lie ahead for the development of the rural nurse practitioner role, interdisciplinary practice models, and collaborative practice arrangements. Although the authors are writing in the context of nursing practice in New Zealand, similarities can be drawn between the challenges presented and those facing us in Canada. For example, similar to the situation in New Zealand, Canadian NP education programs and practice roles in health care are at different developmental stages across the country. These final chapters also discuss the concept of career pathways for rural nurses,

the limited diversity of career paths from a rural perspective, and the need for continuing education in the field of rural nursing.

There are few textbooks that document the practice of rural nursing and address the diversity of practice innovations in rural settings. This collection edited by Jean Ross makes a valuable contribution to rural nursing knowledge and theory development. It also highlights the breadth and depth of rural nursing research produced in New Zealand.

In reviewing the book I became optimistic about the rich store of rural nursing knowledge yet to be discovered and the great potential for innovation in rural health services. It has always been my view that the many innovative programs developed in rural Canada have not received their due in our rural nursing literature. Maybe the time has come for Canadian rural nursing researchers to publish a text with a focus on our own Canadian context and to share our knowledge about and innovations in rural nursing practice and health services.

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L'attirance qu'éprouvent les hommes atteints de schizophrénie pour le cannabis : une étude phénoménologique

Nathalie Francoeur, Cynthia Baker

L'utilisation du cannabis est une pratique courante chez les personnes souffrant de schizophrénie, notamment chez les hommes qui en sont chroniquement atteints. Une étude phénoménologique a été menée avec pour objectif de décrire les perceptions des personnes souffrant de schizophrénie quant à l'attirance qu'elles éprouvent pour le cannabis. Des professionnels de la santé ont recruté un échantillonnage de huit hommes schizophrènes qui vivaient au sein de la collectivité et qui avaient déjà consommé du cannabis ou qui en consommaient au moment de la recherche. Des données ont été recueillies au moyen d'entrevues approfondies et d'un questionnaire sociodémographique. Les auteurs ont appliqué la méthode phénoménologique de Colaizzi pour analyser les données découlant des entrevues. Les résultats indiquent que le cannabis est consommé pour satisfaire des besoins relatifs à la schizophrénie, notamment un besoin de détente, d'estime de soi et de divertissement, et peuvent informer la pratique du personnel infirmier œuvrant auprès de personnes atteintes de schizophrénie, une population souvent stigmatisée et ignorée.

Mots clés : schizophrénie, cannabis

Attraction to Cannabis Among Men With Schizophrenia: A Phenomenological Study

Nathalie Francoeur, Cynthia Baker

Cannabis use is common among persons with schizophrenia, particularly among men with this long-term chronic illness. A phenomenological study was undertaken to describe the perceptions of persons with schizophrenia regarding their attraction to cannabis. A sample of 8 men with schizophrenia who were living in the community and who had a history of current or past cannabis use were recruited by health professionals. Data were collected through in-depth interviewing and a sociodemographic questionnaire. Colaizzi's phenomenological method was used to analyze the interview data. The findings indicate that cannabis is used as a means of satisfying the schizophrenia-related need for relaxation, sense of self-worth, and distraction. The findings may be useful for nurses working with persons who have schizophrenia, a population that is frequently stigmatized and unheard.

Keywords: schizophrenia, cannabis, substance use, phenomenology, self-medication

Schizophrenia is a difficult, long-term mental illness with an average prevalence in North America of approximately 4.5 per 1,000 persons (Tandon, Keshavan, & Nasrallah, 2008). Its symptoms tend to appear during adolescence or early adulthood, although they may develop later in life. Negative symptoms of schizophrenia represent absence of behaviours normally present and include flat affect, lack of motivation, and apathy. In contrast, positive symptoms are behaviours normally absent such as hallucinations and delusions (Varcarolis, Carson, & Shoemaker, 2006). Although medications contribute to symptom improvement, there is currently no cure for this illness.

Substance use is widespread among persons with schizophrenia and has multiple adverse health effects (Green, Noordsy, Brunette, & O'Keefe, 2008). Although cigarette smoking is the most prevalent, an extensive literature links consumption of cannabis with schizophrenia, particularly among men (De Lisi, 2008). Many studies report that cannabis is the second most commonly used substance by males with chronic schizophrenia (Cantwell, 2003). Among persons with schizophrenia, cannabis use has been associated with an increase in the intensity of psychotic symptoms and deterioration in the illness course (Addington & Duchak,

1997). Thus cannabis use represents a problem for the individual's prognosis and for the health-care system.

Although many researchers have investigated the link between cannabis use and schizophrenia, the findings have been contradictory and inconclusive. Furthermore, little attention has been paid to the perceptions of individuals with schizophrenia about what draws them to this substance. A phenomenological study was therefore conducted to explore the attraction to cannabis among persons with schizophrenia who have lived this experience. The study was guided by the following research question: *How do men with schizophrenia who use or have used cannabis perceive their attraction to it?*

Literature Review

Research findings indicate that there is a high prevalence of substance use among persons with schizophrenia (Harrison et al., 2008; Kavanagh, McGrath, Saunders, Dore, & Clark, 2002). A large epidemiological study conducted in the United States estimated the risk of a diagnosis of substance abuse to be 4.6 times greater among persons with schizophrenia than among the general population, and the risk of illicit drug use to be 6 times greater (Regier et al., 1990). While nicotine is the substance used by the largest number among this population (DeLeon & Diaz, 2005), cannabis comes in second (de Beaurepaire et al., 2007; DeQuardo, Carpenter, & Tandon, 1994; Harrison et al., 2008). Cross-sectional, national surveys conducted in Australia, the Netherlands, and the United States indicate that cannabis consumption is approximately twice as high among persons with schizophrenia as in the general population (Arseneault, Cannon, Witton, & Murray, 2004). Gender differences, however, have been reported, with males significantly more likely to use cannabis than females (DeLisi, 2008). Males also appear to be at greater risk for developing a schizophrenia spectrum disorder following a cannabis-induced psychosis (Arendt, Rosenberg, Foldager, Perto, & Munk-Jorgensen, 2005).

There is considerable debate about whether the link between cannabis use and schizophrenia exists because cannabis consumption precipitates the onset of the disease, whether actual or incipient schizophrenia precipitates the consumption of cannabis, or whether both cannabis consumption and onset of schizophrenia are precipitated by other factors (Kalant, 2004). Khantzian (1985) proposes that persons with schizophrenia consume substances to auto-regulate negative symptoms, which suggests that schizophrenia leads to substance use. No difference, however, was found in anhedonia, anxiety, and depression, as

measured by the Positive and Negative Syndrome Scale (PANSS) (Kay, Opler, & Lindenmayer, 1989), between a group of individuals with schizophrenia who had abused substances for a long period and a group who had not (Dervaux et al., 2001). Moreover, a review of five population-based prospective studies found that, among persons with schizophrenia who consumed cannabis, use of this drug had preceded the manifestation of symptoms (Smit, Bolier, & Cuijpers, 2004). Similarly, Arseneault et al. (2004) analyzed existing studies and concluded that cannabis doubles the relative risk for later schizophrenia. However, research has found significant increases in the incidence of cannabis consumption in the general population over the last four decades without a corresponding increase in the incidence of schizophrenia (Hickman, Vickerman, Macleod, Kirkbride, & Jones 2007). Degenhardt, Hall, and Lynskey (2003) tested the hypothesis that increased cannabis use in Australia would increase the incidence of schizophrenia. They compared eight cohorts born between 1940 and 1979. They concluded that cannabis use is not causally related to the manifestation of the disease.

The dysphoria model provides an explanation that is similar to but more general than Khantzian's (1985) theory. It postulates that individuals with a severe mental illness are predisposed to dysphoria and that their efforts to reduce this symptom lead them to the initial substance use (Mueser, Drake, & Wallach, 1998). Zimmet, Strous, Burgess, Kohnstamm, and Green (2000) report a strong correlation between a reduction in substance abuse and a reduction in clinical symptoms when study participants shifted to treatment with clozapine, which, unlike typical antipsychotics, acts on both negative and positive symptoms. The reasons identified for both cannabis use and alcohol use include relaxation, reduced depression, and sociability (Addington & Duchak, 1997).

Many negative effects of cannabis on this population have been reported, including an increase in positive symptoms (Addington & Duchak, 1997), poor compliance with pharmacotherapy, and a greater number of relapses (Gupta, Hendricks, Kenkel, Bahtia, & Haffke, 1996). Cannabis use has also been linked to homelessness among persons with schizophrenia (Caton et al., 1994) and with violent behaviour (Swartz et al., 1998). Economically, research has found that the cost of psychiatric care is higher for those persons with schizophrenia who consume street drugs (Bartels et al., 1993).

In summary, although explanatory models have been developed, the underlying reasons for a tendency among persons with schizophrenia to use cannabis are unclear. A better understanding of the lived experience of their attraction to this drug would be helpful in guiding nurses when caring for persons who live with this chronic illness.

Methodology

Colaizzi's (1978) phenomenological method of analysis was selected for the study. This approach was chosen because it allows for the description of a given phenomenon through a thematic analysis of the perceptions of those who have experienced it. Unlike other phenomenological approaches, Colaizzi's method includes participant validation of the description of the lived experience following the analysis, which enhances the rigour of the research and the credibility of the findings.

Sample

Typically, the sample size for a phenomenological study is a maximum of 10 persons who have lived the experience being investigated (Loiselle, Profetto-McGrath, Polit, & Beck, 2004). Because the aim was to provide a meaningful description of the experiences of a population who have engaged in an illegal behaviour and who tend to have difficulty with social interaction, a small purposive sample of eight persons was recruited. Inclusion criteria were: (1) diagnosed with schizophrenia according to the DSM-IV-TR (American Psychiatric Association, 2003); (2) history of current or past cannabis use according to the medical record; (3) ability to speak either English or French (the investigator was bilingual and able to analyze data in both languages); (4) being followed by a mental health clinic in the Canadian province of New Brunswick or by Addiction Services in Campbellton, New Brunswick; (5) stable condition and not hospitalized at the time of the study. According to Chabannes et al. (1998), a person with schizophrenia is stable when the therapeutic regimen is being followed and positive symptoms have subsided. To ensure that participants met the criteria of stability, before beginning data collection the investigator evaluated negative and positive symptoms using the PANSS (Kay et al., 1989). Individuals with a diagnosis of alcoholism or concomitant use of other substances (other than nicotine) were excluded.

Recruitment

Health professionals at New Brunswick's Mental Health Services and at Addiction Services in Campbellton recruited participants using a recruitment guide and provided them with a "letter of interest." The letter described the study and the nature of the participation being sought. It specified that a person's decision whether or not to participate would have no influence on his or her treatment, follow-up, or care. Those willing to be contacted by the investigator signed a form to this effect and returned it to the health professional, who then gave it to the researcher. Eleven persons indicated a willingness to be contacted by the investigator. However, when they were called by the investigator and

invited to participate, three refused; the reasons for their refusal are unknown. None of the participants was compensated for taking part in the study.

Data Collection

Prior to data collection, a meeting was held with each participant to test his stability using the PANSS. This instrument measures positive and negative symptoms and also generates a global assessment score. Although each health professional who referred a potential participant confirmed that the person was stable, an evaluation using the PANSS provided an objective measure. This psychometrical tool was developed to assess the syndrome of schizophrenia and to ensure that clinicians are consistent in their clinical evaluation. Results determined that all eight participants were stable. A sociodemographic questionnaire was administered at this meeting, following the assessment, and arrangements were made for a second meeting.

An in-depth interview was conducted at the second meeting. The interview was conducted in the participant's first language and lasted between 45 and 120 minutes. The interview guide consisted of eight open-ended questions about one's attraction to cannabis. For example, the participant was asked: *Why are you attracted to cannabis? What effects are you seeking when you use cannabis?* The wording and the order of the questions were flexible in order to allow the participant to respond spontaneously. The participant was encouraged to speak freely about his experiences. Six of the interviews were conducted in the investigator's office in a psychiatric hospital, one was conducted in a supervised residence (in the participant's room), and one was conducted in an outpatient clinic. Seven interviews were audiorecorded with the participants' consent; one participant consented to note-taking only. The interviews were transcribed verbatim.

Data Analysis

The steps in the Colaizzi (1978) method were followed. First, the transcription was read and then reread while the audiorecording of the interview was played. At this stage, the investigator avoided reflection on the information in order to grasp the participants' perspectives. A total of 378 statements related to the phenomenon were extracted and the meaning of each was identified. The meanings were aggregated into a cluster of first 23 and then 18 thematic categories, and finally into three themes with seven subthemes. Three participants were asked to validate the themes and subthemes. They were easily able to relate their experiences to each theme and subtheme but were perplexed by the placement of one subtheme, *increasing concentration*, under *self-esteem*. They saw *increas-*

ing concentration as linked to the theme of *seeking relaxation*. The essential structure of the phenomenon was modified based on this feedback (see Table 1).

Rigour

Lincoln and Guba (1985) propose that credibility, transferability, dependability, and confirmability be used as criteria for trustworthiness in qualitative research. Credibility concerns the value of the findings. To ensure credibility, the investigator asked the participants to validate the analysis and then integrated their comments into the final analysis. The investigator kept a reflexive journal in which preconceived ideas were identified before data collection was begun, and self-reflections were recorded in an effort to keep preconceived ideas from influencing the analysis. Transferability concerns the applicability of the findings to other contexts, while dependability concerns the degree to which another investigator would see the fit between the data and the thematic analysis. With respect to both criteria, characteristics of the participants, sampling, and analysis are described in detail and participants' statements are used to illustrate themes and subthemes. An audit trail was maintained to foster confirmability. All activities related to the project were recorded in the journal, as were impressions, concerns, and uncertainties.

Ethical Considerations

Persons with mental illness are a vulnerable population and ethical principles must be rigorously respected (Duval, 2004). The study was approved by the Ethics Committee of the Université de Moncton and the Ethics Committee of the Restigouche Health Authority in Campbellton. All recruits had signed a form indicating their willingness to be contacted. Health professionals were identified who could provide support to participants if necessary. All participants signed a clear and detailed consent form and were informed about their rights, the risks of participation, the nature of the study, and the nature of their participation in the study. Anonymity and confidentiality were strictly maintained at all times.

Findings

The analysis allowed for the uncovering of the essential structure of the phenomenon through three desired outcomes of cannabis use: relaxation, sense of self-worth, and distraction (see Table 1). Before each theme is described, characteristics of participants will be presented and their insight about their cannabis consumption discussed.

Table 1 *Themes and Subthemes Related to Cannabis Use Among Men With Schizophrenia*

Themes	Subthemes
In search of relaxation	Offers a break from the illness Offers a moment of relaxation Increases concentration
In search of a sense of self-worth	Improves sense of belonging Improves contact with others
In search of distraction	Passes the time Offers sensory experiences

Description of Sample

All participants were single men. Their average age was 31 and their ages ranged from 22 to 42. None of the men had children. One man had a girlfriend. Two spoke French only, two spoke English only, and four spoke both French and English. One had a baccalaureate degree in psychology, three others had completed high school, and four had not completed high school. Three were working part-time (in a bakery, in a sawmill, and cutting grass). The other five were not employed at the time of the interview but had previously worked part time. Two of the men lived in a supervised residence, four lived with their parents, and two lived alone in an apartment. All were receiving social assistance. Five resided in small towns (population: 1,500 to 10,000) and three in villages (population: under 1,500).

Six participants had been diagnosed with schizophrenia between the ages of 17 and 22, one at 34, and one at 37. One participant had never been hospitalized for schizophrenia and another had been hospitalized only once. Five had been hospitalized between five and ten times and one had been hospitalized more than ten times. All were being treated with atypical antipsychotic medications and two were also taking a typical antipsychotic. Three were also being treated with antidepressants and three with an anxiolytic.

The participants had smoked cannabis for at least 10 years. Seven began using cannabis between the ages of 11 and 15, while one did not begin until he was 18. For most, the last instance of cannabis use ranged from the day of the interview to 2 months earlier. However, two participants had stopped using cannabis several years earlier, one as part of a strategy to give up smoking cigarettes and the other to avoid becoming like his father, whom he described as a drug addict. Five participants also smoked cigarettes (see Table 2).

Table 2 Characteristics of Participants	
Characteristics	Number
Age	
22–24	3
25–29	2
35–42	3
First language	
English	2
French	6
Residence	
Supervised	2
Parental home	4
Apartment alone	2
Employment	
Not employed	5
Employed part time	3
Age at diagnosis	
17–22	6
34	1
37	1
Number of hospitalizations	
0	1
1	1
5–10	5
10+	1
Age at which cannabis use began	
11–12	3
14–15	4
18	1

Awareness of Cannabis Consumption

Cannabis consumption clearly was an activity that the participants were aware of and that reflected intentionality. For example, one participant noted: “I didn’t want my parents to know I smoked, because I was sick and I was afraid they’d think I would be doing harm to myself, so I was

hiding it from them.” All participants mentioned also trying other substances, such as LSD, alcohol, or cocaine, but indicated that their preference was cannabis: “I was more into pot”; “I’d choose marijuana over alcohol if I had the choice”; “I’d rather smoke pot than drink.”

Lived Experience of Attraction to Cannabis

The participants had experienced unmet needs with respect to relaxation, self-esteem, and distraction. They sought a means to help them satisfy these needs, and cannabis use was the result. Each theme and subtheme related to this will be described.

In Search of Relaxation

Having schizophrenia and living with its symptoms appears to have created an illness-related need for relaxation: “I was going through all kinds of thoughts and feelings all alone . . . it was hell!” The men made it clear that cannabis use provided this relaxation by offering them a break from their illness, offering them a moment of relaxation, and enhancing their concentration.

Offers a break from the illness. Participants described the effects of schizophrenia on themselves and on their lives as chronic and as offering them rare moments of respite. They noted that it affected their thinking (“It seems I can’t get any smarter than I am; it seems that there’s a limit to how smart I can be”); their social life (“it affected my social life, big time . . . my social life was bad — bad for everybody, even my parents”); and their personhood (“I lost myself, to the point where I wasn’t me; I was, like, dead”). One participant summed up the impact bluntly: “I thought, if I go to hell . . . it [will] be a better place than this.”

They sought a tool that would give them some respite from their illness, and cannabis seemed to offer such respite. One participant explained that cannabis helped him to detach himself from social pressures by allowing him to escape and go elsewhere. Another described how the drug provided him with an escape from the symptoms of schizophrenia and its effects on his life: “It’s really, like, vast — the life that you can have smoking dope, and that’s why people are so much on dope.” One participant described his experience of respite from the illness, noting that he continued to hear voices when smoking marijuana but that the voices sang.

Offers a moment of relaxation. Participants experienced the momentary feelings of relaxation derived from cannabis in different ways. For several, cannabis had a relaxing effect at the level of their thinking: “It relaxes the mind in some way.” For others, the outcome was more general: “It kind of just mellows out the body”; “I can relax more when I do it — like, after I eat or something . . . I have a smoke and I go lie

down and it helps me relax.” For some, the relaxation was derived from laughter. One participant described the laughter associated with cannabis use: “I took it not too long ago . . . It was like I was watching Bart Simpson, and me and my friends, we laughed and we laughed and we laughed and we laughed.”

Increases concentration. Participants noted that their schizophrenia made concentration difficult. They linked this to difficulty relaxing. One man stated that his thoughts had a tendency to wander, which he found tiresome. Participants explained that cannabis helped them to maintain their interest in something and that this let them relax because their ideas were not all over the place: “When you’re not concentrated, you’re changing the channel every 3 to 4 minutes to see what else is on [and cannabis helps you to get concentrated]”; “[Cannabis] keeps me more alert”; “Without the marijuana, with my schizophrenia I can’t get involved in a movie because I lose track of things in the middle of it; if I smoke marijuana and I watch a movie, I’ll be interested for the whole movie”; “If I want to, say, watch a movie and I don’t want to be interrupted, I smoke it, and it keeps my mind on the movie — I’m not thinking about this, I’m not thinking about that, I’m thinking about the movie or what’s coming up.”

In Search of Self-Worth

Participants had not escaped the slings and arrows of prejudice, stigma, social barriers, and hurtful comments. For instance, one man recounted his extreme disappointment at being rejected by the armed forces after revealing that he had schizophrenia: “‘We can’t provide the pills on the battlefield; you can’t come’ — so I was pretty, like, crushed.” They sought ways of increasing their sense of self-worth and described cannabis use as affirming because it improved their sense of belonging and their contact with others.

Improves sense of belonging. Participants explained that cannabis use made them feel appreciated and accepted: “You’re considered a cool person.” One man said that cannabis made him talk and those around him liked what he was saying and didn’t want him to stop, which made him feel part of a group. Another said, “I hung around and stuck with the potheads because I liked them and they liked me.” Similarly, another participant noted that he was “comfortable with that group [users of cannabis] . . . we were all on the same wavelength.” Another man stated, “The advantage that I was looking for was, like, just to blend in, really.”

Improves contact with others. For participants, quality relationships were limited, not by choice but because the disorder intruded on this aspect of their lives. It affected their social abilities and made communi-

cation problematic, further diminishing their self-esteem. According to participants, cannabis use helped them to bridge the gap between them and others. One man described cannabis as eliminating his shyness and giving him the ability to express his thoughts without fear. Another remarked that it made him much more tolerant of others, as he was able to tell himself, "It wasn't as bad as all that." One participant described this aspect of cannabis use in an interesting way: "I was comfortable talking to each one of them . . . I have an analytic mind, so I used to analyze a lot and go into depth and philosophize or whatever . . . I really enjoyed the conversations when I was stoned."

In Search of Distraction

Participants believed that once adulthood begins, schizophrenia affects various aspects of a person's life. Their days often seemed interminable, filled with monotony and illness. One man said he did little with his days except walk to the post office, watch television, and "stare at the ceiling." Cannabis brought some diversion to their long, tedious days. It passed the time and provided some sensory experiences.

Passes the time. Cannabis use helped to make the time go by. It required no particular skill and was something the men found easy to learn. One participant explained that "the time, since I got sick with schizophrenia, it seems to last forever, stretches on forever, and . . . smoking marijuana . . . the time passes so much faster." Another agreed: "It passed the time. It made the time more interesting. That's what really attracted me to pot." One participant noted that, in the absence of activities or regular work, a person has a need for distraction: "Well, in a way I'd like to stop, but it's the only thing I do. Do you know what I mean? I don't get out . . . If I [did] or if I [was] working steadily or something like that, it would be different."

Offers sensory experiences. The other distraction offered by cannabis was that it provided certain sensory experiences that the men seemed to both enjoy and desire. The participants mentioned, for instance, that it made music better, more interesting, and a diversion. Cannabis use enhanced their day and their sense of hearing: "I love music and I can get interested in music more." Cannabis use also opened the doors to their "imagination" and "creativity." It provided one man with an opportunity to express himself through drawing because of its effect on his sense of touch and its visual effects. Others noted that their surroundings were pleasantly altered when they smoked marijuana: "I'd have different feelings [about] my surroundings — like, looking at the snow on the ground, it was, like, I don't know, it made me appreciate everything, in a different way that I like."

In summary, individuals with schizophrenia who are attracted to cannabis appear to be seeking three outcomes when using this substance: relaxation, improved sense of self-worth, and distraction from the monotony that the illness imposes on one's life. The participants found that cannabis had a relaxing effect on them. It also offered a break from schizophrenia and helped them to concentrate on enjoyable activities. They believed that it enhanced their sense of self-worth, their sense of belonging, and their ability to connect with others. They perceived cannabis to be a means of breaking the tedium they experienced, because it helped to pass the time and provided sensory experiences that they found diversionary and enjoyable.

Discussion

There are some similarities and differences with respect to the findings of this study and those reported in the literature. Findings that support those of previous studies include participants' use of cannabis to enjoy a moment of relaxation (Addington & Duchak, 1997), improve their relationships (Alverson, Alverson, & Drake, 2000; Spencer, Castle, & Michie, 2002), and pass the time (Addington & Duchak, 1997; Salyers & Mueser, 2001).

Differences include some components of the nature of the relaxation and the distraction participants derived from using cannabis, and also the effects of cannabis use on the course of their illness. For participants, cannabis provided relaxation in part because it offered a break from the effects of a difficult illness. This benefit has not previously been identified as a reason for using cannabis. Participants also reported that cannabis helped them to stay interested in and attentive to the present moment because it improved their concentration, which they described as poor as a result of the illness. Improved concentration from cannabis use has not been identified in other studies among persons with schizophrenia. Furthermore, cannabis is not a central nervous system stimulant and its effects are primarily associated with feelings of well-being and euphoria and with altered sensory perception (Laqueille, Benyamina, Kanit, & Dervaux, 2003; Ministère des Travaux publics et Services gouvernementaux, 2000).

A component of the distraction actively sought by participants through cannabis use was the sensorial experiences induced by the substance, which temporarily alleviated the monotony of their lives. This has not been identified in previous research as a reason for cannabis use among persons with schizophrenia, although it has been found to be a reason for cannabis use in the general population (Laqueille et al., 2003; Ministère des Travaux publics et Services gouvernementaux, 2000).

Previous research indicates that cannabis use has an adverse effect on the symptoms of schizophrenia (Green et al., 2008). No participant, however, including the two who had stopped using cannabis, mentioned having experienced any negative effects of the substance. This could be because the focus of the study was the nature of their attraction to cannabis.

The findings provide little support for Khantzian's (1997) self-medication model, which postulates that when individuals with schizophrenia use substances it is to relieve the suffering caused by the negative symptoms of the disorder. Although some of the needs identified by the participants in the present study were linked to the negative symptoms of schizophrenia, they were also associated with the impact of the illness on their everyday lives, their social and cognitive functioning, and the distressing evolution of their lives in general. Moreover, all of the men were taking atypical antipsychotics, which act on negative as well as positive symptoms.

The findings illuminate the perceptions of those with schizophrenia about what draws them to cannabis once the illness has set in but not their early illness or pre-illness attraction to this substance. The findings suggest that those with schizophrenia who consume the drug perceive it as a means of helping them to address unmet needs related to the disease. Seven of the eight participants, however, had begun using this substance before they were diagnosed with the illness. Further research investigating the attraction to cannabis at the onset of schizophrenia would help to shed light on this phenomenon.

Limitations of the Study

Some limitations of the study must be pointed out. The validity of the information gathered depended on the openness and honesty of participants, who were being interviewed about a behaviour that is illegal. The nature of schizophrenia, which often involves mistrust and communication difficulties, as well as the illegality of cannabis consumption, may have made it difficult for participants to discuss their experiences. In addition, two respondents were no longer using cannabis and were describing their experiences retrospectively; they may have had memory lapses about these experiences.

Initially the plan was to recruit both male and female users of cannabis for the study, to provide a more diverse sample. Efforts to recruit women were unsuccessful, however, and all those who consented to participate in the study were male. This may reflect the gender difference in the use of cannabis reported in the literature (Hickman et al., 2007). The restriction of the study to a single gender group and the small number of participants, however, serves to limit the transferability of the findings.

Implications for Practice

Because of the study design, the findings are inherently non-generalizable in the usual meaning of the term. Quinn Patton (2002) notes, however, that extrapolations, described as “modest speculations on the likely applicability of findings to other similar situations” (p. 584), are appropriate and useful when based on information-rich samples and targeted data. The findings of this study suggest that nurses should be sensitive to three needs that are experienced by persons with schizophrenia and that those who use cannabis are apparently seeking to address. Nurses could orient the nursing process to explore, with clients, ways of addressing these needs. In order to help mobilize appropriate resources and support, for instance, nurses could explore (with clients) pastimes and recreational activities, the need for relaxation and ways to meet it, ways to help clients increase their self-esteem, clients’ support networks, and clients’ attitudes concerning the effects of schizophrenia on their lives.

Rehabilitation programs offer therapeutic interventions that address some of these illness-related needs. Recent reviews and meta-analyses have demonstrated the effectiveness of a number of psychosocial rehabilitation programs (Velligan & Gonzalez, 2007). For instance, among those with schizophrenia, cognitive behavioural therapy has the potential to improve attention, memory, and task performance (Krabbendam, 2003); supportive employment programs have been found to increase one’s ability to obtain and retain competitive employment (Twamley, Jeste, & Lehman, 2003); and training in social skills has been effective in improving social competence and social functioning (Peer, Kupper, Long, Brekke, & Spaulding, 2007). Given the limitations of this study, however, further research is required, to assess whether interventions addressing the unmet needs identified by the participants would alter the attraction and use of cannabis among persons with schizophrenia.

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Meilleures pratiques en matière de recherche

**La théorisation ancrée de Glaser,
une base pour la recherche en sciences infirmières**

Cheri Ann Hernandez

La théorisation ancrée de Glaser désigne une puissante méthodologie de recherche capable d'éclairer les comportements d'une clientèle dans un milieu donné. Elle convient donc particulièrement bien à la recherche en sciences infirmières. Les infirmières chercheuses ont recours à cette approche plus souvent qu'à toute autre méthode d'analyse qualitative, en raison des enseignements qu'on peut en tirer sur l'expérience des clients et de ses résultats positifs. L'application de la théorisation ancrée, toutefois, suscite beaucoup de confusion. L'auteure présente les éléments clés de la méthode, les questions qu'elle soulève et ses implications pour l'avancement des connaissances en sciences infirmières. Les observations découlant des recherches fondées sur la théorisation ancrée permettent d'instaurer des mesures pour améliorer les relations entre infirmière et client, la qualité des soins et, en définitive, la qualité de vie du client. En outre, elles peuvent servir à élargir les connaissances puisque la solide théorie de niveau intermédiaire qui en résulte peut être soumise ultérieurement à une évaluation quantitative.

Mots clés : recherche en sciences infirmières, théorisation ancrée, qualité de vie

Best Practices for Research

Getting Grounded: Using Glaserian Grounded Theory to Conduct Nursing Research

Cheri Ann Hernandez

Glaserian grounded theory is a powerful research methodology for understanding client behaviour in a particular area. It is therefore especially relevant for nurse researchers. Nurse researchers use grounded theory more frequently than other qualitative analysis research methods because of its ability to provide insight into clients' experiences and to make a positive impact. However, there is much confusion about the use of grounded theory. The author delineates key components of grounded theory methodology, areas of concern, and the resulting implications for nursing knowledge development. Knowledge gained from Glaserian grounded theory research can be used to institute measures for enhancing client-nurse relationships, improving quality of care, and ultimately improving client quality of life. In addition, it can serve to expand disciplinary knowledge in nursing because the resulting substantive theory is a middle-range theory that can be subjected to later quantitative testing.

Keywords: chronic illness, clinical nursing research, grounded theory, psycho-social aspects of illness, quality of life

Grounded theory has been described as an inductive research methodology for the generation of substantive or formal theory using qualitative or quantitative data generated from research interviews, observation, written sources, or some combination thereof (Glaser & Strauss, 1967). The purpose of grounded theory is to generate “concepts and their relationships that explain, account for and interpret the variation in behaviour in the substantive area under study” (Glaser, 1992, p. 19).

Grounded theory was first developed in the discipline of sociology but is now used in fields such as business, education, medicine, nursing, psychology, public health, and social work. It has become so popular in nursing that it is now the most frequently cited methodology for use with qualitative data (Loiselle, Profetto-McGrath, Polit, & Beck, 2004). Nurses choose grounded theory methodology to conduct their research because of its inherent power to provide a deeper understanding of their clients' worlds and thus give them the ability to make a beneficial impact

on those worlds. Unfortunately, many individuals who use this methodology misapply some of its techniques or fail to use the method fully (Glaser, 2005b). The purpose of this article is to demystify some of the confusion that has surrounded grounded theory, provide a succinct summary of this methodology, and pinpoint some problem areas in order to promote better use of grounded theory by nurse researchers. The article focuses on grounded theory as research methodology (Glaser & Strauss, 1967), as currently delineated by Glaser (2003), rather than on the many different approaches to grounded theory such as feminist grounded theory (Wuest, 1995) or constructivist grounded theory (Charmaz, 1990). It may be beneficial as a guide for nurse researchers and graduate students conducting Glaserian grounded theory studies and to nurse educators teaching research methodology courses.

Glaser (1965) first published a description of grounded theory methodology, in an article in *Social Problems*, as the “constant comparative method,” a term that is frequently used as an alternative label for grounded theory. The article was subsequently published verbatim as *the* method of data collection and analysis of grounded theory (Glaser & Strauss, 1967). Much of the current confusion about grounded theory stems from the later collaboration between Strauss and Corbin (1990), who together published two books and several articles on “grounded theory” but did not acknowledge that their method was different from Glaserian grounded theory until they published their final book (Strauss & Corbin, 1998, pp. 10, 12). The method described in that book, published after Strauss’s death in 1996, deviated completely from original grounded theory methodology (Glaser & Strauss, 1967) because of its descriptive, deductive, and verification focus — as opposed to grounded theory’s explanatory, inductive, and discovery focus. Most recently, Corbin (2007) has called their method Straussian Grounded Theory and has asserted that it is not a research methodology but rather a qualitative data analysis approach. Researchers need to be aware of these distinctions when choosing a methodology for their work. The focus in this article is on grounded theory as originally developed (Glaser, 1965; Glaser & Strauss, 1967) and as consistently delineated by Glaser as a general research methodology (Glaser, 1978, 2003). The emphasis is on the “how” of conducting Glaserian grounded theory and not on philosophical orientation, which is beyond the scope of this discussion.

Overview of Glaserian Grounded Theory

Nurses who want their research results to have practical significance must have a good understanding of grounded theory methodology and conduct their research accordingly. There are two major types (or modes)

of grounded theory: discovery mode and emergent-fit mode. Most researchers use the discovery mode. The *discovery mode* of grounded theory is that published in Glaser's numerous books on grounded theory and is used to "discover" a substantive theory as it emerges during the research process. The *emergent fit mode*, first identified by Glaser (1978), follows grounded theory methodology in every way except that the researcher begins with an existing, plausible theory and then allows the data collected to correct (modify) this theory. In the emergent fit mode, the grounded theorist is not doing the grounded theory all over again but, rather, comparing the new data with the theory, to determine how well the chosen theory fits this new area (Glaser, 2001, p. 104). The type of theory discovered or modified using the emergent fit mode could be a substantive theory or a formal theory. For example, Compton (2002) used the emergent fit mode — starting with Hernandez's (1991) theory of integration in type 1 diabetes — to discover a *substantive* theory of integration in Crohn's disease. However, another researcher might decide to begin with the theory of integration and look at integration of new children (by birth or adoption) into families, integration (merger) of companies, product lines, and so on. This latter example of research would end with the discovery of a *formal* theory of integration.

There are two major assumptions about grounded theory. The first is that in every substantive (empirical) area there is "something going on" — that is, there is a problem that participants are trying to resolve, although this resolution process often occurs unconsciously. The second assumption is that the problem, and its resolution, will emerge through the use of the constant comparative method of analysis, as long as the researcher remains *theoretically sensitive* (open to what the data are disclosing).

The following overview of grounded theory methodology is divided into three sections: theoretical sensitivity, the constant comparative method of data analysis, and write-up of the theory. Then the accepted criteria for evaluating grounded theory are delineated.

Theoretical Sensitivity

"Theoretical sensitivity is an ability to generate concepts from data and to relate them according to the normal models of theory" (Glaser, 1992, p. 27). In other words, theoretical sensitivity is the ability of the researcher to be fully open to what the data are indicating and allow the substantive or formal theory to emerge from the data, rather than operating from a personal theoretical bias to which the data are force-fit.

Prior to beginning their grounded theory studies, researchers should acknowledge their preconceptions, also known as personal predilections (Glaser, 2001), about the substantive (clinical) area being researched and

do their utmost to hold these preconceptions “in abeyance” throughout the study. Major blocks to theoretical sensitivity are researchers’ preconceptions, such as personal beliefs or biases regarding a particular substantive area or ideas gleaned from published articles within this substantive area. This is the main reason why the grounded theory researcher is advised not to read the literature in the substantive area until after the core category has emerged (Glaser, 1978, 1992; Glaser & Strauss, 1967). It is anticipated that this delay in reading the literature will help to keep researchers open to discovering what is in the data instead of overlaying the data with their preconceptions and force-fitting the data to these preconceptions. However, most researchers undertake grounded theory research in a clinical area whose literature is very familiar to them. Therefore, it is of utmost importance that researchers carefully identify their preconceptions and take measures to prevent these from limiting their ability to recognize what the research data are indicating.

The Constant Comparative Method of Data Analysis

The constant comparative method of data analysis (sometimes referred to as CCM) is the simultaneous process, in grounded theory, by which data are collected, analyzed, and written up. Glaserian grounded theory can use quantitative as well as qualitative data and therefore is not correctly classified as a qualitative data analysis method. However, nursing researchers who use grounded theory tend to use qualitative data exclusively. Grounded theory is unlike qualitative data analysis methods because, in grounded theory methodology, data collection, data analysis, and memoing are carried out simultaneously rather than one after another in a linear manner. Research participants are selected as needed through *theoretical sampling*, a process in which participants or additional data are selected in the service of the emerging substantive or formal grounded theory. In theoretical sampling the researcher gathers more data on the patterns that are emerging by asking specific questions in subsequent interviews or by selectively sampling available written data sources. Therefore, the researcher who first collects all the data and then begins the data analysis is not doing grounded theory. In grounded theory, data analysis begins as soon as the first data are collected, and memoing of theoretical ideas takes place throughout the data analysis process and during the write-up of the theory.

Data collection. Although the majority of grounded theory researchers use interview data, grounded theory can entail any type of data, quantitative or qualitative, as well as data from any verbal or written source. Interview data can be augmented through observation and written sources, such as the researcher’s field notes or journals kept by research participants. Grounded theory researchers are advised to always collect

their own data, unless this is impossible due to language barriers or site access issues; audiotaping or videotaping will be essential in such situations.

The grounded theory researcher enters the field with a general curiosity to know more about a specific area but does not have definitive (preconceived) research questions or stated (a priori) hypotheses. For example, the researcher might be interested in what it is like to live with type 2 diabetes and therefore has a general question: "What is the main concern/problem of individuals with type 2 diabetes, and what accounts for most of the variation in processing this concern/problem?" (Glaser, 1992, p. 22). In addition, the nurse researcher who is relying on interview data will have some "spill" questions that allow for the emergence of information that is deemed relevant by the participants rather than adhering rigidly to a pre-set interview schedule. These general questions are designed to let participants tell their stories and "take the interview where it needs to go." Often the interview will go in a direction or to a topic that the researcher would never have predicted, but it is within these areas that the problem and its resolution will be found. Glaser and Strauss (1967) aptly describe this interviewing approach:

At the beginning of the research, interviews usually consist of open-ended conversations during which respondents are allowed to talk with no imposed limitations of time. Often the researcher sits back and listens while the respondents tell their stories. Later, when interviews and observations are directed by the emerging theory, he can ask direct questions bearing on his categories. (p. 75)

Theoretical sampling is the method by which data sources (participants, written sources, observations) are selected throughout the research, as needed, rather than decided at the beginning of the research process. Emergent substantive and theoretical codes (described in the next section) are "used to direct further data collection, from which the codes are further developed theoretically with properties and theoretical coded connections with other categories until each category is saturated" (Glaser, 1992, p. 102).

Data analysis. Data analysis should always be carried out by the researcher, because *immersion in the data* is essential for codes to "occur" in the researcher's head as s/he conceptualizes and labels the codes that emerge from the data. As soon as the data from the first interview or other sources are collected, data analysis begins, and it continues throughout the remainder of the study.

Data analysis can be divided into two phases based on the types of codes that are generated: In *open coding*, data are broken down into "chunks" that are given labels known as codes or categories. In later *select-*

tive coding, these categories are tied together through relational statements known as hypotheses. It is important to remember that all codes derived from these two phases are emergent — that is, *all* codes emerge from (are grounded in) the data. While analyzing the data, the researcher is continuously asking, “What is this data a study of?” and “What is actually happening in the data?” (Glaser, 1992, p. 51), two general questions that relate to the two major assumptions of grounded theory (identified previously) — that is, that there is some issue or problem in the substantive area and that participants’ behaviours are resolving this underlying concern.

During *open coding*, written data from interviews, field notes, or elsewhere are coded in a line-by-line manner (Glaser, 1978). Codes (also referred to as concepts, categories, or variables) are placed in the margins beside the “data chunks” (incidents) from which they were derived. These codes are known as *substantive codes*. There are two types of substantive codes: *in vivo* codes and sociological constructs. *In vivo codes* emerge from the language of the substantive data (Glaser, 1992, p. 45) and often conform to the wording of the participants, which is why they are known as *in vivo* codes (Glaser, 1978). Examples of *in vivo* codes are categories such as “turning point” or “minimizing.” *Sociological constructs* are well-known entities in the literature and are simply recognized by the researcher as they emerge from the data. Examples of sociological constructs are “integration,” “self-awareness,” and “power-mongering.” The researcher is cautioned against presuming that the emergent process is some mystical or ethereal process that defies reason. The opposite is true: The researcher carefully reads each incident and either attaches to it a label that accurately represents/depicts it (*in vivo* code) or recognizes the familiar construct that the incident reflects (sociological construct). Therefore, codes occur in the researcher’s head, as s/he is immersed in the data, going from incident to incident (Glaser, 1992, p. 45).

During the open coding phase, the researcher breaks the data down into incidents that are compared with one another for similarities and differences while asking the neutral question “What category or property of a category does this incident indicate?” (Glaser, 1978, p. 39). *Properties of categories*, often called subcategories, are aspects (hence the term “properties”) of categories such as causes, conditions, consequences, dimensions, types, and processes (Glaser & Strauss, 1967, p. 104).

During initial coding, incidents are compared with other incidents and the patterns found are conceptualized as codes. Later, once the substantive codes have been generated, incidents are compared with the codes that have emerged already (Glaser, 1992, p. 32). When the research reaches the point where no more indicators (properties) of a particular category are found, the phenomenon known as *theoretical saturation* is

evident. Individual categories are saturated during this open-coding process (Glaser, 1978). Open coding continues until the *core category* has emerged; this is the central category that accounts for most of the variation in a pattern of behaviour (Glaser, 1978, p. 93) in the area being researched. The core category represents the behaviour that continually resolves the problem in the substantive area (Glaser, 2001, 2003). For example, Hernandez (1991, 1995, 1996) found that, in adults with type 1 diabetes, *integration* was the core category that resolved the problem of *having two selves* — the personal self and the diabetic self. Once the core category has been identified, the researcher has a set of broad categories and their properties (subcategories), one category being identified as the core category and the others being lesser concepts but related to this core category in a manner that has not yet been determined.

After the core category has been found, *selective coding* begins. During this coding phase, only those concepts that relate to the core category are coded, and coding continues until they are all theoretically saturated. At this point the researcher reviews the categories and reflects on them, especially in written form (memos), to determine how they are related to each other. Glaser's (1978) advice to the analyst, to continually watch how s/he is putting the theory together to ensure that the cues come from the data (p. 73), is of paramount importance here. The substantive codes (categories) are related to each other through an emergent (as opposed to preconceived) theoretical code. The *theoretical code* is simply the conceptual model of the *relationship* of the core category to its properties (e.g., causes or conditions) and to other (non-core) categories. In other words, the theoretical code is the relational model through which these substantive categories are integrated into a theory but is not the substantive theory itself. For example, in a study of type 1 diabetes, Hernandez (1991, 1995) discovered the substantive theory of integration, but the theoretical code was a *basic social process* consisting of three phases.

Many different types of theoretical code are found in grounded theory studies. Probably the most predominant theoretical code is the *basic social process* first suggested by Glaser (1978), in which the substantive codes are related to each other through stages or phases. Not all grounded theory is *process* theory; there are *static* grounded theories also. However, most nursing researchers develop process grounded theories. For example, Wilson (1989) discovered an eight-stage sequential process experienced by family caregivers of persons with Alzheimer's disease. Many theoretical coding families have been identified: Glaser (1978) describes 18 but indicates that more are possible. Nine theoretical coding families are identified in *Doing Grounded Theory* (Glaser, 1998) and 22 theoretical codes are described in *Theoretical Coding* (Glaser, 2005a). One way to theoretically code a theory pictorially is to draw it in model form

(Glaser, 1978) so that it provides a schematic of the connections among the categories of the theory (Glaser, 1998). The researcher writes the core and related categories on a blank piece of paper within solid or broken circles or boxes. Then the relationships among them (found in the data during data analysis and memoing) are specified through use of uni- or bi-directional arrows or solid or broken lines and through placement before, after, above, or below one another to denote sequence, process, or hierarchy. The resulting diagram of the theory will be useful in the write-up of the theory, because it acts as a reminder to explain all of the relationships among these categories. Frequently, researchers publish these diagrams in the reports of their research, as a way to enhance reader understanding of their substantive theories (Andrews & Waterman, 2005; Engstrom, Rosengren, & Hallberg, 2002; Giske & Gjengedal, 2007; Wiitavaara, Lundman, Barnekow-Bergkvist, & Brulin, 2007).

Memoing. “Memos are the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding” (Glaser, 1978, p. 83). There are several types of memo that can be used in doing grounded theory, all of which are designed to assist in the generation of the theory. Memos may describe the properties of a category, or begin to make relational connections/linkages between categories or between the properties of a category, or they can be used to capture theoretical ideas for later use. Memos vary in length from a single sentence to as long as several pages (Glaser, 1978). They can be written on index cards or on slips of paper or can even be typed and saved as a computer file, but it is important that each memo be classified, by the category to which it refers, in the top right- or left-hand corner, as this will be useful in the later writing-up of the theory. Memos also serve as a communication tool when there is more than one researcher collecting and analyzing data for a study.

Write-Up of the Grounded Theory

After the constant comparative process, the researcher has numerous memos that theorize about each of the substantive categories and their properties and the theoretical code that relates these categories. These memos are now sorted, into separate piles, according to the individual substantive or theoretical codes to which they refer. The final step is to write the theory using these piles of sorted memos. The important thing to remember when writing the theory is that grounded theory methodology involves writing the research “product” at the theoretical/conceptual level — that is, writing the substantive or formal theory (explanatory level), not writing about the individual experiences of research participants (descriptive level). This does not preclude the use of illustrations in the oral or written presentation of the theory. It means that the focus of

the dissemination should be on the theory itself, and therefore that the “illustration dosage” should be carefully chosen, in the service of the delineation of the grounded theory and as appropriate for the target audience.

Evaluation of Grounded Theory

Three evaluative criteria for judging grounded theory are delineated by Glaser and Strauss (1967): fit, work, and relevance. A fourth criterion, modifiability, was added by Glaser (1978, 1992). *Fit* refers to the fact that the categories, properties, and theory fit the data that have been collected; fit can be thought of as validity (Glaser, 1998). *Work* means that the categories, and the way in which they are related into hypotheses, explain the behaviour that is occurring in an area of study — that is, how the main concern of participants is being continually resolved (Glaser, 1998, p. 18). *Relevance* is achieved when the categories both fit and work (Glaser & Strauss, 1967) and when the theory deals with the main concerns of the participants (Glaser, 1998, p. 18). *Modifiability* is demonstrated when concepts, their properties, and the substantive theory can readily accommodate new data — that is, when any of them can be readily modified by new data (Glaser, 1992, 1998).

Researcher Problems When Using Grounded Theory

Glaser (1992, 2001, 2003, 2005a) identified two main areas of difficulty for researchers who use grounded theory. Some researchers misunderstand aspects of grounded theory methodology or fail to operationalize it fully. Sometimes such problems arise because the researcher or the supervisor of the graduate student is a novice and has not been properly trained in grounded theory methodology. Glaser (1998) asserted that the learning curve for grounded theory is about a year and a half. Therefore, adequate knowledge and training, over time, is essential for those who wish to conduct grounded theory research. Attending grounded theory seminars, reading the various books on grounded theory, and participating in grounded theory research are key strategies for developing knowledge and expertise in conducting grounded theory research.

There are two additional problematic areas identified by the author over the past 15 years of supervising graduate students and serving as a reviewer of grounded theory manuscripts. One of the most common errors is failure to see that Glaserian grounded theory methodology (Glaser, 1965; Glaser & Strauss, 1967) is very different from the Strauss and Corbin (1990, 1998) qualitative analysis method, even though Glaser (1992) passionately pointed out their incongruence and Artinian (1998) identified key distinctions between them. Some researchers have tried to

combine the strategies of the two approaches and cite both sets of authors to substantiate the quality of their grounded theory product; this only intensifies the confusion. The final problematic area relates to theoretical sensitivity, particularly if this is the first grounded theory study the researcher has undertaken. Novice researchers often find it difficult to deal with their preconceptions, which can easily and subtly overlay the data even when students are warned by their supervisors about this problem. Even those graduate students whose supervisors have required them to write a one-page synopsis of their assumptions and values related to the area they are researching, and to hold these “at bay,” may have difficulty doing so. Supervisors should be aware of the types of elective courses that students have taken, as these can be a source of preconceptions; for example, courses that address culture and gender differences can render students unable to recognize similarities and/or differences in the data that conflict with the course content they have learned. Clearly, the challenge is for nurse researchers and graduate supervisors to develop strategies for ensuring that they themselves or their protégés are continually open to what is in their data, instead of viewing the data through their preconceptions. Following the tenets described in *Theoretical Sensitivity* (Glaser, 1978), the most widely used book on grounded theory methodology, can facilitate this process.

Limitations of Glaserian Grounded Theory

This section will address two limitations of Glaserian grounded theory cited by some authors: approach to the literature, and audiotaping of interviews. Glaser and Strauss (1967) warn that the researcher should delay reading the literature until the core category emerges, to ensure that the “emergence of categories will not be contaminated by concepts more suited to different [substantive] areas” (p. 37), and this caution has been reiterated as a grounded theory dictum (Glaser, 1992, p. 31). This legitimate concern is related to a potential lack of theoretical sensitivity, but most nurse researchers are required to include a synopsis of the literature when submitting their research proposals to ethical review boards or funding agencies. Glaserian grounded theory researchers have learned to acknowledge this threat to theoretical sensitivity and to take measures to enhance their openness to the data.

Although Glaser (1978) initially recommended the audiotaping of interviews (p. 21), he has more recently cautioned against this practice because of its costs in terms of time and money, the delay in data analysis and theoretical sampling, and the potential failure to develop certain skills that are essential for grounded theory research (Glaser, 1998, pp. 111–113). Most nurse researchers audiotape interviews for practical reasons:

to fulfil a requirement of ethical review boards or funding agencies, to participate in team or transcultural research, to be able to listen for tone and inflection while coding transcriptions, to have recordings and transcriptions available for secondary analysis by graduate students, or to facilitate their own related work in instrument or intervention development. Since Glaser's concerns about audiotaping are essential considerations, researchers have developed strategies for addressing them. Examples include obtaining skilled personnel and funding for audiotape transcription, taking notes during interviews, transcribing field notes, and ensuring that data analysis and memoing take place immediately after each interview.

Concluding Remarks

Grounded theory has become one of the most popular research methodologies of nurse researchers and is a powerful methodology for use in nursing research. The product of grounded theory research is a substantive or formal grounded theory at the middle-range theory level (Glaser & Strauss, 1967). The insights gained during one grounded theory study point to the need for additional grounded theory research and have resulted in a program of grounded theory research for at least one nurse researcher (Olshansky, 1996). Alternatively, hypotheses from the new middle-range theory can be tested in quantitative research, including nursing intervention research (Hernandez, Hume, & Rodger, 2003, 2008; Hernandez, Laschinger, Rodger, Bradish, & Rybansky, 2004; Hernandez & Williamson, 2004).

Because of the potential usefulness of the grounded theory product for clients, researchers, and clinicians, it is essential that Glaserian grounded theory research be conducted in a way that is consistent with the methodology specified by Glaser and Strauss (1967). The focus of the preceding discussion has been on a concise presentation of Glaserian grounded theory methodology to promote and guide nursing research. Grounded theory, when done properly, holds great promise for gaining a deeper understanding of clients' behaviour, which can foster better client-nurse relationships and improve client quality of life and will ultimately build disciplinary knowledge in nursing.

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Reviewer of the Year for 2007, 2008, and 2009

Over the past decade we at *CJNR* have editorialized many times about how much we value our reviewers' service in providing astute and timely assessments of articles submitted for publication. We have written about the role that peer review plays in academic journals — the challenges involved and the sensitivities of both reviewer and author in this process. Despite the inherent awkwardness and occasional pitfalls of peer review, the world of scholarship has not yet found a viable alternative. Furthermore, the value of peer review for the overall quality of what is ultimately published is undisputable.

A number of years ago we decided to regularly honour reviewers who had been especially consistent and faithful in their efforts on our behalf and had written reviews that were particularly helpful to us and to the authors. Though 3 years have passed since we last published a reviewer tribute, we have been keeping track and would like to honour a reviewer for each of those years.

At the conclusion of the 2007 publication year we selected **Jacqueline Dienemann**, PhD, RN, NEA-BC, FAAN, Professor at the School of Nursing, University of North Carolina, Charlotte, and adjunct Associate Professor at Johns Hopkins University in Baltimore, Maryland. Dr. Dienemann specializes in research on domestic violence and on program evaluation. She teaches program evaluation, oversees master's-level evidence-based capstone projects, guides nursing research programs at two hospitals, and serves on the advisory board for Lake Norman Regional Hospital.

For 2008 our choice was **Sandra LeFort**, PhD, RN, Professor at the School of Nursing, Memorial University of Newfoundland, St. John's. Dr. LeFort's involvement in nursing and health care spans more than 35 years, in clinical work, research, education, and administration. Most recently, she completed a 5-year term as Director of the School of Nursing at Memorial University. Her scholarly interests are in chronic pain, patient education related to the self-management of chronic pain and chronic illness, and clinical ethics. Dr. LeFort has received research funding from the National Health Research and Development Program of Health Canada, the Medical Research Council of Canada, and the Canadian Institutes of Health Research. She has made over one hundred presentations in the area of chronic pain and has 57 publications to her credit.

Finally, for 2009 we selected **Greta Cummings**, PhD, RN, Associate Professor in the Faculty of Nursing, University of Alberta, Edmonton, and founder of the university's CLEAR (Connecting Leadership, Education And Research) outcomes research program in leadership science in health services. Dr. Cummings conducts research on the effects, both positive and negative, of specific leadership practices on outcomes for the health-care system, for the health-care workforce, and for patients. She has received provincial and national funding and currently holds two investigator awards: a Population Health Investigator Award from the Alberta Heritage Foundation for Medical Research (2006–12), and a New Investigator Award from the Canadian Institutes of Health Research (2006–11). Her extensive service contributions include membership on numerous editorial and professional boards. She recently served as President of the Canadian Association of Nurses in Oncology and is currently President Elect of the International Society of Nurses in Cancer Care.

As we recognize and thank these three wonderful reviewers, we would like to say that, after reflecting on several developments over the past decade, we have decided to retire the Reviewer of the Year designation. This choice reflects the evolution of the field and declares “mission accomplished” in terms of upgrading the quality of our reviews.

The sophistication of nursing research has increased greatly, and with it the degree of specialization we look for in reviewers, in terms of methods or subject matter or both. As a result, we are calling more and more on reviewers to examine fairly specific types of articles — and may not call on them again until another article drawing on their area of expertise comes to us, which could take years. Therefore, it is becoming ever more challenging to identify uniquely faithful reviewers, which was one of our goals in instituting the Reviewer of the Year designation.

In addition, the pool of reviewers has expanded and the quality of reviews has improved dramatically. It is becoming easier to identify qualified reviewers, and, despite the extreme time pressures we all face, well-informed scholars at a range of career stages are still agreeing to contribute and are drafting high-quality reviews that now consistently meet our target levels of detail and focus.

We consider all of these trends cause for celebration.

Once again, we extend our congratulations and thanks to *CJNR*'s final three Reviewers of the Year. We are also grateful to all those who have reviewed for us over the years. The ever-increasing quality of the Journal is a tribute to their service.

Sean P. Clarke
Associate Editor