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Erratum

Re: Conklin, J., & Stolee, P. (2008). A model for evaluating knowledge exchange in a network context. *CJNR*, 40(2), 116–124.

The authors wish to acknowledge the support of the Ontario Ministry of Health and Long-Term Care and Ontario's Seniors Health Research Transfer Network for the work described in the article. The views expressed in the article are those of the authors and do not necessarily represent the views of the Ministry or the Network.

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GUEST EDITORIAL

Shifting the Rhythm of Chronic Illness Care

Carol Jillings and Sally Thorne

It was not difficult to find inspiration for a guest editorial given the wonderful set of submissions we were privileged to review for this issue of *CJNR*. The range of manuscripts — focusing on such diverse dimensions as illness narratives, cognition and self-awareness, management/intervention strategies, and knowledge translation — surfaced the broad scope of knowledge that is being generated as well as the creative practice applications that are emerging at the core of chronic illness care.

This issue of the Journal differs from previous issues dedicated to the topic of chronic illness in that it highlights a new conceptual “spin” on the theme of documenting the chronic illness experience. The articles that make up this volume describe research that takes us well beyond an understanding of discrete disease categories and into the domain of chronic disease management. They reflect a trend towards theorizing the problem of chronic disease as a system dysfunction being enacted at the level of individual experience. In conceptualizing the problem of chronicity within a health-care system centred on the management of acute illness, the researchers contributing to this issue explore dimensions of illness awareness and self-care management from unique yet intersecting perspectives.

Additional inspiration for these introductory comments came from an unlikely source: a Sunday broadcast on CBC Radio 2 of a program in Gary Cristall’s series *The People’s Music*. This particular instalment described the genesis of English-Canadian folk music in the early 20th century. Cristall’s discussion of ballads was especially striking: folk ballads have always reflected events in history and their impact on our everyday experiences and emotions. Every kind of music expresses and comments on the human condition, but the folk genre is perhaps most intimately linked to lived reality and context. In our attempts to understand chronic illness — through research that describes, discusses, measures, and extends theoretical understandings — we are invariably led back to the client context and to the lyric and rhythm of the illness experience. In effect, we seek to analyze and understand the ballads that clients render for us,

so that we may be inspired to meaningfully improve the systems of care that variously constrain or support their lives. We draw upon their voices as the heart and soul of what this work is all about. And, as Alison Phinney urges in her Knowledge Translation contribution in this issue, we must move beyond formulaic KT rhetoric as we attempt to mobilize the knowledge we have gained towards meaningful social action and a better way of caring for those whose circumstances have not been a priority for the systems in which we operate. We must take what we know and craft it into applications that ultimately make a difference to people's health.

We have enjoyed the process of watching this issue of the Journal find its own harmonic rhythm. We have found it inspiring to learn how many brilliant minds have been devoted to the problem of chronic illness and are creating evidence-informed means of improving the systems that enable the chronically ill to live as well as they can. We believe that each article in this collection has an important role to play in the broadened thinking and inspired action of our readers as we apply a research perspective to addressing the complex issues inherent in the chronic illness management challenge we face together.

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Discourse

Chronic Disease Management: What Is the Concept?

Sally Thorne

In 2002 the World Health Organization reported that chronic conditions accounted for 46% of the global burden of disease (World Health Organization, 2002). While chronic conditions have always been part of the human experience, advances in medicine and biomedical technologies have extended the expected lifespan for many chronic diseases and have transformed a number of previously fatal illnesses, such as HIV infection, into chronic conditions. An increasingly toxic nanomaterial environment may well be implicated in the proliferation of newer chronic conditions, such as fibromyalgia, as well as increased prevalence rates for well-established conditions, such as asthma. Thus, we now have more chronic conditions and are recognizing them more often.

As a result of the WHO report, health-care systems across the Western world have been scrambling to respond to the increasing awareness of the pervasiveness of chronic disease, by enacting service delivery and process reform. This has created a new appreciation for the extent to which our health-care systems are built upon an acute-care ideology that all but ignores the plight of the chronically ill. To the extent that they are precursors of devastating and costly health problems, chronic diseases must be recognized as appropriate and cost-effective points of intervention and support. There is clear evidence that our health-care systems can no longer afford their predilection for tertiary care innovation as the solution to society's health problems. Thus we are witnessing a renewed enthusiasm for a complete revision of health-service delivery.

A Welcome Shift

This is a welcome sea change for nurses and others who for decades have been qualitatively documenting the experience of persons with chronic illness. An expanding body of "health-care consumer" research has faithfully reported the impact of an acute-care ideology on the social experience and health-care journey of a patient population increasingly

afflicted with chronic conditions. It has surfaced the tension that exists between what our systems offer and what patients think they need (Thorne, Paterson, Acorn et al., 2002; Thorne & Paterson, 2000).

This body of research has revealed to us just how poorly the structures and systems originally designed to meet the needs of the urgent and episodic fare in preventing people from having to use them. It has oriented us towards the need to rethink who holds expertise and within which aspects of the illness constellation, to reconsider the optimal timing and orientation of service delivery, and to critically reflect upon the relevance of population-based evidence for handling complex “n of one” living problems. In so doing, it has alerted us to the extent to which our professional turf battles, embedded reimbursement schemes, and misplaced scientific logic compromise access to the resources and supports that optimize the ability of the chronically ill to live well and independently despite their conditions (Thorne, 1993).

The plight of those with chronic disease has come to epitomize the essential mismatch, within our existing systems, between health-service investment and the social reality of illness. Consequently, reconfiguring health-service delivery from an underlying acute-care philosophy to something that more effectively addresses the chronic illness context has become the focus of massive system-level change, including examination of an array of options for more efficient and effective deployment of scarce resources (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004). As we reflect on these various new service models, careful attention to the language signifiers may provide cues to the ideological slant that each represents in its consideration of the fundamental nature of the problem of chronic disease and what we ought to be doing about it.

Language and Conceptualization

The Chronic Disease Management, or CDM, concept underpinning many initiatives to redesign the current system typically references two prominent approaches. Chronic Disease Self-Management, aligned with the work of Kate Lorig and colleagues, references a system of supports designed to better inform health professionals as to what they have to offer and educate patients as to their responsibility to understand and cope with their own disease (Holman & Lorig, 2004; Lorig et al., 1999, 2001). The Chronic Care Model proposed by Ed Wagner and colleagues is a population-based comprehensive approach to aligning health-care encounters within redesigned delivery systems (Bodenheimer, Wagner, & Grumbach, 2002; Gately, Rogers, & Sanders, 2007; Wagner et al., 2001). Prioritizing what are known as “frequent flyers” — those individuals with preventable and costly sequellae of chronic disease — this latter approach

focuses on biomarkers as the best form of population-based evidence of system effectiveness.

These conceptualizations contain elements of inspired insight, and are presented in a form that is palatable to health-policy planners. Change agents such as Lorig and Wagner have helped to establish an evidence basis for system reform without limiting their scope to that which can be fully grounded in hard evidence. While neither of these approaches explicitly acknowledges qualitative work on patient experience with chronic illness, they seem informed by much that this body of scholarship has systematically surfaced. Thus they recognize that the processes associated with such elements as access, referral, prescriptive authority, and gatekeeping — all designed to accommodate acute and episodic illness — have become barriers to obtaining appropriate health services even among the most insightful, articulate, and competent of chronically ill patients.

These models, often collectively referred to as CDM, have been extremely helpful in illustrating, at the system level, that the vast majority of chronic disease management occurs not in a 15-minute medical visit but, rather, in the hours, days, months, and years that patients and families invest in their own health and well-being. They have forced a kind of engagement that is different from the tradition of giving “orders” and expecting the patient to “comply.” (I use the word *comply* instead of the currently more popular *adhere*, since the latter is simply a polite way of continuing to entrench the idea that population-based data and professional perspectives are inherently the optimal approach to a chronic illness problem.) Rather than gloss over the expertise imbalance with a trick of language, CDM forces us to respectfully acknowledge that the diseased body in question is entrusted to the care of the patient (and his or her family/community) rather than being the rightful property of the health-care system. So this shift has countless advantages, and for the most part it is orienting us in a highly appropriate direction — towards meaningful change in how we do business with regard to the delivery of chronic care.

But Will It Solve the Problem?

Despite these significant advantages, a population-based, CDM approach is not without limitations (Gately et al., 2007). However, much of the effort to date has been focused on “selling” CDM rather than on entertaining thoughtful critique. As one step towards opening up a space for constructive dialogue on possible “course changes” along the implementation journey, I turn to insights from the qualitatively derived evidence of what patients experience. In my opinion, these serve as a primary

source for interpreting what CDM will and will not resolve within the mandate of optimally serving society.

Most worrisome to me is the fact that the CDM model still views the crux of the problem as the disease, implying the goal of bringing the best of what science has to offer to bear in controlling the effects and progression of organ system malfunction. This “disease” orientation inherently privileges professional expertise in naming, defining, and theorizing what is relevant about a particular condition. Few would deny that science has produced enormous gains in understanding and ameliorating untoward aspects of certain chronic diseases. Relatively rare, however, are instances of medical prescription providing meaningful benefit in isolation from a comprehensive and coherent plan for “living with” the illness. By focusing on diseases, we continue to misrepresent the fundamental locus of authority, which is the patient rather than the professional. When we blind ourselves to the context in which lives that include chronic conditions are lived, we limit the benefits we are able to realize from this major investment in system redesign.

The focus on “management” signals a shift away from the dominant notion of “treatment,” in which the diseased organ is the singular focus, implying a search for a medical intervention to resolve it. Because they are by definition incurable, chronic diseases have long been a source of frustration for the health-care system. Reframing the problem as one of management shifts the intended outcome from “cure” to stewardship. It therefore extends the frame of reference from short to long term and also challenges us to consider outcomes that become increasingly difficult to isolate from their embedded and dynamic social as well as pathophysiological environments.

Despite this more enlightened orientation, the notion of management remains slippery when it obscures clarity as to who is actually doing the managing — the patient or the professional. While nursing has paid considerable attention to the ongoing work of the individuals and families who live with chronic conditions, system planners have demonstrated little capacity to conceptualize the nature of that work or the mechanisms by which it is facilitated or hindered in producing optimal outcomes over time. In the context of exponentially rising health-care costs, there is a natural resistance within the health-policy community to blur the edges of what constitutes the responsibility of the formal health sector within society. Therefore, chronic illness management systems have focused on the oversight and monitoring of chronic disease biomarkers by professionals — despite an increasing recognition that known biomarkers are a mere drop in the bucket in the larger scheme of relevant indicators — rather than on the complexities of the everyday life of the person affected by chronic disease. In some contexts, this emphasis on the

professional contribution to the messy constellation of what accounts for living well with chronic disease has been recognized as problematic. In response, language around “shared care,” “patient self-management support,” or “patient as partner” has emerged to justify initiatives that begin to shift that balance of attention.

Expanding the Conceptualization

In our attempts to understand the challenge from the perspective of the patient rather than the professional, my colleagues and I inductively generated the concept of Everyday Self-Care Decision-Making to capture what is involved in living daily with a diversity of chronic conditions (Paterson & Thorne, 2000; Thorne, Paterson, & Russell, 2003). This conceptual approach reflects the core idea that living as well as possible with a chronic condition requires an increasingly sophisticated and integrated capacity to weigh alternatives, make choices, attend to evidence, listen to one’s unique body cues, and develop an individualized system by which to know whether one is doing better or worse over time. It orients us to the attention required to handle disease-related matters within the inherent complexity of relational and contextual changes and challenges over the life trajectory.

From the everyday self-care decision-making angle of vision, disease management often constitutes a minor element within the context of living what for most of us is an incredibly complex life. Although the facts and principles underlying medical management are important and useful, they tend to be the focus for relatively short periods of time in the scheme of things, taking prominence at the time of initial diagnosis and during changing conditions but reverting to “background noise” for much of one’s everyday existence (Paterson, 2004). And as one might imagine, the competencies required to consult with a patient around disease management tend to be quite different from those required to support healthy living on an ongoing basis.

Forms of disease management based on mass population tend to focus on patients with the most serious problems understanding the basic principles of healthy living and adhering to medical recommendations. They are careful to emphasize doing things correctly (i.e., following orders) rather than engaging in experimentation or creative variation. While they may begin to address the needs of the least thoughtful or reliable of patients, they paradoxically risk alienating or misleading those with the greatest potential to do well despite their disease.

Studies with patients who have become expert in everyday self-care decision-making reveal that they do not achieve that expertise through compliance with recommendations or adherence to standardized approaches.

Rather, those who attain expertise figure out at some point along the way that it is their life that will be lived and they must become the ultimate authority on that life. They learn through informed strategic experimentation what their own limits are, identify their own unique disease activity markers, and find creative ways to minimize the extent to which disease management characterizes their everyday life. When conditions change or symptoms worsen, experts may rapidly shift to intense preoccupation with their illness, but for the most part relegate disease management to what become patterned practices and health habits that enable optimal wellness.

Patients on the road to such expertise often experiment with complementary (non-Western) therapeutic approaches, since symptomatic relief and feelings of wellness are their key objectives (Thorne, Paterson, Russell, & Schultz, 2002). They become quite comfortable disregarding scientific critique about the lack of evidence, since they understand both the irrationality of assuming that population norms match individual cases and the politics of what warrants a clinical trial (generally, that which is predictably lucrative to BigPharma, rather than that which can be grown in one's backyard). They often express frustration with the current care delivery system, noting the complexity added to their lives by such dysfunctions as waiting times, controlled prescriptive authority, and the politics of referral, and recognizing that these disjunctures often extend beyond the nuisance factor to become iatrogenic health hazards. Emerging and established experts are often somewhat alienated from that system, using it as they must and manipulating it when they can.

Although the CDM movement orients certain elements to conventional care systems in recognition of the dynamics of chronic illness, for the most part it continues to position the problem of chronic illness squarely in the domain of population-oriented, evidence-based service delivery. Thus, it may ignore some aspects of what expert chronically ill patients have been telling us for some time, and thereby runs the risk of failing. As a population-based approach, CDM strives towards system standardization; in contrast, expert patients tell us quite convincingly that what works best for the average patient will not work for all. CDM bases its outcome evidence on discrete measures, while expert patients know that individual lives and physiologies have their own unique manifestations and that biomarkers reflect only one measurement point in an evolving kaleidoscope of what constitutes both disease progression and effective living. It claims a multidisciplinary team approach, while expert patients know that this approach remains dominated by a medicalized perspective on what is truly needed and warranted within a system designed to serve health. Indeed it rarely extends the idea of the health-care team beyond conventional practitioners to a truly integrated approach to support a new way of living.

Conclusion

What we have learned from the study of expert patients alerts us to a looming problem worthy of our attention. Although the current philosophy of CDM may be efficient and effective in producing baseline disease management competence, it can detract from our ability to support the acquisition of genuine expertise in living with a chronic disease. By focusing on systematic services for the newly diagnosed and detection of the most obstinate and recalcitrant of patients, it may hinder the development of genuine patient expertise within this complex living challenge.

Nursing seems ideally positioned to adopt the perspective of expert patients that there is no singular way to live well with a chronic condition, that the learning process is complex and incremental, and that the role of medical science must be contextualized within an understanding of the living that is taking place. Because our discipline inherently operates in the world of generalized knowledge applied to unique and particular individual cases, we sustain a foundational conviction of the value of individualized relational practice in meaningful intervention, even as we acknowledge the challenge of creating hard evidence that it works. We know that every patient we encounter lives within a unique social and material context that shapes both the diseases acquired and the manner in which he or she responds to them.

Therefore, as we embrace the CDM movement, it is incumbent upon us to remain vigilant to the inherent tension between standardization and individualization, between people and systems. It seems prudent to look to informed and expert patients as a vital source of knowledge about how to achieve optimal individual results across a diversity of patient contexts and conditions. We must also be on guard against the allure of quick fixes such as CDM measures and “patient navigators,” in lieu of true health-system reforms.

The angle of vision that nursing has always brought to chronic illness is one whose time has come. As we move forward in this new wave of thinking about chronic disease, we must clearly demonstrate the difference that is made when nurses are well positioned to engage in the ongoing, dynamic, and proactive care of which we are capable. Nursing research has a pivotal role to play in informing the alignment of management approaches with these complexities of human experience. Armed with such knowledge, we can ensure that the problem of chronic illness is universally conceptualized not simply as an organ system to be monitored or a physiological process to be contained, but as a life to be fully lived.

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Recours à l'enquête narrative pour recueillir l'expérience de l'autogestion du diabète dans une population autochtone

Sylvia S. Barton

C'est selon l'approche de l'enquête narrative qu'a été analysée l'expérience de personnes autochtones vivant avec le diabète de type 2 dans une collectivité rurale. La méthode utilisée pour guider la recherche a été l'enquête narrative fondée sur l'herméneutique phénoménologique. Un échantillon de 4 personnes descendant de la nation Nuxalk qui vit à Bella Coola (Canada) a été choisi à dessein. Ces personnes ont été sélectionnées pour leur aptitude à présenter des récits de vie étoffés et à faire apparaître du sens dans leur propre histoire de diabète. Trois principes clés ou interprétations analytiques prédominantes se sont dégagés, qui pourraient contribuer à la recherche sur la santé autochtone d'une manière générale. L'article est axé sur notre compréhension accrue du diabète dans un contexte culturel précis. L'analyse met en relation diverses orientations philosophiques, épistémologiques et méthodologiques avec la recherche auprès de personnes autochtones vivant avec le diabète.

Mots-clés : personnes ou peuples autochtones, descendant de la nation Nuxalk, diabète, enquête narrative

Using Narrative Inquiry to Elicit Diabetes Self-Care Experience in an Aboriginal Population

Sylvia S. Barton

A narrative inquiry approach was used to explore the experience of Aboriginal people living with type 2 diabetes mellitus in a rural community. Narrative inquiry based on hermeneutic phenomenological philosophy was the methodology used to guide the research. A purposive sample of 4 persons of Nuxalk ancestry living in Bella Coola, Canada, were selected for their ability to present rich life narratives and to reveal meaning in their particular diabetes stories. Three key insights or overarching analytical interpretations emerged and could contribute broadly to Aboriginal health research. The focus of the article is the expansion of our understanding of diabetes within a specific cultural context. The discussion connects various philosophical, epistemological, and methodological orientations to research with Aboriginal people living with diabetes.

Keywords: Aboriginal peoples, First Nations, Nuxalk ancestry, diabetes, narrative inquiry, Aboriginal knowledge, nursing practice, cross-cultural research

A narrative inquiry into Aboriginal stories of diabetes (Barton, 2006) was a research project that came to fruition in response to an epidemic in Aboriginal communities across Canada. The claim of a widespread prevalence of diabetes in Aboriginal communities is found in social epidemiology and cultural and medical anthropology literature focused on the experience of diabetes as it is constructed and lived within the context of Aboriginal culture (Health Canada, 2000; Waldrum, Herring, & Young, 2006; Young, Reading, Elias, & O'Neil, 2000). The purpose of the study was to examine an Aboriginal person's experience of living with diabetes. The methodology guiding the research was narrative inquiry (Clandinin & Connelly, 2000) and dialogue and conversation were used to obtain a "storied" view of experience. The inquiry highlighted my 3 years of co-participation with one man and three women of Aboriginal ancestry, a journey that elicited their rich life narratives and the meaning of their diabetes stories. It entailed 5 years of scholarly and personal exploration, including listening, learning, sharing, and writing in order to gain a cultural view of human experience. These views refer to how I was trying to understand experience as something always shaped by culture. The end result was the co-construction of a diabetes narrative as a process of healing and well-being in an Aboriginal context.

Methodologically, the analysis was guided by three sets of narrative inquiry: theoretical; practical, text-oriented; and interpretive-analytic. Guided by these topics based on hermeneutic phenomenological philosophy, I introduce key insights framed as three overarching analytical interpretations that could contribute broadly to Aboriginal health research. From this position, I draw several conclusions about the importance of conducting research on experiences and narratives of diabetes in a First Nation community. The purpose was to elucidate the personal and human elements, as well as the cultural and healing dimensions, that surfaced through a narrative inquiry approach. The focus of the article is the expansion or transformation of our understanding of diabetes within a specific cultural context. The discussion connects various philosophical, epistemological, and methodological orientations to research with Aboriginal people living with diabetes.

The inquiry was undertaken in a context of little qualitative work on the Aboriginal experience of living with diabetes, and no qualitative work exploring the phenomenon from a cultural perspective based on the existential dimensions of time, place, body, and relationship. This claim is founded on nursing research that argues for a “socialized” understanding of health and illness based on narratives of experience (Garro, 1995; Hernandez, Antone, & Cornelius, 1999; Tarlier, Browne, & Johnson, 2007). The inquiry is meant to contribute to the knowledge base on Aboriginal diabetes health by eliciting the experiences of four extraordinary people in achieving harmony and balancing the states of being Aboriginal, being diabetic, and being well. It does not predict or generalize, but rather attempts to truly understand the diabetic issues and concerns of Aboriginal people, including the significance of diabetes events for Aboriginal people, their families, and their communities. The study is also intended to stimulate inquiry into the diabetes experiences of other Aboriginal peoples whose land is part of Canada, as well as indigenous peoples whose lands are part of countries such as Australia, New Zealand, and the United States.

Theorizing that Aboriginal peoples’ lived experience of diabetes is always constructed within a social, cultural, and political context, I begin with three overarching analytical interpretations that emerged from the inquiry and are based on the participants’ experiences. I then consider the cross-cultural, professional, and theoretical results of these interpretations in terms of health-care research and practice. The inquiry’s contributions to colonial and postcolonial theories concern the complex socio-cultural realities of the Aboriginal experience of diabetes. Research and scholarship informed by postcolonial theoretical perspectives in nursing, for example, show how diabetes narratives are shaped by personal, social, and material conditions and how contemporary understandings of health

and illness are inseparable from perspectives on race, ethnicity, and culture (Anderson, 2000; Anderson et al., 2003; Browne, Smye, & Varcoe, 2005).

In this research, I also asked how non-essentialist views of culture might be developed in nursing, and I grew to appreciate the fact that language use is a critical aspect of the decision not to conflate culture with ethnicity. Certain terms can inadvertently undermine the intent of the research and the rich narrative insights and interpretations. This calls for a description of culture, so that terms such as *cultural differentiation*, *cultural view of experience*, and *cross-cultural* are not interpreted in static and essentialist ways. Thus, as implied in my narrative insights and reflexive stance, culture is best described as a living understanding as expressed narratively, through stories. This is also a view of culture that is based on hermeneutic phenomenological philosophy, which is consistent with the theoretical ground of the research methodology: narrative inquiry.

Cultural Differentiations and Diabetes Experiences

The first overarching interpretation asks how an Aboriginal person living with diabetes experiences the world. It was from such questioning that a desire to know the cultural worlds in which Aboriginal peoples experiencing diabetes live as human beings was satisfied. *Aboriginal experiences of living with diabetes are profoundly different from non-Aboriginal experiences as they have come to be known.* At a time of rapid global change and increasing social, political, and cultural complexity, there is a growing need to view Aboriginal diabetes as an epidemic. Among public, voluntary, and health-sector organizations, there is an urgent need to understand the evolving phenomenon of diabetes as experienced by Aboriginal peoples, to develop strategies based on the stories they are constructing about themselves as diabetic peoples, and to respond to the challenges that shape who they are while living with diabetes as a process of healing and well-being.

The research revealed an awareness of profound cultural differences: an understanding of an Aboriginal diabetic self through George's stories, Aboriginal experiences of diabetes through Emilie's stories, a recognition of diabetes as a gateway to Aboriginal healing through Violet's stories, and Aboriginal reflections of living with diabetes through Hazel's stories. These are rich narratives in which the participants speak of language and spirituality; family and social networks; elders; cultural and communication patterns; diabetes issues and concerns; diabetes care; illness and bereavement practices; and traditional healing options. Their thoughtful, penetrating insights into cultural orientations, into diabetes as a process of healing and well-being, and into underlying belief frameworks reveal

the profound difference between Aboriginal and non-Aboriginal experiences of diabetes.

Consistent with the work of Kelm (1999), the findings suggest that nurses and other health-care providers have a limited understanding of Aboriginal history and the colonial relations that influence Aboriginal health and illness, especially chronic illness. This poor understanding is also likely shaped by “de-socialized” notions of how people experience diabetes as a chronic illness. Postcolonial theories serve to remind us of the forces of colonization that shape health care and people’s experiences of diabetes in ways that are profoundly important to nursing. Like most indigenous groups globally, Aboriginal Canadians have, throughout their history, experienced ethnic destruction, broken treaties, forced displacement, wars, imported illnesses, legal discrimination, and human rights abuses. Although their health circumstances are improving, they have the shortest lifespan of any ethnic group in the country and continue to experience some of the highest mortality and morbidity rates. The cultural orientations inherent in the notion of an Aboriginal diabetic self are entwined with notions of Aboriginal identity. One cannot generalize when speaking of Aboriginal Canadians, because the cultural orientations of an Aboriginal people are unique to their particular tribal community (e.g., the Nuxalk Nation of Bella Coola) and to their influence on the formation of a diabetic identity. Essential to the harmonious balancing of diabetes, culture, and wellness is recognition of the fact that Aboriginal people with diabetes have many stories to tell and that these stories need to be valued and to be accorded the same respect as life stories.

In non-Aboriginal cultures, learning is sometimes separated from experience. Although some Western epistemologies and philosophies of science (i.e., Cartesian) may disconnect knowledge and experience to some degree, there are many epistemologies that do not. For the scientist Michael Polanyi (1969), for instance, experience is the basis for all inquiry and knowledge. Also, there are many non-Aboriginal postmodernist scholars who do not separate learning from experience; these include scholars working from a critical feminist location (hooks, 1989) and those exploring relational epistemologies (Thayer-Bacon, 2003) or social constructionist learning theories. In traditional Aboriginal teachings, experiences are always connected to learning. Inquiry into the Aboriginal experience of diabetes concerns the holistic experience of living with the disease. It begins with an Aboriginal person who is living with diabetes and experiencing healing and wellness, not just weakness and sickness. George, Emilie, Violet, and Hazel tell us what it is to be a diabetic person experiencing wellness. They know that, if they start there, the strength and resources within other Aboriginal people who have diabetes will be seen first. They are aware of the need to shift away from the

labelling of people with diabetes and from a focus on diabetes as pathology. Yet the more one attempts to explain diabetes, the more one removes it from its context.

In sharing their Aboriginal stories of diabetes, the participants did not try to define an experience of diabetes; rather, they always located it within a context of living and values. Diabetes is, then, seen as a living thing, just as Aboriginal cultures must be viewed as living things. When Aboriginal experiences of diabetes are explored as living things, they become complex things, because they will vary. The Aboriginal stories of diabetes told by the participants may not change, but those who hear them will change. Those who hear the diabetes stories again and again over time, and acquire different experiences, will come to truly understand them and be influenced by them.

In terms of context, language and spirituality are critical factors. The primary language of the participants was English, and cultural differentiation was revealed through various Aboriginal phrases and words that often were worked into everyday speech. Some of the participants still knew their Native language but spoke of experiencing interruptions in speaking the language of their ancestors, then relearning the language and passing it on through special cultural classes held in the school located in their community. From a spiritual perspective, the participants mixed some form of Christianity or other religion with Native spirituality, which they spoke of practising in ways that guided their approach to life, including their diabetic life, in a sacred and holistic manner.

In terms of family and social structure, the participants placed great emphasis on children, family, and extended family, revealing how the notion of family formed the basis of their Aboriginal societies. Depending on the particular social experience or situation, the participants also spoke of their cultures as placing a heavy emphasis on individuality, equality, and the important roles played by each person in the family, the group, the community, and the society. Each participant placed great value on the elders and their practical knowledge, including diabetes experiential knowledge. The participants spoke of teaching younger people to always treat elders with respect and to be responsible for bringing honour upon one's family, tribe, ancestors, and community.

The participants revered their elders and ancestors for their wisdom, knowledge, and advice. They spoke of the tensions that now existed in some families as a result of acculturation, poverty, and the breakdown of traditional Native society, but also of the continuing acts of reverence towards the elderly. By telling their Aboriginal stories of diabetes, the participants sought to view the world from different eyes and to move away from one pattern of diabetes practices to embrace many ways of responding to diabetes. They played an important part in decisions that affected

the well-being of the family, particularly in terms of the love extended to children and grandchildren. They also played a significant role in decisions that affected the healing and well-being of family and community members with diabetes as well as in the healing process and wellness.

Part of the Aboriginal healing process and wellness with regard to diabetes is realizing that there are many ways of perceiving the world. The participants did not tell just one story. They told many stories, in order to share as many perspectives as possible, because that is what is entailed in finding harmony. Harmony exists only as a result of difference, because everyone will not experience diabetes in the same way. This diversity is inherent in finding a harmonious balance between diabetes, culture, and wellness. Recognizing diabetes as a gateway to Aboriginal healing, the participants viewed diversity as something to be celebrated. Their cultural style of communicating was reserved, thoughtful, and subtle, their feelings and emotions expressed in a direct way. Their voices were always calm, soft, and polite, their conversation characterized by long pauses, silent reflection, metaphor, and more stories.

From a healing and wellness perspective, the participants' narratives reflected both difficulty and ease with accessing diabetes care in their community. Transportation and geographic barriers posed by living in Bella Coola were significant, particularly if the weather was harsh or if there were health-care providers who were new. This was part of the healing perspective and a way of recapturing one's wholeness. Part of finding that wholeness were stories about the valuing of traditional healing practices mixed with stories revealing both comfort and discomfort in seeking care from health professionals in a clinic or hospital. Within those contexts, the participants spoke of family and community members experiencing many conditions besides diabetes, including obesity, alcohol misuse, and accidents that were fatal or resulted in severe, disabling injuries.

Diabetes as a gateway to Aboriginal healing and well-being is about the reclamation of wholeness. It is about forming diabetic identities, retaining one's language, reclaiming spirituality, and whatever it is that makes a difference. It is about a healing and wellness process in the sense of reclaiming wholeness of mind, body, and soul. And it is about reclaiming wholeness of the universe, perceiving balance and imbalance within it, because human beings are reflections of the wellness of the universe. The healing process is not only making food choices within perceptions of a modern diet consisting largely of starch, refined carbohydrates, and fat, but also those steps taken to heal Mother Earth. Our consumption of her, just as with fresh fruit, vegetables, and traditional foods, has changed over time, due to a variety of factors. On a grandiose scale it relates to our need for a higher standard of living, and on a small, practical scale it

relates to Aboriginal people's limited incomes, availability of consumer goods, and acculturation. Another influential factor, however, was the change in the participants' diets related to living with diabetes and eating the particular foods that make a diabetic person heal and feel well. These changing conditions were expressed along with physical symptoms such as aches, pains, and fatigue. They were also combined with emotional despondency, which was perceived as caused by one's disharmony with the environment, with the spiritual world, and within personal relationships. The participants' stories revealed that mental imbalances can be seen as resulting from violations of cultural prohibitions, negative energy, and evil spirits. They also revealed that spiritual practices and traditional ceremonies are part of the pursuit of harmony between being diabetic, being Aboriginal, and being well.

The participants recognized a variety of treatments for diabetes, a condition they viewed as having been introduced to indigenous cultures by outsiders; they considered mainstream medical care to be the most appropriate treatment. Their stories revealed that diabetes is at times treated concomitantly with traditional medicinal, spiritual, and ceremonial purification practices. Their stories also related Aboriginal experiences of alcohol misuse, which was considered an extreme reaction to one's imbalance in relation to self, others, and the world. These stories about alcohol misuse were connected to those about loss of culture, identity, and Aboriginal souls.

Last, Aboriginal reflections of living with diabetes had to do with interpreting a sacred phenomenon: the participants always spoke of reclaiming wholeness as sacred work. The interconnected narratives comprised stories of bereavement and of family members and friends visiting an ill or deceased person. Depending on how traditional the people in the stories were, those visited would be the subject of a variety of healing ceremonies, often performed communally. The stories told of the spirits of the dead being honoured regularly for generations, and of death being merely the beginning of a journey into the next world. These stories in particular demonstrated the profundity of the participants' belief in the healing power of plants and herbs, their strong connection to the earth and the universe, and their deep respect for all things, both living and non-living.

These reflections on more sacred work led to stories about healing and wellness frameworks that were holistic, combining physical, mental, emotional, and spiritual well-being. Physical problems were understood as usually caused by emotional, mental, spiritual, and physical imbalances. Harmony and a sense of balance in all things, including mind, body, spirit, and the environment, were considered important to a sense of wellness. The participants helped me to interpret their healing beliefs

related to diabetes as more circular and indirect than the linear cause-and-effect view of mainstream medicine. Thus diabetes as a process of healing and well-being cannot be separated from spirituality; it goes beyond religion to reflect the interconnectedness, sacredness, and balance of all things.

Existential Understandings of Aboriginal Diabetes

The second overarching interpretation stems from the discovery of an existential framework by which the participants' life narratives and Aboriginal stories of diabetes were understood. *Existential understandings of diabetes in relation to time, place, body, and relationship are connected to an Aboriginal person's distant past, recent past, and present life.* It appears that, due to a demand for evidence-informed practice, analysis, and understanding, organizations that would never have done so in the past — or would not have done so with such intensity — are now conducting social sciences and humanities research focused on experience. The knowledge generated by having Aboriginal people tell their stories of diabetes is providing alternative interpretations of the tensions and conflicts that emerge in a world rife with consequences, values, politics, and moral dilemmas.

Based on an existential framework for interpreting the meanings in Aboriginal stories of diabetes, time was revealed to be a dimension in which past, present, and future are a continuous whole and in which the diabetic self is embedded within one's life narrative. The sense of place described in the stories not only revealed a dimension in which situation renders inseparable Aboriginal people, the land, and their stories, but also elucidated how Aboriginal experiences of diabetes are embedded within one's life narrative. The body was revealed to be a dimension in which the physical presence is both visible and concealed to oneself and others and also a dimension that elucidates the ways in which diabetes as a gateway to healing is embedded in one's life narrative. And the interpretation of relationship revealed a dimension in which human beings are interconnected with others and also elucidates how Aboriginal reflections of living with diabetes are embedded in one's life narrative.

One is much more likely to appreciate the details of such interconnectedness of cultural knowledge, which has implications for diabetes practices, diabetes research, and health policy, if they are presented through the existential notions of time, place, body, and relationship. Existential understandings of diabetes are firmly connected to an Aboriginal person's distant past, recent past, and present life in terms of the notion of an Aboriginal self, inquiring into Aboriginal experiences of diabetes, recognizing diabetes as a gateway to Aboriginal healing, and interpreting Aboriginal reflections of living with diabetes. Such a frame-

work also allows for a sense that culture is only one of many factors that influence healing and well-being. Age, gender, income, literacy, education, lifestyle, amount of time in a particular location, personality, and so on are equally important to a holistic understanding of Aboriginal experiences of diabetes.

Such contemplation from multiple viewpoints will contribute to the creation of a platform of human understanding upon which social structure and human agency intersect. Further, acts of conducting research, questioning, and theorizing serve to enrich our quest to know ourselves, our histories, our cultures, and our successes and failures, all of which shape our being in the world with others. During the present inquiry, I experienced a pedagogy of thinking and doing (theory and practice) by serving as witness to the Aboriginal stories of diabetes. By pedagogy, I mean the process of teaching, treating, responding, educating, or generally being with Aboriginal people who have diabetes, which requires constant acting in situations of experience and relationship.

Last, an existential understanding of Aboriginal diabetes underlines the importance of valuing an alternative culture of research through a focus on relationship. The concept of relationality is key to increasing engagement with the knowledge hidden within Aboriginal experiences of living with diabetes. It was viewed from a critical cultural perspective that infers relationality in context, with an understanding that it is shaped by social, political, and historical factors (Doane & Varcoe, 2005). In terms of what relationality looks like in the context of the researcher-participant relationship, the choice of a relational methodology — narrative inquiry — located Aboriginal epistemology within it. Methods provided ways to develop awareness of identities and power differentials that existed in the process of conducting research. An equitable relationship between the researcher and the participants, for instance, was achieved through the narrative inquiry process of co-participation and co-construction of Aboriginal stories of diabetes, resulting in feelings of empowerment by participants.

Thus, relationality led to other questions about meaning that arose from further interpretation, originating from a storied landscape of Aboriginal diabetic knowing. This is a particular kind of knowing that recalls Smith's (1994) writings on the hermeneutic imagination and the pedagogic text. How can we orient our lives with those of Aboriginal people who are experiencing diabetes when we can no longer take for granted what the Aboriginal diabetic person is, in any discrete sense? How can we orient our lives with theirs when we do not make problematic all of the usual categories for understanding Aboriginal experiences of diabetes in our mainstream culture (high blood glucose levels, behavioural non-compliance, obesity, etc.)? And how can we orient our

lives with theirs when we consider questions of meaning of Aboriginal diabetic identities as those which cannot be answered except self-reflexively — that is, from the question of who I am in relation to my practice and research? These are questions that require serious consideration if they are to be answered in ways that entail authentic relational action.

Acts of Mutual Respect and Caring

The third overarching interpretation originates from doing research on the diabetic person's secrets and intimacies, which constitute the world of diabetes and require that acts of caring be part of the research process (van Manen, 1998). *Mutual respect, as in Aboriginal experiences of being honoured, may be understood as the ways in which one person thinks and behaves towards another person through acts that express high regard and caring.* One is reminded of the words of Goethe (1963), "One learns to know only what one loves, and the deeper and fuller the knowledge is to be, the more powerful and vivid must be the love, indeed the passion" (p. 83). In other words, loving the people one knows allows one to know the people one loves. This makes me connect my own personal experience of becoming a mother to my deepened and fuller knowledge of relationality within the family. From a new angle, I am discovering, by being in relationship with my daughter, what love is, why it has to be shared, and how my passion for my daughter feeds me so genuinely. It is interesting that people tend to relate more lovingly to each other when children are present. We all have an enormous capacity for loving, and my daughter reminds me every day that we must give energy to others. I am gaining from my daughter a deeper sense of what people experience when they want to have more relationships in their lives, want to love within all of these relationships, and want to be loved within them in infinitely different ways. Family has become for me an island of light, amusement, and wisdom. It is a place I run to with my discoveries, torments, and hopes, at any time of day, and feel welcomed.

In the retelling of our professional relational experiences, caring acts, love, and passion need to be recognized and acknowledged in our work together. The sharing of such personal reflections and what they mean may contribute to the creation of new scholarship possibilities. In our research, we need to aspire to the kind of scholarship that fosters partnerships characterized by culturally competent practice and that promises to benefit Aboriginal people themselves. This depends on relationality, but our health-care and research systems hold new possibilities for dialogue — possibilities for people to develop the ability to interpret their inner and outer worlds and to find the strength they need to overcome their specific diabetic challenges. It is through that inherent strength that

they come to realize that their responses to diabetes are often experienced concomitantly with the trials and tribulations of a host of other illnesses, adversities, and tragedies.

These kinds of research partnerships, which do not shy away from relationality with Aboriginal participants, if on the right track, will raise questions about the ownership of knowledge, as well as the ethical questions and dilemmas that emerge from experiences of being in relationship with Aboriginal peoples. It will also require researchers to ask themselves what it means to be in respectful relationships with Aboriginal participants. Wilson (2003) explains:

The concept of relationality permeates recent scholarly writing by Indigenous scholars. They question whether in fact it is even possible for [colonial] system researchers to understand this concept with the depth that is required for respectful research with Indigenous peoples. (p. 173)

The issue of relationality is key to Aboriginal diabetes research. It determines what kind of relationship Aboriginal people want with researchers, both non-Aboriginal and Aboriginal, and the ability of Aboriginal people to work with practitioners. We need to ask whether it is even possible for practitioners and educators to understand this concept with the depth that is required in order to provide respectful diabetes care for Aboriginal people. It is in contemplating such questions, I believe, that this inquiry informs and offers guidance with respect to culturally congruent care, or “sensitive, creative, and meaningful care practices to fit with the general values, beliefs, and lifeways of clients” (Leininger & McFarland, 2002, p. 12). The inquiry also offers guidance with regard to cultural safety, which is awareness of power imbalances, the nature of interpersonal relationships, and institutional discrimination, whereby the recipients of care decide whether or not they feel safe with the care given, the level of trust established, and differences in perceptions identified and negotiated (Browne & Fiske, 2001).

As a person with nursing practice, education, and research experience, I believe that health professionals who conduct research are in an excellent position to contribute relational, culturally competent expertise in diabetes-related practice, education, and research. Cultural competence may be defined as “the explicit use of culturally based care and health knowledge in sensitive, creative, and meaningful ways to fit the general lifeways and needs of individuals or groups for beneficial and meaningful health and well-being or to help them face illness, disabilities, or death” (Leininger & McFarland, 2002, p. 84). It will be meaningful, however, only if it incorporates Aboriginal perspectives and theoretical explorations of culture, as well as cultural differences and context-specific knowledge about poverty, into the relationality and dialogue of cultur-

ally competent work, and only if it considers the time required to establish, maintain, and sustain relationships within active, busy lives.

But as a result of enlightened leadership within research, pressing Aboriginal health issues are being addressed, new approaches adopted, and new methodologies applied. At the same time, scholars who conceive of knowledge development as a social and communicative process are in a position to close the gap that exists between theory and story. Much of what we do as social and cultural beings is to tell our stories. It is only through the personal expertise needed to negotiate a relationship based on authentic mutual respect, which is also reciprocal, shared, and constantly interchanging, that knowledge derived from understanding Aboriginal experiences emerges.

Last, the narrative inquiry was about eliciting from life stories the insight, essence, and resonance of our philosophical and cultural expressions and our desire for them to be recognized. Congruent with Aboriginal ontology and epistemology, the relationships formed were about witnessing a contemplative effort by Aboriginal people to reclaim confidence in their identities, impart a political voice, and heal from colonial injustices. It was about developing a relationship with four participants in order to know a whole life. As a result, the participants were *at home* with the study, as was I as the researcher.

Thus the concept of relationality as part of an alternative research culture recognized the unity or coherence of a life story in which the experience of living with diabetes as a process of healing and well-being was nested. It was about new ways for the participants and the researcher to engage with each other. It was also about analyzing the existence of temporality, memory, and imagination, which influenced both the participants and the researcher as well as our experiences of the research process itself. I believe that relational forms of inquiry will advance nursing development and practice beyond the boundaries established by methodologies that claim to know another culture on the basis of brief encounters. Thus continuous reflection on the concept of relationality within the inquiry provided me with ways of conducting research with George, Emilie, Violet, and Hazel, all of which spoke “narratively, to the ebb and flow of our overlapping lives, and to the creative new ways research by nurses can be developed and practiced” (Barton, 2004, p. 525).

Cross-Cultural Contributions

In examining the cross-cultural contributions, I focus on what the inquiry can mean to Aboriginal people living with diabetes, to their families, to their communities, and to the world. Included are reflections on

Aboriginal diabetic issues and concerns within a context of cultural differentiation, cultural complexity, and cultural interaction. The cross-cultural evidence includes notions of being diabetic, being Aboriginal, and being well, within an Aboriginal framework of diabetic seasons. Themes within the diabetic stories could help to lay the foundation for sounder social health policies. The intention is to reveal yet other ways that the Aboriginal diabetes experience may be positioned amid streams of thought. As van Manen (1998) suggests, “to *know* the world is profoundly to *be* in the world in a certain way, the act of researching — questioning — theorizing is the intentional act of attaching ourselves to the world, to become more fully part of it, or better, to *become* the world” (p. 5).

Diabetes, crises, stress, illness, and aging exist in all societies. Each culture has developed its own ways of defining well-being and making sense of physical, mental, emotional, and spiritual imbalances, its own ways of preventing or responding to disharmony within healing paths, of managing physically altering events and phases, and of establishing roles and behaviours for both health professionals and recipients of diabetes care. The behaviours encompassing diabetic disharmony and well-being are not ones we possess at the point of diagnosis but rather ones that we learn and share through cultural processes over time.

Aboriginal perceptions of place consider hidden connections between humanness and the natural world. Aboriginal perceptions of body consider the deep significance of healing and well-being while living with diabetes. And Aboriginal perceptions of relationship consider honouring the diabetic self whose identity evolves beside family, friends, and community.

It was not until I spent time in First Nations communities as an outpost nurse, living partly with Aboriginal people, that I began to observe lives in self-transformation, self-reflection, and self-learning. It was there that I developed an appreciation for diabetic issues and concerns within a context of cultural complexity. This appreciation led to a true recognition of the cultural differences between colonial views of health and illness and Aboriginal views of healing and well-being — to a witnessing of culture(s) as context and interaction.

There, amidst the nursing realities of sparse living conditions and historical and religious influences, I began to take a deep interest in the quality of life. This enabled me to position myself as a researcher alongside participants in a relational landscape. Thus this inquiry into the Aboriginal experience of diabetes had its beginnings in my advanced nursing practice, where I developed a fascination with the circumstantial nature of our lives. I began to listen as I had never listened before — actively, sensitively, emotionally, and viscerally.

Professional Contributions

The narrative inquiry provides health professionals with reflections on practical matters arising from a concern with ethical issues and cultural pluralism, development of culturally competent knowledge, programs of diabetes care, and social health-care policy. The fundamental emphasis of the health professions on understanding and treating diabetes (medicine) or understanding and treating human responses to diabetes (nursing) lends itself to a concern for Aboriginal cultures. Indeed, it is primarily through nursing that I have discovered a deep interest in culture as an experiential phenomenon. It is the complex concept of Aboriginal cultures that lies at the heart of the difference between understanding and treating diabetes, or understanding and treating human responses to diabetes, both effectively and ineffectively.

When as health professionals we correct abnormal blood glucose levels, adjust oral glycemic medication, or prescribe antibiotics for infection, we seldom consider the cultural influences on an Aboriginal diabetic person. I would like to believe we are beyond the view that diabetes is diabetes whether it is managed in the city of Vancouver, in the Bella Coola Valley, or in rural British Columbia. But the reality is that because of our colonial tendency to view diabetes through a lens of human physiology, we focus much less on understanding it through a lens of relationality in the context of traditional and contemporary medicine.

The primary focus of health professionals is not just the provision of treatment per se, but the Aboriginal person who decides to receive the treatment, heed the advice, and persist with the changes inherent in a challenging diabetic life. Nursing and the health professions, therefore, are profoundly influenced by ethical issues and cultural pluralism. Even in situations where traditional medicine has been severely colonized, there exists a context of traditional medicine where being diabetic, being Aboriginal, and being well are located. It is in those situations that Aboriginal interest in the effectiveness of traditional remedies for the management of symptoms related to being ill reveals aspects of cultural pluralism. And it is in those interpretations where Aboriginal interest in the effectiveness of traditional remedies for the management of symptoms related to being ill reveals aspects of cultural pluralism.

It is in the integration of ideas about Aboriginal healing drawn from family and community medicine, and reflective of physical, mental, emotional, and spiritual well-being, with colonial medicine that responses originate and are sometimes made visible. Aboriginal people learn to honour these connections between thinking and wisdom, and then act on those perceptions of body, mind, and emotion, deriving from the

spirit the humanness that guides their understanding of diabetes. It was by being with Aboriginal people in all facets of storied life that I could witness the turning of the pages of diabetes stories. They were stories within stories, and they spoke of ethical issues and cultural pluralism as a result of living with diabetes, whereby a humbling, compassionate, and honoured existence became known. Thus only slowly and gradually, and only because of patience and a desire to inquire narratively, did I succeed in learning something of significance.

When Aboriginal people are given a reason to share their life stories, a glimpse into their identity stories reveals an ethic guiding their humanness. This ethic directs the colourful threads of a life — the depth of existence to live by, to be transformed by, and, through transcendence, to be remembered by. It is where the underlying principles of balance, harmony, and respect, which are common across the indigenous world, provide the foundation for the development of culturally competent knowledge and diabetes programs of care. Aboriginal life stories invite one to listen, and listen again, to Aboriginal diabetic self-stories. They leave us with a deep sense of what it means for an Aboriginal person to live a life through the influences of traditional and contemporary medicine, where issues of self-government, socio-economic development, and environmental protection are not separated from community health development. This is where Aboriginal social health policy is best realized — not in the inertia of broad social structural change but in the changes that occur through community-based diabetic initiatives. Thus the concept of diabetic healing, which integrates traditional medicines and professional services, may be considered a significant, culturally safe development.

Health professionals need to connect with Aboriginal people who have diabetes, recognizing that each person is part of a family and a historical community — a place within the *stream of time*. We need to connect with families and communities in order to affirm and value the language, cultural practices, and knowledge of the people, in partnership with them, in order to build new relational practices that overcome the colonial remnants — *images of time*. We need to pay attention to the realities of the communities where we practise and live. We have a responsibility to participate in the creation of new possibilities for dialogue, as in an existential understanding of diabetes as the *sugar clock*. And because effective practices of health professionals take place in relationship with Aboriginal people, who experience diabetes within an unfamiliar body, we need to keep in mind their broader existence and the complex historical contexts of culture, ancestry, and environment. We begin to negotiate a relationship with an Aboriginal person in the midst of *feeding the diabetic body*, dealing with *exercise and body weight*, and trying to manage

body discomfort. We explore, in respectful ways, how to walk with them through intersections of multiple world views and perspectives in relation to *working on the diabetes* and *figuring the diabetes out*.

Theoretical Contributions

An inquiry into Aboriginal stories of diabetes must be situated within the complexity of sociocultural realities. What sociocultural realities are socially significant for our understanding Aboriginal experiences of diabetes? Critical social theorists (Freire, 1990; Habermas, 1971) and post-colonial theorists (Bhabha, 1994; Thomas, 1994) would argue that any in-depth analysis must include, in addition to cultural difference, the influence of the colonization and power relationships within which diabetes, healing, and well-being take place. In the present inquiry, the stories of four people living with diabetes were intended to illustrate how, in their daily lives, these people attended to both culture and colonization. They all, in different ways, integrated language and cultural knowledge into their lives and drew upon cultural norms and values. In doing so, they developed equitable relationships and processed the influences of colonization.

Within the stream of thought of critical social theory lies the potential for developing a critical consciousness within a shared view of the dialogical and developmental human being. The inquiry captured the social significance of the concept of self and the capacity for transformation. By focusing on four Aboriginal elders living with diabetes, the inquiry elicited a view of the transformative self within their positive, non-stereotyped construction of images, which revealed Aboriginal reflections of *honouring the diabetic self*. These were people who passed on traditional knowledge, especially traditional healing knowledge, and who, through special connections to the healing spirit, had strong cultural as well as diabetic identities. They illuminated a notion of human enlightenment that was *walking in both worlds*, which was revealed to themselves and others as the ability to engage in culturally overlapping realities.

In terms of colonial power relationships within Aboriginal stories of diabetes, the experiences and situations of the participants contained remnants of their relationships with health professionals, particularly during initial relational encounters. As a result, I was able to discern how the four people sought places and ways in which to develop relationships outside the formal relationships of health and illness with their inherent or assumed hierarchical structure. Hospitals and clinics can be intimidating places for any diabetic, more so for a diabetic whose healing experiences have not always been favourable and have at times been painful. The participants had vivid memories of colonial relationships, consisting

of authority, control, and unilateral decision-making, which in fact still existed outside the traditional medicine system followed in their Aboriginal community.

The type of relationship sought by these elders was in fact more of a partnership, in which *a diabetic self is revealed to others* — people who can be trusted. The traditional colonial relations between non-Aboriginals and the community were being replaced by meaningful community participation in a school curriculum framed by language and culture and by the active pursuit of family involvement and support. Such strategies had resulted in *a diabetic sense of community* — a view of diabetes care and awareness located within teaching-learning-sharing relationships between diabetics, health professionals, and community members and based on a relational philosophy, whereby each person with diabetes is part of a family and a community. By using cultural norms in their life stories, the participants illustrated their respect for Aboriginal beliefs and practices related to traditional medicine. They brought to life notions of Aboriginal holism, the use of metaphor in thought and speech, and existential understandings of diabetes that included time as *cultural time* and place as the *resonance of lived space*.

In terms of the relational literature, I discovered amid indigenous scholarly writings, such as those of Battise (2000) and Smith (1999), a focus on social struggles enacted in social practices wherein Aboriginal people encounter an ethnocentric perspective, authoritative relationships, racist attitudes, and prejudicial perceptions of inferiority or deficits. I came to realize that conditions such as these have been experienced in colonial systems of health care, causing some Aboriginal people to resist the oppression by participating as little as possible.

George, Emilie, Violet, and Hazel, despite the obstacles, have engaged and even excelled in acts of diabetic healing and well-being, in part because, as told in their stories, they have attended to issues of both culture and colonization. Their stories have, in a holistic way, incorporated Aboriginal culture, language, community norms, and values, their mutually respectful relationships helping them to process the influences of tragedy and hardship. It was not only what they did, but how they did it, that was significant. Their stories tell of interrelationships and connections not only to people but to the past (*echo of the past*) and to present-day *situations and experiences*.

Their narratives are not yet complete. They are part of an ongoing discovery of how living with diabetes can serve to overcome ineffective diabetic practices and can involve other diabetics, families, and communities in knowing a world of diabetes that is not only forgiving but accommodating and gracious. They bring to life diabetic notions that contain lessons for others living with diabetes and also demonstrate respect for

different contextual relationships. The stories advance practice and research in relation to Aboriginal experiences of diabetes, for what happens in their narratives cannot be separated from their daily lives with other diabetic people or with families, friends, or the community in which they live. Thus George, Emilie, Violet, and Hazel *become the space they are in*, whereby the focus of diabetes as a practice of healing and well-being is the creation of opportunities for listening, learning, and sharing in *landscapes of transformation*.

Conclusion

Three overarching analytical interpretations emerging from the inquiry can contribute broadly to Aboriginal health research. I have been able to draw several conclusions about the importance of conducting research on the experiences and narratives of diabetes in a First Nation community. The purpose of the inquiry was to expand or transform our understandings of diabetes within a specific cultural context. The discussion centred on various philosophical, epistemological, and methodological orientations to research with Aboriginal people living with diabetes.

The elicitation of Aboriginal life stories and diabetes stories within a process of narrative inquiry provided an opportunity to look for material supporting alternative explanations within cultural experiences of diabetes. Each interpretation was plausible because of its supporting contextual evidence. The inquiry served to highlight the value of analyzing stories at a universal as well as local level over a number of years.

The inquiry was also intended to help nurses and interdisciplinary health-care providers better understand diabetes in Aboriginal communities. The rich descriptive insights of the Nuxalk culture and its connection to the narratives of diabetes provide a context for understanding how diabetes can and ought to evolve in nursing research and practice. The interpretations presented are rich and local. It was through this awareness and methodological approach that I theorized the complexity of the diabetes experience within a First Nation community and how such knowledge can help nurses to engage with and promote the health of First Nations peoples.

The process of translating aspects of Aboriginal healing philosophy into practice also entailed my interpretations as a co-participant with the four Aboriginal people living with diabetes. A synthesis and discussion of those interpretations through the cross-cultural, professional, theoretical reflections responded to questions about the landscape of the Aboriginal diabetes experience in Canadian society (Clandinin & Connelly, 2000). Such reflexivity revealed the participants' narratives of diabetes as well as the creative responses and adjustments that existed in their diabetes and

life experiences. It displayed the insights circumscribed by relationships, history, and the land, as well as favourable constructions of Aboriginal healing needs and identities, which can lead to improved Aboriginal health generally. It puts forward a more balanced perspective of the Aboriginal experience of living with diabetes in a thriving knowledge society. It is a location where opportunities to peer into the narrative spaces of understanding and explanation that emerge from identity stories make a difference in a world of growing cultural integration, increasing social complexity, and rapid technological change.

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Évaluation d'une intervention favorisant la perception personnelle chez les adultes souffrant d'un diabète de type 1 et d'hypoglycémie non perçue

**Cheri Ann Hernandez, Margaret R. Hume
et N. Wilson Rodger**

L'objet de cette étude prospective avant-après était de déterminer les éventuels avantages psychosociaux et physiques d'une intervention favorisant la perception personnelle chez les adultes souffrant d'un diabète de type 1 et d'hypoglycémie non perçue (HU). Vingt-neuf adultes en tout ont participé aux 8 séances d'intervention, d'une durée de 3 heures chacune. Des mesures psychologiques (intégration, qualité de vie des personnes diabétiques) et physiques (nombre de signaux corporels, événements liés à la non perception de l'hypoglycémie, HbA1c) ont été faites au départ, puis 6, 12 et 18 mois après les séances. Après l'intervention, les participants détectaient davantage de signes d'euglycémie et d'hypoglycémie; leur intégration et leur contrôle métabolique (HbA1c) présentaient également une hausse significative. Le nombre d'événements liés à la non perception de l'hypoglycémie n'avait pas diminué et on notait des résultats instables en ce qui concerne la qualité de vie des personnes diabétiques. Une intervention favorisant la perception personnelle peut avoir des avantages physiques et psychosociaux, de même qu'elle a des implications pour l'éducation en matière de diabète. Cette intervention doit être testée dans une étude contrôlée, randomisée et multicentrique.

Mots-clés : signaux corporels, perception du diabète, hypoglycémie non perçue, intégration

Evaluation of a Self-Awareness Intervention for Adults with Type 1 Diabetes and Hypoglycemia Unawareness

**Cheri Ann Hernandez, Margaret R. Hume,
and N. Wilson Rodger**

The purpose of this prospective before-and-after study was to determine whether there are psychosocial and physical benefits of a self-awareness intervention for adults with type 1 diabetes and hypoglycemia unawareness (HU). A total of 29 adults participated in the self-awareness intervention of 8 sessions, each lasting 3 hours. Psychosocial (integration, diabetes quality of life) and physical (number of body cues, HU-related events, HbA1c) measures were taken at baseline and at 6, 12, and 18 months post-intervention. Post-intervention the participants detected more cues of euglycemia and hypoglycemia and experienced significant increases in integration and metabolic control (HbA1c). The number of HU-related events was not decreased and diabetes quality-of-life results were unstable. A self-awareness intervention can have physical and psychosocial benefits and has implications for diabetes education. This intervention needs to be tested in a multi-centre randomized control trial.

Keywords: body cues, collaborative alliance, diabetes self-awareness, glycemic control, hypoglycemia unawareness, integration

Introduction

Hypoglycemia is considered the main obstacle to achieving consistent glycemic control in type 1 diabetes. The risks and fears of hypoglycemia are compounded with the development of hypoglycemia unawareness (HU), which is manifested by decreased ability to perceive or discern the onset of hypoglycemia (Frier, 1993). HU is a serious clinical problem in the treatment of type 1 diabetes, occurring in up to 50% of long-term patients (Pinn & Gale, 1992).

Factors that cause alterations in the normal glucose counterregulatory system, such as frequent hypoglycemia (Cryer, Davis, & Shamoon 2003; Liu, McManus, & Ryan, 1996), longstanding diabetes (Pinn & Gale, 1992), and intensive insulin therapy (Liu et al., 1996), are associated with the development of HU. The main clinical concern with HU is greater risk of severe hypoglycemic episodes (Cryer, Fisher, & Shamoon, 1994;

Pinn & Gale, 1992), with its many concomitant risks such as accidents, loss of consciousness, seizures, and even death. HU may also have a detrimental impact on quality of life (Wredling, Theorell, Roll, Lins, & Adamson, 1992). The management of HU is multifaceted. It may include assisting individuals to become more aware of cues associated with varying glycemic levels. Inability to recognize glycemia-related cues precludes prompt treatment for abnormal blood glucose, thus preventing adequate self-management of diabetes. The present study entailed a self-awareness intervention (SAI) for adults with type 1 diabetes and HU.

Background

A growing body of literature points to the need to help patients become more sensitive to their individual glucose-related cues and symptoms, particularly those indicating hypoglycemia (Cryer et al., 1994; Hernandez, Bradish, Rodger, & Rybansky, 1999; Hoffinan et al., 1989). The ability to sense blood glucose fluctuations is an important aspect of self-management of type 1 diabetes (Cox et al., 1989). Patients frequently maintain blood glucose at high levels to offset fear of hypoglycemia, which puts them at increased risk for chronic complications such as retinopathy, neuropathy, and nephropathy (Diabetes Control and Complications Trial [DCCT] Research Group, 1993). Self-monitoring of blood glucose indicates the blood glucose level at the time tested, so hypoglycemia may go undetected even in those who are monitoring regularly. In addition, patients who have switched from fingertip to forearm testing may miss hypoglycemic episodes due to the inaccuracy of forearm testing at hypoglycemic levels (Meguro, Hosokawa, Funae, & Atsumi, 2005).

The educational approach of teaching patients a core group of symptoms for hypo- and hyperglycemia can actually contribute to misdirected adjustment to the diabetes regimen, because these symptoms may not be the characteristic glycemia-related cues experienced by individual patients (Hernandez, Bradish, et al., 1999; Weinger, Jacobson, Draelos, Finkelstein, & Simonson, 1995). Some persons with HU have symptoms of hypoglycemia that they had not previously recognized and so might benefit from interventions to help them recognize those early warning signs (Clarke et al., 1995). Several studies have found that individuals can be taught to become sensitive to blood glucose levels (Cox et al., 1989, 1991; Cox, Gonder-Frederick, Julian, & Clarke, 1994; Hernandez, Laschinger, Rodger, Bradish, & Rybansky, 2004) and that sensitivity can be sustained over time (Cox et al., 1994). Sensitivity to blood glucose levels is enhanced through the identification of a greater number of symptoms for hypoglycemia (Cox, Cryer, Gonder-Frederick, Clarke, &

Antoun, 1993), with a combination of internal and external cues (Cox et al., 1989; Hernandez, Bradish, Laschinger, Rodger, & Rybansky, 1997), and through a variety of self-tests (Hernandez et al., 1997). Research has focused on improving awareness of blood glucose cues through Blood Glucose Awareness Training (Cox et al. 1989, 1991, 1994; Nurick & Johnson, 1991) and self-awareness education (Hernandez et al., 2004). To our knowledge, however, no intervention has specifically targeted only persons with HU. The present evaluation of a self-awareness intervention was designed to enhance self-awareness in type 1 adults with HU.

Conceptual Framework

This research was conducted within the theoretical framework of Hernandez's (1991) Theory of Integration, which was developed in and has been used in both type 1 and type 2 diabetes (Hernandez, 1995a, 1996; Hernandez, Antone, & Cornelius, 1999). Integration is described as a three-phase process of integration of the personal self (entity that existed prior to diagnosis) and the diabetic self (new entity that emerged upon diabetes diagnosis). By tuning into body cues and sensations, and using this body knowledge to make appropriate regimen adjustments, individuals with diabetes developed expertise in their own diabetes that allowed them to achieve glycemic control. Aspects of the theory of integration were used to design the SAI and to implement it employing the collaborative alliance education method (Hernandez, 1994).

The Study

Aims

This study was an evaluation of a new educational intervention to help participants become self-aware and detect important body cues for varying levels of glycemia. Its purpose was to evaluate the effectiveness of an SAI in (1) promoting increased awareness of body cues associated with various levels of glycemia, and (2) enhancing the well-being of type 1 diabetic adults with HU. Specifically, the study was designed to determine the effectiveness of the SAI in increasing the number of cues for varying levels of glycemia, reducing the number of HU-related incidents, promoting increased levels of integration and diabetes quality of life, and improving hemoglobin A1c levels. The research questions were: 1. *What is the effect of an SAI program on the number of body cues identified for different levels of glycemia?* 2. *What is the effect of an SAI program on the number of HU-related incidents?* 3. *What is the effect of an SAI program on perceptions of integration?* 4. *What is the effect of an SAI program on perceptions of diabetes quality of life?* 5. *What is the effect of an SAI program on metabolic control?*

Design

This was a prospective before-and-after study carried out in southwestern Ontario, Canada. A power analysis was not performed as this was a pilot study. The sample size was determined by the number of individuals who could be reasonably accommodated in a classroom situation, given the nature of the educational intervention and the amount of funding available. Data were collected at the first intervention session (baseline) and at 6, 12, and 18 months post-intervention.

Participants

A convenience sample of 29 type 1 diabetics with HU was recruited through endocrinologists' offices. Selection criteria were: over 21 years of age, type 1 diabetes for at least 5 years, diagnosed with HU, and currently self-monitoring blood glucose with a glucose meter. HU had been diagnosed previously by endocrinologists but the diagnosis was verified using an eight-item hypoglycemic awareness survey (Clarke et al., 1995). Patients self-selected to participate in either a morning group or an evening group.

Self-Awareness Intervention (SAI)

The SAI was delivered using the collaborative alliance education method (Hernandez, 1994). Collaborative alliance has been described as a relationship between the client and the educator that is characterized by mutual trust and respect and reciprocity in the areas of participation, power, and acknowledgment of expertise (Hernandez, 1991). In the collaborative alliance education method, the client is acknowledged as being an active participant and a self-determining expert in his or her own diabetes. Therefore, the participants in the present study took part in choosing education content, methods, sequencing, and strategies, and in delivering the education program.

The SAI consisted of eight 3-hour sessions held biweekly. The major topic areas and research activities are presented in Table 1. At the first session, the participants were given an SAI manual and introduced to the concept of self-awareness through a video that had been developed during previous SAI research (Hernandez et al., 2004). Both the manual and the video described self-awareness as (1) being constantly sensitive to body cues and sensations and listening to your body; (2) knowing your body's particular cues and signals that result from low, normal, and high blood glucose; (3) knowing what circumstances might precipitate these cues; and (4) knowing your body's norms for different times of the day, days of the month, and perhaps even seasons of the year. The manual provided diabetes information related to self-awareness and the development of

collaborative alliances. It included possible homework and classroom activities as well as forms for documenting individual progress. At the beginning of each session, general topics (e.g., hypoglycemia) were identified as themes for the session. However, consistent with the collaborative alliance teaching method, the activities within each topic, their sequencing, and the time spent on them were co-determined by the participants, based on their needs and preferences, and homework assignments, though strongly encouraged, were voluntary. Self-monitoring of blood glucose, as a means of objectively validating blood glucose levels and the detection of relevant body cues, was an important aspect of both classroom and homework activities.

Data Collection

The study questionnaire included demographic data and published instruments with known validity and reliability to measure integration and diabetes quality of life.

Integration. Integration was measured by the total score on the *The Diabetes Questionnaire* (TDQ), a 15-item instrument with a six-point Likert format (1 = *strongly disagree*; 6 = *strongly agree*). The questionnaire was pilot tested with 224 patients with type 1 or type 2 diabetes and proved to have both content and construct validity. Reliability has also been demonstrated: Pearson's $r = .75$ for test-retest reliability and Cronbach's alpha .84 for internal consistency of the total scale, and .77 and .80, respectively, for the Psychoemotional Adjustment and Somatic Sensitivity subscales (Hernandez, 1995b). Internal consistency results for the TDQ in this study were .80, .85, .87, and .85 at baseline, 6 months, 12 months, and 18 months, respectively.

Diabetes quality of life. Diabetes quality of life was measured by the total score on the *Diabetes Quality-of-Life* (DQOL) scale, a 46-item instrument with a five-point Likert format and four subscales: satisfaction (1 = *very satisfied*; 5 = *very dissatisfied*); impact (1 = *no impact*; 5 = *always impacted*); diabetes worry (1 = *never worried*; 5 = *always worried*); and social/vocational worry (1 = *never worried*; 5 = *always worried*). This instrument was pilot tested with 192 adults and adolescents with diabetes and was shown to be valid (content and concurrent validity), stable (Pearson's $r = .92$), and internally consistent (Cronbach's alpha = .92) (DCCT Research Group, 1988). Internal consistency for the DQOL was .89, .83, .88, and .82 for baseline, 6 months, 12 months, and 18 months, respectively.

Metabolic control. Metabolic control was assessed through the hemoglobin A1c (HbA1c) and the number of HU-related incidents (meter glucose readings below 3.5 mmol/L without prior warning signs, driving infractions/accidents, hypoglycemic episodes requiring treatment assis-

Table 1 *Self-Awareness Intervention (SAI)*

Session	General Content	SAI Classroom Activities	Homework	Research Activities
Class 1	Introduction to Self-Awareness (SA) and Collaborative Alliance Method	SA video, SA manual and discussion SA assessment and exercises Blood glucose monitoring (BGM) in conjunction with exercises	SA exercises Interview with family members	Completion of questionnaires Random blood glucose and Hb A _{1c} Simultaneous meter checks with lab
Classes 2-4	Hyperglycemia, HU, SA strategies	Small and large group discussion of homework findings Discussion of hypoglycemia cues SA exercises	SA exercises BGM Family member interview Denial exercise	Repeat meter checks until accuracy demonstrated Clinical consultant review of meter care and operation
Classes 5-6	Hyperglycemia SA strategies Review and summary	Small and large group discussion of homework findings Discussion of hypoglycemia cues SA exercises	SA exercises BGM Hyperglycemia diary SA learning from others	
Class 7	Euglycemia SA strategies	Large group discussion of learning from homework exercises Discussion of euglycemia cues SA exercises	SA exercises BGM	

<p>Class 8</p>	<p>Personal SA strategies Focus on HU strategies How to develop collaborative alliance relationships</p>	<p>Individual and/or group feedback on homework findings Discussion of personal SA strategies Collaborative alliance role play</p>	<p>SA exercises BGM</p>	<p>Learning assessment and program evaluation, part 1, by external consultant</p>
<p>6 months post-test</p>				<p>Completion of questionnaires Blood drawn for HbA1c Simultaneous meter checks with lab Learning assessment and program evaluation, part 2, by external consultant</p>
<p>12 months post-test</p>				<p>Completion of questionnaires Blood drawn for HbA1c Simultaneous meter checks with lab</p>
<p>18 months post-test</p>				<p>Completion of questionnaires Blood drawn for HbA1c</p>

tance, visits to the emergency room or hospitalization). The analysis method of HbA1c used for all but the 18-month time point was high-pressure liquid chromatography, a method that is the acknowledged gold standard for glycated hemoglobin determination (Daneman & Ellis, 1996). At the final time point the laboratory had converted to an automated chemistry analyzer method. The normal reference range for HbA1c was 0.43 to 0.61 for both methods.

For the purpose of ensuring accuracy of the participants' blood glucose meters, laboratory determinations were compared with participants' meter readings at the first SAI session and at the 6- and 12-month post-intervention sessions. Meter readings were required to be within 15% of the laboratory values.

Other measures. A learning assessment and program evaluation were completed by an external consultant at the end of the final (eighth) SAI session and 6 months post-intervention. The results of this two-part evaluation are published elsewhere (Hernandez, Hume, & Rodger, 2003).

Ethical Considerations

Ethical clearance for the study was obtained from the university's Research Ethics Board. The research nurse obtained informed consent at the beginning of the first SAI session. Confidentiality was ensured throughout the study.

Data Analysis

Statistical analyses were performed using SPSS version 8. The data from the two groups were combined for the analysis after unpaired *t* tests revealed no pre-intervention differences in demographic characteristics. Repeated measures analysis of variance (RM-ANOVA) was used to test the study questions to identify any pre- and post-intervention differences in numbers of symptoms/cues detected for high, low, and normal blood glucose; number of HU-related incidents; and levels of integration, diabetes quality of life, and glycemic control. The 0.05 level of significance was used for all tests.

Results

Results are presented for all post-intervention time points, but the focus of the present analysis is the 12-month and 18-month findings, since the 6-month findings are published elsewhere (Hernandez et al., 2003). Results of the study outcome measures are summarized in Table 2.

Participants

Data were collected from 23 participants at all four time points and are included in the analyses reported here. The sample comprised 12 men

and 11 women ranging in age from 29 to 75 years with a median age of 54 (*mean age* = 50.52). Duration of diabetes ranged from 10 to 47 years with a mean duration of 26.5 years. All participants were Caucasian. The majority reported “English Canadian” as their ethnic background, 57% were married, 64% reported having a college or university education, and 53% reported an annual household income greater than \$40,000. Those who dropped out of the study did so due to illness of self or family member or lack of transport to all SAI sessions; one participant explained that she dropped out because she had learned enough to help her detect her “lows” and therefore did not need to continue with the study.

Physical Outcome Measures

The number of symptoms of glycemia (i.e., the number of cues recognized for low, normal, and high levels of glycemia) was the first physical outcome variable (study question 1). RM-ANOVA showed a significant change in number of symptoms for *low* over time ($F [3, 19] = 4.44, p < .05$). Post hoc paired t tests showed that participants identified more symptoms for *low* at 18-month follow-up than at 12-month follow-up ($t [21] = -2.73, p < .05$), but there were no significant differences between 18-month follow-up and either baseline or 6-month follow-up for this variable. Symptoms for *normal* also showed significant change over the four time points ($F [3, 19] = 3.33, p < .05$). Post hoc paired t tests showed no significant effects for the 18-month time point. Significantly more symptoms were reported at 12 months than at baseline ($t [21] = -2.57, p < .05$). No significant differences over time were shown for symptoms for *high* or for total number of symptoms.

The HU-related events included low blood glucose episodes requiring treatment, hospitalization for low blood glucose, driving incidents (accidents, near accidents, and receiving tickets or warnings for poor driving), and blood glucose readings below 3.5 mmol/L without warning cues. RM-ANOVA showed no significant differences by time point on any of these variables (question 2).

RM-ANOVA showed a significant change in HbA1c over time ($F [3, 19] = 7.54, p < .01$) (question 5). Post hoc paired t tests revealed that the levels at 18 months differed significantly from those at baseline ($t [22] = 3.99, p < .01$) and at 6 months ($t [21] = 3.98, p < .01$).

Psychosocial Measures

Changes in integration over time points were analyzed using RM-ANOVA. There was a significant change in integration over time (question 3) in that TDQ scores showed appreciable change across the time points ($F [3, 20] = 4.35, p < .05$). Post hoc paired t tests revealed that TDQ scores were much higher at 18 months than at baseline ($t [22] =$

Table 2 Study Outcome Measures					
Measure	Range	Mean	SD	F	Sig.
Psychosocial Measures					
<i>TDQ</i>					
Baseline	55–87	75.30	7.81	4.35	.016
6 months	53–88	76.46	8.65		
12 months	65–90	79.30	7.67		
18 months	65–90	79.68	6.99		
<i>DQOL*</i>					
Baseline	61–144	93.31	18.70	18.51	.000
6 months	55–172	126.17	26.77		
12 months	48–122	88.05	17.37		
18 months	73–156	120.93	22.25		
Symptoms of Glycemia					
<i>Symptoms for low</i>					
Baseline	0–7	3.41	1.94	4.44	.016
6 months	0–10	3.36	1.99		
12 months	0–11	2.68	2.26		
18 months	1–13	3.32	2.63		
<i>Symptoms for high</i>					
Baseline	0–5	1.83	1.59	0.57	.640
6 months	0–6	1.91	1.76		
12 months	0–9	2.17	1.99		
18 months	0–12	2.26	2.60		
<i>Symptoms for normal</i>					
Baseline	0–0	0.00	0.00	3.33	.041
6 months	0–4	0.54	0.96		
12 months	0–3	0.50	0.91		
18 months	0–3	0.41	0.96		
Total symptoms					
Baseline	1–10	4.80	2.93	1.84	.179
6 months	0–20	5.75	4.10		
12 months	1–22	4.70	3.01		
18 months	1–25	5.35	3.25		

Self-Awareness Intervention for Adults with Type 1 Diabetes

Measure	Range	Mean	SD	F	Sig.
Hypoglycemia Unawareness Events					
<i>Required assistance</i>					
Baseline	0–52	13.33	17.40	0.86	.478
6 months	0–52	9.43	14.78		
12 months	0–26	6.86	11.01		
18 months	0–39	7.10	11.59		
<i>Hospitalization</i>					
Baseline	0–10	0.76	2.19	1.11	.370
6 months	0–1	0.14	0.36		
12 months	0–2	0.14	0.48		
18 months	0–1	0.19	0.40		
<i>Driving incidents</i>					
Baseline	0–2	0.29	0.72	1.00	.410
6 months	0–1	0.10	0.30		
12 months	0–4	0.26	0.80		
18 months	0–2	0.14	0.48		
<i>Blood glucose < 3.5</i>					
Baseline	0–50	16.55	15.99	2.23	.121
6 months	0–50	7.55	10.40		
12 months	0–45	9.72	10.96		
18 months	0–104	19.85	31.69		
Total HU events					
Baseline	3–77	30.35	23.83	2.11	.137
6 months	0–76	15.95	20.87		
12 months	0–61	15.82	18.14		
18 months	0–111	27.65	36.42		
Metabolic Control: HbA1c					
Baseline	.067–.125	0.088	.015	7.54	.002
6 months	.064–.122	0.085	.014		
12 months	.062–.135	0.084	.017		
18 months	.058–.124	0.080	.015		
* Unless otherwise indicated, data are presented with median and range.					

-2.87, $p < .01$) and at 6 months ($t [22] = - 2.83, p = .01$). The difference between the 12-month and 18-month DQOL scores was non-significant.

RM-ANOVA also showed significant changes in DQOL scores over time ($F [3, 20] = 18.51, p < .05$). Post hoc paired t tests showed that DQOL scores were significantly higher at 18 months than at 12 months on this measure ($t [22] = - 6.62, p < .001$) and significantly higher than at baseline ($t [22] = - 5.74, p < .001$). There was no significant difference between 18 months and 6 months for the DQOL scores. A high score on the DQOL reflects lower perceived quality of life; therefore, diabetes quality of life was reported to be highest at 12-month follow-up and significantly lower at 18-month follow-up (question 4).

Discussion

This is the first study to demonstrate that a self-awareness intervention designed specifically for type 1 diabetics with HU can have both physical (more body cues for low and normal blood glucose, improved HbA1c) and psychological (integration) outcomes. This is also the first study to demonstrate that some individuals with HU recognize body cues for normal blood glucose, although previous studies documented this phenomenon in persons without HU (Hernandez et al., 2004; Hernandez, Bradish, et al., 1999). Ability to detect cues associated with normal blood glucose may be an important factor in maintaining blood glucose within the normal range. Recognition that cues for normal are absent may alert individuals to check for cues of abnormal blood glucose, to check blood glucose values, and to respond appropriately. Further research is needed to assess this assertion.

Cox and associates have found that Blood Glucose Awareness Training for individuals with type 1 diabetes can enhance accuracy in detecting both hypo- and hyperglycemia (Cox et al., 1989, 1991) and improve glycemic control (Cox et al., 1989) and that these benefits could be sustained over time, with accuracy increasing in those with booster training (Cox et al., 1994). In future research with a self-awareness intervention, the addition of a booster training intervention group should be considered. The present results show that individuals diagnosed with HU can learn to detect hypoglycemia cues, although these will be different from cues originally experienced; this is essential information for diabetes education.

An important aspect of this self-awareness intervention was teaching participants to tune in to their own body cues and identify those that signal various levels of glycemia, rather than giving them a standard list of cues to look for, as is currently the case in education programs and in

some research (Weinger et al., 1995). Researchers have found that individuals with type 1 diabetes frequently exhibit glycemia-related symptoms that are not reported in the literature nor taught in diabetes classes (Hernandez, Bradish, et al., 1999; Hernandez & Williamson, 2004) and that these symptoms differ from patient to patient (Nurick & Johnson, 1991). This finding was verified in the present study. It has been observed that patients lose their cues for detecting low blood glucose after many years with diabetes (Pinn & Gale, 1992), but a study with adolescents and young adults found that cues for both hypo- and hyperglycemia could change over the span of 1 year (Hernandez & Williamson, 2004). This finding was verified in the present study with adults — that is, changes in body cues (some dropped, some added) for both hypo- and hyperglycemia occur within a short time frame. Given the above findings, and given the fact that no detriments to health or well-being were found by researchers investigating the impact of Blood Glucose Awareness Training or self-awareness training, it is imperative that persons with diabetes be taught to tune in to individual symptoms of varying levels of glycemia as a strategy for enhancing their diabetes self-management.

An important consideration for future research is the use of total number of cues as a self-awareness measure. Many participants lost particular cues for hypo- or hyperglycemia over the study period. However, the ability to recognize that such cues are no longer indicative of a particular glycemic level is an important advance in self-awareness, one that could improve blood glucose estimation and perhaps even prevent poor treatment decisions. It may be that the detection of *particular* body cues is more important than the *number* of cues in signifying the actual glycemic state. Cox et al. (1995) found that improved detection of low blood glucose was unrelated to an increase in the number of symptoms and that Blood Glucose Awareness Training helped participants to use their available body cues more effectively. Another suggestion is to look at the *intensity* of the hypoglycemia symptoms experienced (Frier, 1993). Future research should incorporate more than number of glycemia cues as the measure of self-awareness.

Researchers have affirmed that patients evaluate glycemic control through a combination of measures, both objective (glucose tests) and subjective (feelings, functioning), and have recommended that health professionals teach patients to adapt guidelines for self-care through informed decision-making (Hunt, Pugh, & Valenzuela, 1998; Thorne & Paterson, 2001). The present study took these recommendations one step further by teaching individuals to detect and respond to reliable and relevant body cues within an environment in which the participants and the intervention facilitator were collaborators in the experience. This collaborative environment likely promoted the ability to self-assess and

respond appropriately, because partnership supports self-care management (Thorne & Patererson, 2001) whereas situations of power imbalance between health professionals and clients do not (Glasgow, Davis, Funnell, & Beck, 2003).

The SAI reflected the recommended ongoing collaboration between health professionals and individuals with complex chronic illness, with a particular emphasis on “collaborative exploration of patient-identified problems and the development of individualized treatment plans” (Bayliss et al., 2007, p. 171). A movement of lay-led self-management intervention for chronic illness spearheaded by Kate Lorig, head of the Chronic Disease Self Management Program in California, has spread to the United Kingdom and other countries (Newbould, Taylor, & Bury, 2006). Newbould et al. (2006), in their review of the literature on lay-led programs, find many short-term benefits of these programs but conclude that a pluralistic approach to chronic illness is necessary — including both professional-led and lay-led interventions to support self-management. The SAI represents a variation of this recommendation, because lay participants and a nurse facilitator interacted as equals in terms of participation, power, and acknowledgement of expertise (Hernandez, 1994), with all participants having an opportunity to provide input and advice to their fellow participants. Redman (2007) asserts that patient self-management, defined as the “ability to detect and manage symptoms, treatments and their consequences” (p. 88), results in improved outcomes. Redman describes self-management at its best as allowing “expression of individual choices and priorities through skilled practice, so that the chronic condition recedes into the background of a life constructed to one’s satisfaction” (p. 90). This description is consistent with the focus on “living with diabetes” that characterizes individuals in the last phase of integration (Hernandez, 1991, 1996; Hernandez, Antone, et al., 1999), and greater integration was one of the outcome measures promoted by the SAI.

Limitations

As this pilot study was an uncontrolled trial, the findings should be treated with caution. The participants were Caucasian and well-educated, characteristics that are not completely representative of the type 1 diabetic population with HU. Other limitations include the absence of a control group, instability of the DQOL instrument, and problems with loss of ancillary forms used by participants for logging data on incidents related to hypoglycemia awareness. It is unknown why the scores on the DQOL instrument vacillated over time, so that diabetes quality of life was significantly decreased at 6 and 18 months but significantly increased

at 12 months post-intervention. However, there is evidence that quality of life did improve over the study period. Self-report of diabetes life satisfaction, measured on a visual analogue scale, increased significantly between baseline and the 6- and 18-month follow-up time points. In addition, the external consultant found that participants reported high levels of confidence and satisfaction with the SAI activities at 6-month follow-up (Hernandez et al., 2003). The DQOL may not have been an appropriate measure for this sample as it was developed and tested on younger patients (< 40 years of age) who had minimal or no complications (DCCT Research Group, 1988), whereas the present sample had a median age of 54 and did have complications. In future research, multiple quality-of-life measures will be incorporated, both generic (e.g., the SF-36 [Ware & Sherbourne, 1992]) and diabetes-specific (e.g., DSQOLS [Bott, Overmann, Muhlhauser, & Berger, 1998]), once the English-language version of the DSQOLS has been validated.

Conclusion

The findings demonstrate that a self-awareness intervention operationalized through the collaborative alliance education method can have positive physical and psychosocial outcomes for adults with type 1 diabetes and HU. Participants experienced increased integration and better glycemic control, as measured by HbA1c, and were able to detect more body cues for hypoglycemia and euglycemia.

The findings support postulations in Hernandez's (1991) theory of integration, related to the impact of self-awareness and the effectiveness of the collaborative alliance education method to improve this self-awareness skill, a skill that enhances diabetes self-management ability. Specifically, as self-awareness improved, so did self-reported integration and HbA1c levels. These findings support the value of having a conceptual framework to guide research in type 1 diabetes. Another support for the theory of integration was the effectiveness of the collaborative alliance education method in promoting self-awareness. The utility of this method should be tested for use in other diabetes practice environments and with other chronic illnesses.

The management of HU is complex, requiring a multifaceted approach. Education aimed at increasing sensitivity to varying glycemic levels can be a valuable aspect of that approach. In spite of the study's limitations, the results demonstrate that important benefits can be realized through self-awareness education using a collaborative alliance education method. Further multi-site research is warranted, with a larger number of participants, using a control group for comparison, and of longer study duration.

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Considérer les maladies cardiovasculaires et le diabète chez les membres des Premières nations selon une perspective de cycle de vie

Andrew Kmetc, Jeffrey Reading et Elizabeth Estey

Le poids des maladies cardiovasculaires et du diabète, ainsi que les facteurs de risques associés tels l'obésité, le tabagisme, l'intolérance au glucose, l'hypertension et les facteurs alimentaires, présentent une combinaison de facteurs préjudiciables pour la santé des membres des Premières nations du Canada, dans l'immédiat et à long terme. Les auteurs adoptent une perspective de cycle de vie, pour examiner les effets à long terme sur la santé développementale et le risque de maladie ultérieure, des facteurs de risques qui sont prévalents durant la gestation, l'enfance, l'adolescence, la vie de jeune adulte et la vie adulte. Il en résulte une perspective élargie pouvant engendrer des approches novatrices pour aborder la maladie chronique chez la population autochtone du Canada.

Mots-clés : santé des membres des Premières nations, cycle de vie, maladie chronique, cardiovasculaire, diabète

Taking a Life Course Perspective on Cardiovascular Disease and Diabetes in First Nations Peoples

Andrew Kmetc, Jeffrey Reading, and Elizabeth Estey

The burden of cardiovascular disease and diabetes and associated risk factors, such as obesity, smoking, impaired glucose tolerance, hypertension, and dietary factors, present a mix of factors that are detrimental to the immediate and long-term health of First Nations peoples in Canada. The authors use a life course perspective to examine the long-term effects of risk factors that are prevalent during gestation, childhood, adolescence, young adulthood, and adult life on developmental health and later disease risk. The resultant broader perspective may generate innovative approaches to addressing chronic disease in Canada's Aboriginal population.

Keywords: Aboriginal health, life course, chronic disease, cardiovascular, diabetes

Introduction

In addressing the problems of chronic disease during the 20th century, epidemiologists, health professionals, and policy-makers targeted adult risk factors such as obesity, physical inactivity, high blood pressure, high cholesterol, high blood glucose levels, and smoking (Kuh, Ben-Shlomo, & Lynch, 2004). In the developed world, this approach and its programs have been successful in alleviating many problems associated with chronic diseases. Results from the 40-year Framingham Heart Study indicate that, in the United States, more than one half of the decline in mortality due to coronary heart disease observed in women and one third to one half of the decline observed in men has been attributed to modification of adult risk factors (Sytkowski, D'Agostino, Belanger, & Kannel, 1996). However, the overall reduction in adult risk factors and chronic disease is limited to specific populations. While rates for some chronic diseases have declined in Western populations, chronic diseases are a growing cause of mortality and morbidity among marginalized populations such as Canada's Aboriginal peoples (First Nations, Inuit, and Métis) (Smeja & Brassard, 2000). In 1991, 31% of Aboriginal adults reported having a chronic health problem; in 2002/03, 63.7% of Aboriginal adults reported at least one long-term health condition (First Nations Centre, 2005). The health and well-being of Aboriginal peoples in Canada is comparable to that of people in developing nations (Cooke, Beavon, & McHardy, 2004).

While overall mortality from all causes has declined within the First Nations population, the severity of chronic diseases has grown. In the year 2000, for example, circulatory diseases accounted for approximately 30% of all deaths within the First Nations population (Waldram, Herring, & Young, 2006).

Diabetes is a major risk factor for cardiovascular disease (CVD) in the Aboriginal population (First Nations Centre, 2005; Harris et al., 2002), highlighting the connection between these two conditions and their common risk factors. In this article we discuss the burden of CVD and diabetes in Aboriginal populations in Canada. We then use a life course epidemiology perspective to examine the literature on the main risk factors, at different life stages, and their potential long-term effects. The usefulness of such a perspective in assessing Aboriginal health has been acknowledged (Estey, Kmetic, & Reading, 2007; Waldram et al., 2006; Wethington, 2005). Because of our use of a life course perspective to engage with the literature on chronic diseases among Aboriginal peoples, this article will be of interest to the nursing research community; the life course approach provides a framework for organizing and examining existing research in order to plan research-based and practice-based activities and to identify knowledge gaps with a view to future research and action.

In the last 20 years, life course epidemiology has emerged as a comprehensive approach that takes a broader view than the adult risk model described above (Kuh, Ben-Shlomo, Lynch, Hallqvist, & Power, 2003). Life course epidemiology has been defined as the study of long-term effects of physical and/or social exposures during gestation, childhood, adolescence, young adulthood, and adult life on one's developmental health and disease risk (Kuh et al., 2003). It offers a way to conceptualize how underlying socio-environmental determinants of health, experienced at different life stages, can differentially influence the development of chronic diseases as they are mediated through proximal specific biological processes (Moore & Davies, 2005). In the study of CVD, for example, life course epidemiology goes beyond classic risk factors such as adult obesity, smoking, high blood pressure, and physical inactivity, to consider the role of intrauterine nutrition, birth weight, childhood obesity, smoking initiation ages and rates, adolescent blood pressure, and socio-economic status across the life course (Kuh et al., 2004). While adult risk factors are an important piece of the chronic disease "puzzle," life course epidemiology views the interaction of social, biological, and psychological events over time as equally critical. Despite the potential of life course epidemiology for mapping and comprehending the complexities of Aboriginal health issues, such an approach has not been used with Aboriginal populations in Canada. Taking a broad life course perspective,

this article focuses on biological risk factors. It would require an entire article to fully discuss the implications of the social determinants of health and their interaction with biological risk factors. In the meantime, this article may help to inspire confidence in and support for life course research in Aboriginal health.

We caution against the use of general statements about the health conditions of Aboriginal people as a whole. Given the great diversity of Aboriginal peoples in Canada, health status can vary significantly across and within Aboriginal communities. What is true generally may not be true or relevant for a specific group or community. For example, the prevalence of diabetes has been found to vary according to ancestry, language group, cultural grouping, geographic location, and socio-economic status (Delisle, Rivard, & Ekoe, 1995; First Nations Centre, 2005). While the goal of this article is to address CVD and diabetes in the Aboriginal population in general, reference will be made to particular groups (i.e., First Nations, Métis, and Inuit) in accordance with the research literature being cited.

Cardiovascular Disease in Aboriginal Populations

The most common type of CVD is coronary heart disease, also referred to as ischemic heart disease or coronary artery disease. Although the exact cause of CVD is unknown, a number of risk factors have been identified; these include high cholesterol, high blood pressure, smoking, diabetes mellitus, and low levels of high-density lipoproteins. A number of these factors are linked to lifestyle and socio-economic status (Dorner & Rieder, 2004; Sonmez et al., 2004). In many Aboriginal populations, however, these risk factors stem from the ongoing effects of colonialism (Waldram et al., 2006).

In the past several decades, political, social, and economic changes experienced by many Aboriginal populations as a result of increasing “Westernization” and acculturation have manifested in nutritional and behavioural changes such as a calorie-dense and sedentary lifestyle (Anand et al., 2001). These changes have contributed to an increase in CVD (Anand et al., 2001; Shah, Hux, & Zinman, 2000; Yusuf, Reddy, Ounpuu, & Anand, 2001). The 2002/03 First Nations Regional Longitudinal Health Survey (First Nations Centre, 2005), which documents self-reported heart conditions in First Nations communities, shows a prevalence slightly higher than that for the Canadian population (7.6% vs. 5.6%); however, First Nations adults aged 50 to 59 years show a prevalence of 11.5%, compared to 5.5% for the general population. In addition, in a study of 41 First Nations communities in the province of Ontario, CVD hospitalization rates were found to have doubled, from 76

per 10,000 persons in 1984 to 186 per 10,000 in 1995, while declining in the rest of the province (Harris et al., 2002; Shah et al., 2000). A parallel trend was found in the admission rates for acute myocardial infarction (Shah et al., 2000).

Diabetes in Aboriginal Populations

Type 2 diabetes is a metabolic disorder characterized by insulin resistance, relative insulin deficiency, and hyperglycemia (elevated blood glucose). When blood glucose levels become extremely high, excess glucose can cause damage to the body. If blood glucose levels remain high for years, blood vessels and nerves may become damaged, increasing the risk for eye, heart, blood vessel, nerve, and kidney disease (Burant & American Diabetes Association, 2004). Type 2 diabetes typically appears in adulthood and is exacerbated by obesity, inactive lifestyle, stress, depression, and poor diet (Barnett & Kumar, 2004). Since chronic obesity leads to increased insulin resistance, which can develop into diabetes, these two conditions are often co-morbid and interconnected (Lazar, 2005). The association between obesity and diabetes is not definitively known, but the most likely link is adipose tissue: it has been identified as a source of chemical signals (hormones and cytokines) that render cells resistant to insulin (Lazar, 2005).

In the last half century, type 2 diabetes has emerged as a serious problem in many Aboriginal communities: type 2 diabetes has already reached epidemic proportions (Young, Reading, Elias, & O'Neil, 2000) and its prevalence is expected to rise steadily (Health Canada, 2000). There is recent evidence that 19.7% of First Nations adults have been diagnosed with diabetes, with the figure increasing to 35% for those 55 and older (First Nations Centre, 2005). In certain populations, such as the Oji-Cree, the prevalence of type 2 diabetes and impaired glucose tolerance has been observed to be 40% — among the highest of any subpopulation in the world and five times the Canadian average (Harris, Gittelsohn, et al., 1997). In a study with two Algonquin communities in northeastern Quebec (Delisle et al., 1995) and the Oji-Cree community of Sandy Lake in northwestern Ontario (Harris, Caulfield, Sugamori, Whalen, & Henning, 1997), the prevalence of type 2 diabetes was found to be as high as 80% among women aged 50 to 64.

Diabetes is occurring in much younger age groups in First Nations communities than in the general population. Of those living with diabetes in First Nations communities, more than half (53%) are under 41 and 65% are under 45 (First Nations and Inuit Regional Health Survey National Steering Committee [FNIRHS], 1999). Previously referred to as adult-onset or non-insulin dependent diabetes, type 2 diabetes has typ-

ically not been observed in youths (Health Canada, 2000). However, it has been detected in First Nations children as young as 5 to 8 both in the Island Lake region of northeastern Manitoba (Dean, Mundy, & Moffatt, 1992) and in northern Ontario (Harris, Perkins, & Whalen-Brough, 1996). In addition, screening for diabetes in a remote northern Ojibwa-Cree community using fasting plasma glucose levels revealed a high prevalence rate (3.6%) among girls aged 10 to 19 (Dean, 1998; Dean, Young, Flett, & Wood-Steiman, 1998).

A person can have type 2 diabetes for up to 12 years before being diagnosed, and eye damage can occur well before diagnosis, making the need for early diagnosis and screening extremely critical (Harris, 1993; Harris & Eastman, 1996). A study currently underway in the province of Alberta (titled *Believing We Can Reduce the Aboriginal Incidence of Diabetes*, or BRAID) is assessing the use of portable technology for type 2 diabetes screening and also whether an opportunistic screening approach will result in improved estimation of diabetes prevalence (Kaler, King, & Toth, 2006).

In addition to concerns about its prevalence and increasing incidence, diabetes is associated with severe complications of other chronic diseases (Young, Reading, et al., 2000). In the following section we review the interactions between CVD and diabetes in Aboriginal populations.

Interactions between CVD and Diabetes in Aboriginal Populations

Cardiovascular disease and diabetes are often interconnected and mutually influencing. For instance, a study conducted with Aboriginal people in Manitoba a decade ago estimated that, between 1996 and 2016, diabetes would be responsible for a five-fold increase in stroke and blindness and a ten-fold increase in CVD, dialysis starts, and lower-extremity amputations (Greene, Blanchard, & Wajda, 1999).

The adoption of a Western diet and lifestyle patterns is thought to be putting Inuit communities at increased risk for chronic disease. For example, obesity and physical inactivity have increased in some Inuit communities and the previously below-average incidence of diabetes among Inuit people has been changing at an alarming rate (Young, Moffatt, & O'Neil, 1993). The prevalence of diabetes among the Labrador Inuit climbed from 1.9% of the population in 1991 to 4% in 1999 (Health Canada, 2005). The potential influence of changes in diabetes trends on CVD is worth considering. However, the evidence documenting rates of CVD within Inuit communities is inconclusive. While some authors argue that Inuit people tend to have lower rates of CVD as a result of their traditional marine diet (Dewailly et al., 2001), others

suggest that the scientific evidence for CVD is weak and unreliable (Bjerregaard, Young, & Hegele, 2003). Bjerregaard et al. (2003) suggest a need to reassess the data on CVD in Inuit populations and to re-evaluate the potential of a traditional diet to protect against rapid Westernization and its health risks.

In addition to experiencing an overall higher prevalence of type 2 diabetes (First Nations Centre, 2005), many First Nations women are diagnosed with gestational diabetes mellitus (GDM) (Mohamed & Dooley, 1998), which is defined as any degree of glucose intolerance for which the onset or first recognition occurred during pregnancy (Matthews, 2003). The greatest concerns with GDM are its persistence beyond the gestational period and its effects on the fetus; a study in the Sioux Lookout Zone in Ontario found that 70% of women diagnosed with GDM developed overt diabetes within 3 years of diagnosis (Mohamed & Dooley, 1998). Concerns about women's health extend to CVD as well. Monsalve, Thommasen, Pachev, and Frohlich (2005) note that women are at a disproportionately high risk for CVD as a result of a high prevalence of metabolic syndrome and high triglycerides.

While in this section we have set out the links between CVD and diabetes, in the following section we will review the evidence on diabetes, CVD, and their associated risk factors across the life course. This discussion is intended to provide a more holistic and detailed review of the literature and Aboriginal experiences of health.

A Life Course Perspective on CVD and Diabetes in Aboriginal Populations

In charting the evidence that links events during the life course to diabetes and CVD and their associated risk factors, we will, whenever possible, draw on information from studies involving Aboriginal people. When such information is not available, we will draw from the general health research literature to facilitate the discussion of gaps and areas that call for further research and action.

Intrauterine Effects and Birth Weight

Several studies have illustrated the association between suboptimal patterns of fetal and infant growth and adult chronic disease. These studies lay the foundation for what is known as the "fetal origins hypothesis," which suggests that physiologic or metabolic "programming" during gestation and infancy determines, to a large extent, the occurrence of various chronic diseases, including diabetes and CVD, in later life (Barker, 1995a, 1995b, 1995c; Hales & Barker, 1992).

Birth weight is typically used as an indicator of intrauterine conditions and fetal growth, and is thought to relate to the development of many chronic diseases. A number of studies report a strong link between low birth weight and the occurrence of heart disease and hypertension later in life (Barker, 1995a, 1995b, 1995c; Fall, Vijayakumar, Barker, Osmond, & Duggleby, 1995).

High (> 4,000 grams) or low (< 2,500 grams) birth weight has been shown to be associated with increased risk for diabetes in later life (Pettitt, Forman, Hanson, Knowler, & Bennett, 1997; Pettitt & Knowler, 1998). Despite Aboriginal women's increased smoking during pregnancy, which has been shown to decrease birth weight, Aboriginal and non-Aboriginal populations have similar proportions of low birth weight (Gilchrist et al., 2004; Pirogowicz et al., 2004; Wenman, Joffres, & Tataryn, 2004). However, First Nations babies are almost twice as likely as non-Aboriginal babies to be classified as high birth weight (Rodrigues, Robinson, Kramer, & Gray-Donald, 2000). A study of First Nations births in the province of Saskatchewan from 1950 to 1984 found an association between high (but not low) birth weight and diabetes for Saskatchewan Registered First Nations (OR 1.63 [95% CI 1.20, 2.24]), which was stronger for female infants (Dyck, Klomp, & Tan, 2001); the researchers suggest that excess fetal nutrition is the overriding intrauterine factor in the pathogenesis of type 2 diabetes in the First Nations population. As Aboriginal birth weights are being classified as high, normal, or low using non-Aboriginal standards, birth weight correlations should be considered preliminary at best.

Maternal Diabetes

A condition that is more moderate than type 2 diabetes, but with similar risk factors and effects, is impaired glucose tolerance (IGT). IGT is a condition in which the blood glucose level is higher than normal but not high enough to be diagnosed as type 2 diabetes (Matthews, 2003); it is sometimes referred to as borderline or chemical diabetes. IGT has the potential to develop into full-blown diabetes with its resultant chronic conditions.

Glucose tolerance is known to deteriorate in all pregnant women in response to the physiological and hormonal changes that accompany pregnancy (Hod, 2003). In approximately 2% to 3% of pregnancies in the Western world, the deterioration occurs at a level sufficient to fulfil the diagnostic criteria for gestational diabetes (Whitaker, Pepe, Seidel, Wright, & Knopp, 1998). In gestational diabetes, while high levels of maternal glucose are freely transferred to the fetus, maternal insulin cannot cross the placenta (Freinkel, 1980). The developing fetal pancreas responds to the exaggerated glucose load of the diabetic mother by producing insulin,

which, in addition to its hypoglycemic effects, acts as a fetal growth hormone (Pederson, 1954).

It is difficult to determine actual prevalence rates for gestational diabetes, as first-time diagnoses of type 2 diabetes, and not etiologic GDM, could be contributing to the high rates of GDM observed in many Aboriginal communities. Surveys conducted in northern Quebec and northern Ontario suggest that, among Aboriginal women, gestational diabetes may affect up to 13% of pregnancies (Godwin, Muirhead, Huynh, Helt, & Grimmer, 1999; Harris, Caulfield, et al., 1997; Rodrigues, Robinson, & Gray-Donald, 1999). However, just under half of all pregnancies among women over the age of 35 are associated with either pre-existing type 2 diabetes or gestational diabetes (Harris, Gittelsohn, et al., 1997). In a study carried out recently in Saskatchewan, the prevalence rates, risk factors, and outcomes of GDM in Aboriginal and non-Aboriginal women were directly compared for the first time. Among residents of the Saskatoon District Health region, the 1-year prevalence rates for GDM were 6.4% for Aboriginal women and 3.7% for non-Aboriginal women; among residents outside this region, the corresponding rates were 22.8% and 3.1% (Dyck, Klomp, Tan, Turnell, & Bector, 2002).

While maternal diabetes is a concern among Aboriginal communities (Mohamed & Dooley, 1998), it is also a strong predictor of high birth weight (Godwin et al., 1999; Harris, Gittelsohn, et al., 1997; Rodrigues, Robinson, Ghezzi, & Gray-Donald, 1999). The prevalence of maternal diabetes in Aboriginal populations and its effects on birth weight are highlighted in a Saskatchewan study with First Nations women: infants from GDM pregnancies were found to be 2.4 times more likely to have high birth weight (> 4,000 grams) (95% CI: 1.1, 5.6) than their non-GDM counterparts (Dyck et al., 2001).

In addition to increased rates of high birth weight, offspring of women with GDM may have increased IGT, increased rates of childhood obesity, and increased risk of type 2 diabetes (Pettitt & Knowler, 1998; Silverman, Rizzo, Cho, & Metzger, 1998). In a study with Pima Indians, Dabelea et al. (2000) examined families in which some siblings were born before the mother was diagnosed with diabetes and some after. Children exposed to diabetes in utero had a higher body mass index than their unexposed siblings, and four times the risk of diabetes. Dabelea and Pettitt (2001) conclude that approximately 40% of type 2 diabetes among Pima children aged 5 to 19 can be attributed to maternal diabetes during pregnancy. These results highlight the role that the fetal environment can play in an individual's health later in life. Canadian studies examining the relevance of these results would be useful.

Some studies suggest that early detection of GDM coupled with a proper diet and healthy lifestyle can reduce the negative fetal outcomes associated with GDM (Jovanovic-Peterson, 1994). For obese women with GDM, calorie restriction, especially with regard to carbohydrates, can reduce hyperglycemia (Farquhar, 1969) and improve maternal and fetal health outcomes (Cummins & Norrish, 1980). Interventions focused on prevention and early detection are therefore essential.

Maternal Obesity

Obesity is a risk factor for both gestational and type 2 diabetes. Further, maternal diabetes results in high birth weight, which is associated with obesity and the development of type 2 diabetes in offspring. Thus, obesity can be considered a multigenerational risk factor for diabetes and its associated co-morbidities, including CVD. This situation illustrates the need to target obesity and gestational diabetes through a life course approach.

Some studies suggest that maternal obesity, which is often associated with GDM, may be the overriding factor in mediating obesity in offspring (Boney, Verma, Tucker, & Vohr, 2005; Whitaker et al., 1998). An American study that followed children from birth to 6 or 12 years of age found that GDM was not independently significant in increasing metabolic syndrome risk in children but that offspring of obese mothers faced a two-fold increased hazard (Boney et al., 2005). Considering the implications of these results for Aboriginal populations in Canada, pre-pregnancy and pregnancy could be extremely effective points in the life course to target obesity and thus reduce the burden of type 2 diabetes throughout adolescence and adulthood. While the research reviewed above shows that targeting maternal health is central to a life course approach to Aboriginal health, maternal health is best achieved through attention to community health.

Breastfeeding

The protective effects of breastfeeding have been noted by Health Canada, especially within the Aboriginal population (Breastfeeding Committee for Canada, 2002; Macaulay, Hanusaik, & Beauvais, 1991; Pettitt et al., 1997). For example, a study with Aboriginal children in Manitoba identified prolonged breastfeeding as a strong protective factor against type 2 diabetes: a child breastfed for more than 12 months was shown to have only 24% of the risk of a bottle-fed child (Young, Chateau, & Zhang, 2002). The protective effects of breastfeeding have also been observed in studies with Pima Indians (Pettitt et al., 1997; Pettitt & Knowler, 1998). Breastfeeding rates are lower for Aboriginal infants (60%) than for infants in the general Canadian population (80%) (First Nations Centre, 2005). The protective effects of breastfeeding could

greatly benefit Aboriginal health, but it is essential that the conditions underlying the differences in breastfeeding rates be understood. Furthermore, research, interventions, and practices should be developed and undertaken in culturally sensitive and appropriate ways.

Childhood, Adolescent, and Adult Obesity

Longitudinal studies with non-Aboriginal people have shown that obesity in childhood and adolescence predicts adult obesity (Guo, Roche, Chumlea, Gardner, & Siervogel, 1994; Serdula et al., 1993), which is associated with type 2 diabetes (Barrett-Connor, 1989) and coronary heart disease (Hubert, Feinleib, McNamara, & Castelli, 1983). While high rates of pediatric obesity have been reported in studies with several racial groups (Kumanyika, 1993), Aboriginal children are at particularly high risk (Bernard, Lavalley, Gray-Donald, & Delisle, 1995). Thus, understanding the etiology of pediatric obesity throughout the life course could have public health implications for Aboriginal children and adults.

Obesity in childhood has been shown to increase the risk of childhood diabetes. A study with First Nations children aged 4 to 19 found alarming obesity rates: 64% of girls and 60% of boys were reported as being obese (Young, Dean, Flett, & Wood-Steiman, 2000). In the Regional Health Survey of 2002/03, however, only slightly more than 14% of those aged 12 to 17 were reported as being obese, suggesting regional variation in obesity among Aboriginal youths (First Nations Centre, 2005).

A study of the correlation between obesity and television viewing undertaken in the Sandy Lake First Nations community (Hanley et al., 2000) found that children who watched more than 5 hours of television per day were associated with a 2.5-fold increase in the risk of becoming overweight, compared to children who watched less than 2 hours per day. In the same study, children with higher fitness levels and greater fibre intake were less likely to be overweight. In another study, overweight Cree school-aged children and adolescents were found to engage in significantly less physical activity and to eat significantly fewer servings of fruits and vegetables than their normal-weight peers (Bernard et al., 1995). Nova Scotia's 1997 First Nations and Inuit Regional Health Survey found that 98% of children watched an average of 2.9 hours of television per day (FNIRHS, 1999).

When asked about the availability of sports and cultural facilities in their community, fewer than half of Ontario Aboriginal youths reported having sports facilities available; the most commonly cited needs were for a community swimming pool, followed by playground equipment, an arena, and drop-in centres (FNIRHS, 1999). As issues of obesity in Aboriginal communities relate to a lack of physical activity and a seden-

tary lifestyle, lack of facilities, and food insecurity and poor nutrition, these areas may be useful targets for research throughout the life course.

Smoking Throughout the Life Course

Smoking is a major health issue among Aboriginal people (FNIRHS, 1999). Although smoking is known to be harmful to one's health and has been associated with the development of chronic disease, there is some debate in the literature about its total impact as a risk for chronic disease. While some of the literature on the association between smoking and chronic disease is reviewed in this section, there is a need for further investigation of this association. The impact of maternal smoking on chronic disease risk is particularly important for understanding early life influences of smoking on chronic disease development in Aboriginal communities, as there is a very high prevalence of maternal smoking in Aboriginal communities (FNIRHS, 1999) — almost double the Canadian average (First Nations Centre, 2004). Individual smoking rates are also an area of potential concern and further research. Most smokers begin smoking by age 15 (Health Canada, 2004), which means that they have virtually an entire lifetime to accumulate risks for chronic diseases associated with smoking environments and activities. As reported by parents in Manitoba, 19% of all Aboriginal children under the age of 18 smoke; the peak age for taking up smoking is 16, with some youths starting as young as 11 (First Nations Centre, 2004).

A clear association has been shown between maternal smoking and intrauterine growth restriction in both Aboriginal and non-Aboriginal populations (Horta, Victora, Menezes, Halpern, & Barros, 1997; Wenman et al., 2004). However, the relationship between maternal smoking and childhood weight is still inconclusive. A large proportion of Aboriginal women continue to smoke throughout pregnancy, which makes understanding the impact of maternal smoking on disease risks, such as low birth weight and obesity (Grove et al., 2001; Reilly et al., 2005; von Kries, Toschke, Koletzko, & Slikker, 2002), relevant for Canada's Aboriginal population.

Smoking is also directly associated with central metabolic syndrome, a condition that has been identified as comprising obesity, dyslipidemia, and insulin resistance (Parker et al., 2003). In a study with 2,273 American adolescents, 5.6% of whom met the criteria for central metabolic syndrome, the prevalence of the condition was 1.2% for those not exposed to tobacco smoke, 5.4% for those exposed to environmental tobacco smoke, and 8.7% for active smokers (Weitzman et al., 2005). The fact that chronic cigarette smoking markedly aggravates insulin resistance in type 2 diabetes patients is another reason to discourage smoking and encourage smoking cessation (Targher et al., 1997). Given the rates of smoking,

obesity, and insulin resistance among Aboriginal youths, research in this area could have profound implications for Aboriginal health.

While the strong association between smoking and CVD is well known (Greenhalgh, 1981; Haustein, 2003; Swales & De Bono, 1993), the effects of smoking on CVD throughout the life course are not. Since quitting smoking greatly reduces the risk of CVD, smoking cessation programs have the potential to substantially lower the risk for this chronic disease. For example, within a year of quitting, a former smoker's risk for heart disease is reduced by nearly 50% (Ghadirian, 2005). A study conducted with men under the age of 55 found that their risk for CVD within the first year of quitting was not significantly different from that of current smokers, but after 2 years the risk declined and was equal to that for non-smokers (Ghadirian, 2005). The residual risk for CVD following smoking cessation is dependent on total previous exposure to tobacco smoke, length of time without cigarettes, and health status at the time of quitting. However, after 10 to 15 years without cigarettes, the health status of most former smokers is not significantly different from that of lifelong non-smokers (Ghadirian, 2005). This means that targeted smoking cessation strategies have the potential to decrease disease risks and promote better health.

Compared to the general population, Canada's Aboriginal population has a much higher proportion of current smokers and lower proportions of former smokers and lifelong non-smokers (First Nations Centre, 2005). While smoking cessation programs are being developed and implemented, given the addictive nature of smoking the key to tackling this serious health risk lies in prevention (Miller Chenier, 1997). Strategies tailored to children and youths are essential, as is the targeting of parents, whose lifestyle patterns are often mimicked by children. In developing and implementing such programs, one should keep in mind the cultural significance of tobacco in many Aboriginal groups as well as the interface between cultural and recreational tobacco use (Daniels, 2003; Winter, 2000).

Conclusion

This review has shown that a life course perspective can assist policy-makers, care providers, and researchers by presenting a broad view of the burden of CVD and diabetes and their associated risk factors. While we have used the life course perspective to organize and assess the literature on CVD and diabetes, it is our hope that this approach will inspire other researchers, practitioners, and policy-makers to examine the burden of disease and design interventions in Aboriginal populations from a broader, more inclusive perspective. In addition to the expanded adult risk model presented as a life course perspective in this article, it is

important to examine the environmental, social, cultural, and political influences on disease risk and resilience. As shown in the literature, the complex interaction of historical and sociopolitical conditions and access to health care are strong indicators of health disparities and inequities (Adelson, 2005; Browne & Smye, 2002). Our exclusion of a discussion on the social determinants of health was purposeful: it is a topic that warrants an article of its own. While we hope that the social determinants of health will continue to receive attention in the Aboriginal health research literature, the purpose of this article was to emphasize the need to rethink the adult risk model and how disease risks are classified and categorized. As life course epidemiology provides a framework for engaging with the social determinants of health, we hope that such research will become a focus in the future.

No discussion of Aboriginal health, however, is complete without reference to the influences of colonialism on the current and future health and well-being of Aboriginal peoples (Brant-Castellano, 2004; Browne & Smye, 2002). In addition to the emotional, spiritual, psychological, and physical impact of colonialism on Aboriginal health, Aboriginal health as a discipline is impacted by this history. In adopting a postcolonial perspective on Aboriginal health, the Aboriginal health research community has acknowledged the need to engage Aboriginal peoples in research — from the development of the research question to the dissemination and evaluation of the results (Brant-Castellano, 2004; Estey, Kmetz, & Reading, 2008). This engagement is necessary for the conduct of ethical research as well as to ensure the relevance of research and the effective use of research findings. The idea of cultural safety in the nursing literature as a means of ensuring effective nursing practice in postcolonial settings embodies a similar perspective (Polaschek, 1998). As nurses are often the first point of contact for Aboriginal patients, the inclusion of theoretical perspectives, such as life course and postcolonialism, is brought to a point of practice through nurses. It is for this reason that we believe the ideas contained in this article will be of interest to the nursing community. For the research community, we hope that this analysis encourages the development of long-term cohort studies in Aboriginal health contexts similar to those in other populations (Sayers et al., 2003).

Finally, we turn to the policy implications of this discussion. We hope that this article will give policy-makers a deeper understanding of the Aboriginal health research landscape and the methodological potential of using a life course perspective to critically appraise and use the research. Acceptance and use of a life course perspective can in turn produce more holistic and long-term interventions and programs that have greater potential to improve the health and well-being of Aboriginal peoples in Canada.

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Portrait de la cognition des patients : la compréhension des autosoins chez les patients souffrant de diabète

Katherine D. Lippa et Helen Altman Klein

L'autogestion du diabète est un processus dynamique complexe. Malgré les directives données aux patients pour leur permettre de s'auto-soigner, beaucoup ont encore de la difficulté à contrôler leur taux de glucose. La présente étude s'appuie sur les techniques de recherche en matière de prise de décision, pour étudier la conceptualisation des autosoins chez les patients ayant un contrôle glycémique faible, modéré et bon. Dix-huit personnes souffrant de diabète de type 2 ont été interrogées sur leur expérience du diabète, leur compréhension de la maladie et leur comportement relié aux autosoins. Des méthodes qualitatives ont été utilisées pour analyser les réponses et décrire les schémas cognitifs. Les auteures décrivent la compréhension des principaux aspects des autosoins et de leur relation avec l'autogestion qu'avaient les participants. Chez la majorité d'entre eux, la compréhension de la maladie était insuffisante – en général, parce que les directives fondées sur des règles les dépassaient ou qu'ils ne les comprenaient pas. La compréhension de la dynamique sous-jacente à la régulation du glucose s'est avérée essentielle à une autogestion efficace. Les éducateurs spécialisés en diabète devront enseigner la dynamique sous-jacente à l'autogestion aux patients et mettre l'accent sur l'aptitude à résoudre les problèmes et à prendre des décisions.

Mots-clés : Diabète, cognition, prise de décision

Portraits of Patient Cognition: How Patients Understand Diabetes Self-Care

Katherine D. Lippa and Helen Altman Klein

Diabetes self-management is a complex dynamic process. Although patients are given guidelines for self-care, many still struggle with glucose control. This study uses techniques from naturalistic decision-making research to examine how patients with low, moderate, and good glycemic control conceptualize self-care. Eighteen people with type 2 diabetes were interviewed about their experiences with diabetes, understanding of the disease, and self-care behaviour. Qualitative methods were used to analyze responses and describe patterns of cognition. The authors describe participants' understanding of major areas of self-care and its relationship to self-management. The majority of participants failed to adequately understand the disease, typically because they were overwhelmed by or misunderstood rule-based instructions. Understanding of the dynamics underlying glucose regulation was found to be critical for effective self-management. Diabetes educators need to teach patients about the dynamics underlying self-management and to emphasize problem-solving and decision-making skills.

Keywords: diabetes, chronic diseases, cognition, decision making, human factors, psychology

Glucose control for people with diabetes is a complex dynamic process. One participant in the present study put it this way: "You know your body comes with an automatic control of your blood sugar and it takes care of that and did for years. But now you've lost the automatic control so you must manually take care of yourself." Diabetes self-management, like any task that calls for manual control of a dynamic process, requires considerable knowledge. But diabetes self-management entails much more than knowing about pancreatic functions and counting carbohydrates. Successful self-management requires ongoing effort to detect problems, understand dynamic relationships, and handle complex situations (Klein & Lippa, 2008).

Diabetes educators provide medically accurate information and training for newly diagnosed patients (Ellis et al., 2004; Reeves & Steil, 2004). Yet more than 60% of patients still fail to engage in appropriate self-care (Manos, 2004). For these patients the instruction and information provided are insufficient to allow them to become proficient self-managers. In order to deal with the dynamic complexity of glucose regulation,

patients need not only information but expertise as well (Hernandez, 1996; Patterson & Thorne, 2000).

The development of the naturalistic decision-making paradigm within cognitive science has helped us to understand how people cope with complexity and develop the skills necessary to succeed at similar high-stakes, high-uncertainty, ill-defined tasks in real-world environments (Orasanu & Connolly, 1993). The focus of naturalistic decision-making is analysis of successful and unsuccessful decision-making by experts in critical situations (Lipshitz, Klein, Orasanu, & Salas, 2001). Such analysis has led to improved performance and decision-making in fields as diverse as driving, military operations, aviation, and anesthesiology (Kaiser & Schroeder, 2003; Klein & Steel-Johnson, 2007; Klein, Vincent, & Isaacson, 2001; Lane, Slavin, & Ziv, 2001). Although people with diabetes are not professional self-managers, the complex tasks they face are similar to those faced by many of the professionals studied in the naturalistic decision-making paradigm (Klein & Lippa, 2008). This project draws upon research in naturalistic decision-making to explore patients' cognition with regard to diabetes self-care. It has both quantitative and qualitative components. The quantitative elements, published elsewhere, examine the nature of expertise in diabetes self-management and its relationship to glycemic control. Many of the classic characteristics of expertise are shared by successful diabetes self-managers (Lippa, Klein, & Shalin, 2008). In this article we present more extensive qualitative descriptions of how proficiency in glucose regulation is related to patients' understanding of the elements of diabetes self-management.

Methods

Design

Semi-structured interviews were used to obtain rich, descriptive data on participants' understanding of type 2 diabetes and self-care practices in typical and atypical situations. All participants provided informed consent; the study protocol was approved by the Wright State University Institutional Review Board.

Participants

Twenty people with a prior diagnosis of type 2 diabetes mellitus volunteered to participate. Recruits either were introduced by friends/relatives who received course credit for their participation or volunteered after seeing a flyer in a pharmacy or grocery store. They received no remuneration. Two recruits were dropped because they had difficulty responding to the interview questions, leaving a total of 18 participants.

Material and Procedures

Each participant was interviewed individually by one or two interviewers for between 60 and 90 minutes. An interview guide ensured that all topics were covered, but in a flexible order so as to maintain a natural flow of conversation. First, the interviewer asked about the participant's demographic characteristics and clinical history. Participants were also asked about their diagnosis and how they learned about diabetes — for example, *What led up to your diagnosis? How did you learn to take care of your diabetes?* They were then asked about their daily care practices and their understanding of these practices — for example, *What is your diet like? Why do you follow this diet? Could you describe how you take care of your diabetes on a typical day?*

We used the critical incident method common in naturalistic decision-making research to look more closely at how the participants thought about diabetes (Crandall, Klein, & Hoffman, 2006; Klein, 1999). We asked the participants to describe critical incidents — those events that were particularly challenging or salient in their experience of diabetes. We also asked about situations when their glucose was high or low. For each episode recounted, we asked the participant to describe the sequence of events and what they were paying attention to in order to decide how to resolve the problem. For episodes of high blood glucose the questions included *How did you notice it was high? Did you do anything to help bring your blood sugar down?*

Finally, participants were asked direct questions about self-care, such as *What things make blood sugar go up?* During direct questioning the participants could demonstrate declarative knowledge, which, due to a lack of opportunity or a lack of understanding, might not have been apparent in descriptions of practical problem-solving and management behaviour.

Self-Care Questionnaire

After the interview, each participant completed a questionnaire derived from a standard measure (Glasgow, McCaul, & Schafer, 1987; Hampson, Glasgow, & Toobert, 1990). Items probed self-management behaviour with regard to diet, exercise, medication, and glucose monitoring, as well as the participant's lowest and highest serum glucose readings during the preceding week and most recent HbA1c result. While these self-reports likely contain some inaccuracies, the questionnaire has proved reasonably valid (correlations with active measures of behaviour range between .40 and .87) and reliable ($\alpha = .86-.97$). This measure allowed us to relate understanding to self-care behaviour and glycemic control.

Transcription and Coding

Initially, six pilot interviews were transcribed and coded using literary transcription and open, emergent coding (Kowal & O'Connell, 2004; Strauss, 1987). This code list was iteratively refined to produce 78 non-redundant codes that could capture maximal content (Flick, 1998; Miles & Huberman, 1994). Codes were operationally defined using key words and concepts. Use of a computerized data-analysis program, Atlas.ti, helped us to divide transcripts into single-idea units and to apply one or more codes to each segment (Chi, 1997; Kelle, 2004). To assess coding reliability, one researcher coded a subset of transcripts on two separate occasions, 3 months apart. There was substantial agreement between codings ($kappa = .78$), supporting the reliability of the coding scheme.

Data Analysis

Analyses combined descriptive statistics with qualitative description. Descriptive statistics summarized demographic characteristics and provided the frequencies at which participants mentioned different aspects of self-care (i.e., diet, carbohydrates, glucose monitoring). Qualitative descriptions permitted identification of patterns of reported self-care and a detailed view of patients' problem-solving processes. Participants varied tremendously in terms of level of adherence, glycemic control, and understanding of diabetes. To address this variation, we divided the participants into three groups according to reported level of glycemic control: those with poor glycemic control (HbA1c greater than 7.0), those with moderate control (HbA1c between 6.0 and 7.0), and those with good control (HbA1c less than 6.0). The first group had eight participants; the other two groups had five participants each.

Results

Participants varied in terms of time since diagnosis ($range = 8$ months–35 years; $mean = 10.8$ years; $SD = 10.0$) and age ($range = 19$ –76 years; $mean = 53.9$ years; $SD = 17.3$). The sample included 7 women and 13 men, varying in education (8 high school or less; 8 college; 2 postgraduate) and vocation. Four participants had worked in fields related to health care. There were no significant differences between poor-, moderate-, and good-control groups in terms of demographic characteristics. Reported A1c results ranged from 3 to 18, with 58% of the results falling over the recommended guideline of 6.5. For the preceding week, the (reported) highest blood glucose readings ranged from 86 to 450 mg/dl ($mean = 180.2$ mg/dl; $SD = 109.4$) and the lowest from 65 to 130 mg/dl ($mean = 90$ mg/dl; $SD = 23.1$).

All participants reported having access to information about diabetes self-care. Eight participants had attended classes on diabetes self-care and 10 had received personal instruction and nutritional counselling from a doctor, nurse, or dietitian. In addition, 12 reported reading books or pamphlets about diabetes self-care. All participants received diabetes care at least every 6 months from a family doctor or an endocrinologist.

The following sections present patient portraits — qualitative descriptions capturing the cognition and problem-solving differences among participants with poor, moderate, and good glycemic control. Each portrait is designed to exemplify how a patient with a particular level of control thinks about diabetes.

Portrait: Poor Glycemic Control

I am probably not a good diabetic.... I take my medicine. I work a lot of hours, probably a good number of hours during the day...I am doing physical exercise.... There [are] real basic rules. I try not to eat as much bread, things like that. I try to eat more vegetables. I try to eat more fruit. And even eating the fruit — there is a fructose in there and a sugar in there... Do I do it [monitor] daily? No...if you're lucky I am doing it once a week, sometimes once a month.

This participant was typical of those who had poorly controlled glucose. He reported that his most recent A1c result was 9.0, and he admitted to struggling with self-management behaviours. He had health insurance that paid for his diabetes care and he had taken a 2-day diabetes education course. He acknowledged that diabetes was “something that I am aware of every day.” His failure to achieve glycemic control seemed to stem not from lack of motivation or intelligence, but rather from insufficient understanding of self-care. This patient exemplifies three trends found in the cognition of poorly controlled self-managers: oversimplification of rules (i.e., bread is bad; vegetables are good), poor understanding of the purpose of recommended self-care, and little understanding of the functional dynamics of glucose control.

Medication. The factor that was easiest for most poorly controlled patients to understand was medication, because they were used to taking prescription drugs for medical problems. The participant quoted above took his medication “most of the time,” though he did not understand its function and had no idea how to handle missed doses. Moderate adherence to prescriptions with minimal understanding was typical of those with poor glycemic control. For example, three quarters of these participants did not know the names and dosages of the drugs they were taking. A typical description would be “I don’t know what it is; it starts with a G.”

Monitoring. Poorly controlled participants also did not understand the purpose of monitoring or its relationship to other self-care activities. All but one of these participants said that regular monitoring was important, yet only half of them actually monitored regularly — the other half either never monitored or, like the participant portrayed above, did so sporadically. Except for one person, who was on a sliding insulin scale, none of the participants in this group could describe the purpose of glucose monitoring. Only two participants said they would seek medical help if they had extraordinarily high readings (i.e., over 400) and none reported modifying their self-care in response to glucose readings.

Exercise. Most participants with poor glycemic control did not exercise. Others (as captured in the portrait) had, after their diagnosis, reinterpreted daily work or household activities as physical exercise. These participants neither increased their physical activity in response to their diabetes nor moderated their physical activity in accordance with their glucose levels; rather, they relabelled their daily activities to be more in accord with self-care recommendations. None of the participants with poor glycemic control articulated a relationship between exercise and glycemic control. This lack of understanding, combined with a busy lifestyle, may have been a factor in their poor adherence.

Diet. Six of the participants with poor glycemic control had some set of rules for controlling their glucose levels. These participants had developed simplified dietary systems that acknowledged the importance of limiting carbohydrates and they adhered to some principles with respect to “healthy eating,” such as following a balanced diet or eating fruits and vegetables. It is not clear how many of these rules came from diabetes education materials and how many simply fit popular notions of a healthy diet. Participants sometimes found these simplified dietary rules confusing. For example, the patient described above apparently saw a contradiction between eating more fruits and limiting sugar intake. Participants pointed to difficulties maintaining an appropriate diet because of busy schedules and lack of healthy alternatives to fast food.

Two of the participants with poor glycemic control had only a vague understanding of dietary control:

Researcher: *You said that you have a kind of diet.*

Participant: *Not really organized. I mean, I know some things I shouldn't eat too much of.... I eat less than I used to, I think, and I don't use much sugar on stuff.*

This participant understood that diet is important but did not know what food choices to make. Participants often reported following one or two simplistic dietary principles — for example, avoiding foods with refined sugar — but otherwise neglecting to control carbohydrate intake.

Problem-solving. Blood glucose levels change in response to many factors, such as illness and stress, which are outside patient control. It is therefore important for people with diabetes to be able to identify and address unsafe glucose levels. Participants who had poor control had difficulty detecting and resolving problems. When asked about episodes of high or low glucose, only two participants could describe an episode of hypo- or hyperglycemia that was sufficiently mild to be treated at home. Both episodes were detected via subjective symptoms associated with low blood sugar and in both cases the participant ate to elevate their glucose. In one case this was effective; in the other case overeating resulted in hyperglycemia 2 hours later. The other six participants in this group could not detect minor glucose imbalances using symptoms and did not monitor enough to detect imbalances using serum glucose levels. They reported one or more incidents requiring emergency room care because of glucose imbalance. Such poor problem-solving is consistent with limited understanding.

Summary. Overall, the participants with poor glycemic control had little understanding of basic self-care. They:

- did not know how medication works nor what to do if unable to adhere to their prescriptions
- did not know the function of glucose monitoring, how to interpret serum glucose levels, or how to use feedback to modify behaviour
- were unable to interpret subjective symptoms or glucose levels in order to detect problems and could not take action to remediate problems
- did not understand the role of exercise in glucose control and therefore were unmotivated to increase their level of exercise
- were confused by the dietary instructions they had been given and defaulted to simplified dietary systems
- did not know the factors entailed in diabetes self-care sufficiently to adjust self-care behaviours to lifestyle demands

Portrait: Moderate Glycemic Control

I watch my diet. I try to keep my carbs even with every meal. I take oral medicine... I do...three to four carb servings... [I test] at least once a day, sometimes twice a day...[it depends on] what my first one was in the morning or if I'm sleeping different[ly] or if I'm doing something different.

This participant was typical of those with moderate glycemic control. Her most recent reported A1c result was 6.9 and she ranked in the middle for self-reported adherence. She worked as a unit clerk in a hos-

pital and had taken diabetes education classes. She believed that she knew how to handle diabetes but was concerned about modifying her diet to accommodate both her diabetes and her high cholesterol, a complexity not covered in her classes. She struggled with balancing the demands of two disorders. Others reported similar difficulty managing multiple diagnoses. Typical of individuals with moderate glycemic control, she understood the basics and was trying to make sense of the principles behind self-care. However, she had difficulty in complex and atypical situations.

Medication. Like most of the participants with moderate glycemic control, this woman did not understand exactly how her medications worked but did know their names and dosages and did take them regularly. She had a theory that her medication made her metabolize food better. Three of the five participants with moderate glycemic control described medication functioning as centred on using glucose better or keeping glucose out of the blood.

Monitoring. All participants with moderate glycemic control monitored their glucose regularly. Three of these participants monitored on a schedule multiple times per day and used the readings to keep a general watch on their glucose levels:

I check my blood sugar three times a day. I check it when I get up in the morning, I check it...at dinnertime or just before dinnertime to see whether it's real high or if it's up there a little bit or if it's real low, and then I check it before I go to bed.

The other two monitored regularly but timed their monitoring in response to somatic cues and unusual events that they thought might be linked to glucose imbalance. For example, the portrayed participant monitored at least once a day but would monitor a second time if she felt that something had disturbed her glucose levels. Participants in this group knew how to interpret their glucose readings and often modified their activities in response to a reading, such as by eating fewer carbohydrates after a high reading.

Exercise. Like participants with poor glycemic control, those with moderate control did not articulate or understand the connection between exercise and glucose levels. And, like those with poor control, three of these participants interpreted daily activities as exercise. Only one understood that exercise helped maintain healthy glucose levels.

Diet. Participants with moderate glycemic control had a significantly more sophisticated understanding of diet than those with poor control. Some, like those with poor control, had general rules for controlling their glucose. However, whereas those with poor control tended to focus on eliminating food groups, these participants were more likely to focus on controlling the number of servings of different food groups per meal.

In the above quote, the participant speaks of having “three to four carb servings” per meal. However, even these more sophisticated rules were inadequate for dealing with unusual events such as vacations or bouts of illness.

Two participants found the number of rules overwhelming. One of these had created an overly simplified system similar to those used by the participants with poor control. The other became engrossed in the details of the rules provided and lost track of the dietary principles behind the rules:

...the person in dietary [said], when we asked...what butter to choose, she [said] you see what the first ingredient is and if it says water that's the best type of butter...and salads if you like salads or love vegetables...fish is good... Oriental food they cook so fast that sometimes not as much fat will go into that. And you can eat those and it doesn't hurt you as much.

Problem-solving. Four of the five participants with moderate glycemic control recognized routine glucose imbalances. Problems were detected either through somatic cues that prompt monitoring or during routine glucose monitoring activities. The participants who detected glucose irregularities responded to low glucose levels by eating or by drinking a sugary beverage. However, no one in this group reported taking action to ameliorate high glucose levels. The mechanisms of raising glucose were better understood than those of lowering glucose. This may be because glucose can be raised quickly, while lowering high glucose levels has a longer time course.

Summary. Participants with moderately controlled glucose had some understanding of self-care procedures but did not fully grasp the principles behind them. They:

- had a vague understanding of how medications work, though probably insufficient to guide action in the case of disruptions
- monitored regularly and in some cases used monitoring to provide feedback on unusual events
- did not understand the purpose of exercise for self-care and therefore were unmotivated to exercise beyond their daily activities
- followed fairly sophisticated dietary rules but were sometimes overwhelmed by the number and complexity of those rules
- were adept at detecting problems but could not take action to ameliorate high glucose levels

Portrait: Good Glycemic Control

Five participants had well-controlled glucose levels. These participants fell into two distinct patterns of self-care. Two maintained the same routine

every day, eating the same foods and engaging in the same activities. One of these was a 63-year-old retired truck driver:

Participant: *I eat three times a day — certain times, certain food.*

Researcher: *So, the same thing every day?*

Participant: *Every day.*

Researcher: *What do you eat every day?*

Participant: *Boiled egg for breakfast, salad for lunch, and sometimes a chicken breast [in] the evening, if not maybe another salad. And I also eat popcorn.*

The other three participants in this group had a good understanding of diabetes and the demands of self-care:

I test four times. I test once in the morning, and then three times 2 hours after I eat. At night I may not test 2 hours after I eat; I might test before I go to bed because I like to see what happens after fasting. So the testing allows me to track what is going on.... I try not to have more than 50 carbohydrates a meal. I noticed that I can have between 50 and 80 and not have it go up and I won't feel sick with my sugar up. I noticed that if I have less than 50, 2 hours later my sugar is down [and] I am going to have to eat a candy bar or something to get it back up, or a piece of bread... I try to walk an hour a day.

This participant was diagnosed 3 years previously and had a reported A1c of 5.9. Although he had never taken a diabetes education class, he had spent time reading and received instructions from his family physician. His cognition was typical of those with well-controlled glucose levels: he had a detailed understanding of the requirements of self-care, knew why each of the actions he took was effective, and viewed diabetes as a dynamic control system involving taking actions, monitoring feedback, and adjusting activity accordingly.

Medication. All of the participants who achieved control through understanding and one of the participants who achieved control through routine knew the names and dosages of their medications. Three of these four also understood the physiological mechanisms of their medications.

Monitoring. All of the participants in this group monitored multiple times a day, according to a schedule. They also monitored when they were uncertain how their bodies would respond to eating unusual foods, to illness, or to other atypical events. Monitoring was central to their self-care practices, because they used glucose levels as feedback to customize their self-care regimens:

I had wings and pizza one night, and I had three pieces, and 2 hours later it was fine. My sugar was fine. Then about 2 weeks later I had four at a

party... I took my blood sugar 2 hours later and it was at 225. I looked at my wife and I said, "Hey, look at this — three pieces don't affect me but four pieces do."

Here, monitoring helped to shape future choices. Only the three participants who had a detailed understanding of diabetes mentioned using glucose monitoring to modify self-care behaviours.

Exercise. Only two of those with well-controlled glucose levels (one who controlled via routine and one who controlled via understanding) exercised regularly. However, unlike the participants in the other groups, four of the five participants in this group understood that exercise can lower glucose levels in both the short term and the long term.

Diet. Some participants achieved good control by eating the same foods every day, while others did so by knowing how various foods are metabolized and by developing idiosyncratic diets. The pizza incident recalled above documents how food choices can be moderated by careful attention to diet and feedback from glucose monitoring.

Problem-solving. The two participants who controlled their diabetes by routine had problems only when they experienced an uncommon event such as an infection, and were then treated by a health professional. The three participants who achieved control via understanding were adept at detecting problems. They were able to monitor their bodies and match somatic cues to general glucose levels; they integrated symptom awareness with glucose monitoring to diagnose glucose imbalances. They were also able to manage both hypo- and hyperglycemia. These three were the only participants in the sample who had strategies to ameliorate high glucose.

Summary. Participants with well-controlled glucose levels:

- fell into two patterns — they either had a fixed routine, or depended on an in-depth understanding of self-care and of how medications function
- monitored multiple times a day, according to a schedule
- did not exercise more than the participants with low or moderate control but understood the link between exercise and glycemic control

Those with an in-depth understanding also:

- used monitoring to determine the efficacy of their self-care behaviours
- developed idiosyncratic diets based on subjective feedback and glucose monitoring
- were able to detect and ameliorate episodes of hypo- and hyperglycemia

Conclusions

Like other domains that require the management of dynamic control systems, effective diabetes self-management calls for the development of the skills and expertise needed to solve problems and understand functional relationships. We have described some of the ways in which diabetes self-managers with different levels of glycemic control understand self-care. Those participants with poor control had no understanding of the dynamics of glycemic control. They did not know the components of self-care, could not interpret serum glucose monitoring results, and were confused by the dietary instructions they had received. They could not plan appropriate self-care regimens and could not detect or recover from glucose imbalances. Those with moderate levels of glycemic control had a basic understanding of the procedures necessary for daily self-care but did not understand the relationships among these procedures. As a result they had trouble adapting self-care guidelines when faced with unusual external events or physiological circumstances. They could plan their daily self-care but could not incorporate disruptive events into their plans or recover from imbalances. Among those with good glycemic control, some controlled their glucose through strict regimentation while others used feedback to control their glucose. The former group had a limited understanding of diabetes self-care, whereas the latter group had developed sophisticated mental models of the dynamics underlying diabetes and used frequent monitoring to help modify actions in order to control those dynamics; this group was able to engage in detailed planning, decision-making, and problem-solving.

Implications for Diabetes Training

Current diabetes training provides patients with critical basic rules and procedures to help them get started with self-management and handle routine self-care activities. Nevertheless, most patients have critical gaps in their understanding of appropriate self-care behaviours and the principles behind them. Many of the participants with poor glycemic control found the rules to be too complex. Such patients need help applying the rules they have learned to their daily lives so as not to become overwhelmed, confused, and frustrated. Instead of being given standard information in large classes, these patients could benefit from individualized instruction and recommendations tailored to their own lives. Spreading instruction across several months so that patients can incorporate lifestyle changes slowly and providing ongoing professional feedback about their self-care behaviours could also be beneficial. Those with moderate glycemic control used rules and procedures effectively during routine care but could not go beyond the rules to compensate for glucose imbal-

ances or coordinate diabetes care with unusual events or circumstances. Such patients need help understanding how to use the principles behind glucose control and practice in decision-making and problem-solving. Those who had well-controlled glucose levels and used feedback to control their diabetes had started self-care with rules and procedures but had slowly, over time, modified the guidelines they were given to accommodate increasing knowledge about the specific functioning of their own bodies.

So how should we go beyond the rules to teach people with diabetes how to control their glucose levels? The key is to give patients the cognitive tools they need to understand glucose dynamics, plan self-care, make decisions about self-management, and recover from glucose imbalances. Teaching people what to eat is a good start, but we need to move beyond this, teaching them to make good decisions on their own and solve problems as they arise. While there have been studies looking at the role of problem-solving in diabetes self-management, there have been few attempts to teach self-management problem-solving skills (Hill-Briggs, 2003; Patterson & Thorne, 2000). One way to provide these skills is to give patients the opportunity to practise making decisions about their self-care in a safe environment and to give them feedback on their choices. Training based on cognition and decision-making has been effective in improving planning, decision-making, and recovering from negative events in many complex domains (Pliske, McCloskey, & Klein, 2001). Decision-making and problem-solving could be taught in diabetes education classes through a series of carefully developed scenarios. Each scenario would present a problem related to self-care and the educator would help the class to think through the problem and evaluate different alternatives. In this way, patients would learn how to react to unusual situations (such as holidays or business trips) and critical events (such as high and low glucose levels). Moreover, by working through multiple scenarios patients would learn what aspects of the environment and their actions affect their glucose and how to use that information to make effective decisions.

Diabetes self-care is complex and difficult. It entails the management of a dynamic system and the coordination of many different elements. Understanding patient cognition and providing training for decision-making and problem-solving cannot solve the problems of diabetes self-care. There are many other social, medical, and institutional problems that must also be addressed. But examining how patients understand self-care and the dynamics of glucose regulation may at least allow us to use tools that have been developed for solving similarly complex problems in other domains to help improve patient education, autonomy, self-care, and glucose control.

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Surveillance de l'affection rénale chronique dans une clinique gérée par du personnel infirmier et supervisée par des médecins : l'expérience CanPREVENT

Anita E. Molzahn, Maryse Pelletier Hibbert, Denise Gaudet, Rosalie Starzomski, Brendan Barrett et Janet Morgan

L'objet de cette étude était d'examiner la nature des soins apportés aux personnes souffrant d'affection rénale chronique, dans le cadre d'une étude plus large sur les cliniques gérées par du personnel infirmier et supervisées par des médecins, ainsi que la description que les patients, le personnel infirmier et les néphrologues font de leur expérience de ces cliniques. Les entretiens ont été réalisés avec 7 infirmières, 5 médecins et 23 patients. La collecte de données a également nécessité l'examen de 40 graphiques choisis au hasard. Les thèmes recensés étaient en lien avec les caractéristiques de l'infirmière, les soins axés sur le patient, la promotion de la santé, l'enseignement, la gestion des problèmes, le temps, les protocoles, la consultation et les orientations, la logistique de la clinique, les travaux d'écriture/la documentation, ainsi que la collaboration entre infirmières et médecins. Difficultés et résultats ont également été décrits dans le cadre de l'expérience vécue à la clinique. Les patients ont participé activement à l'autocontrôle et fait état de niveaux de satisfaction élevés concernant les soins de même que d'améliorations des résultats sélectionnés. Dans l'ensemble, les perceptions de ce modèle de soins étaient positives et l'approche justifie de plus amples recherches.

Mots-clés : clinique gérée par du personnel infirmier, affection rénale chronique

Managing Chronic Kidney Disease in a Nurse-Run, Physician-Monitored Clinic: The CanPREVENT Experience

**Anita E. Molzahn, Maryse Pelletier Hibbert, Denise Gaudet,
Rosalie Starzomski, Brendan Barrett, and Janet Morgan**

The purpose of this study was to examine the nature of the care provided to people with chronic kidney disease within a larger study of nurse-run, physician-monitored clinics, as well as how patients, nurses, and nephrologists described their experience with the clinics. Interviews were conducted with 7 nurses, 5 physicians, and 23 patients. Data collection also entailed review of 40 randomly selected charts. Identified themes related to characteristics of the nurse, patient-centred care, health promotion, teaching, dealing with problems, time, protocols, consultation and referrals, clinic logistics, paperwork/documentation, and nurse-physician collaboration. Challenges and outcomes were also described as part of the experience with the clinic. Patients were actively engaged in self-management and reported high levels of satisfaction with care as well as improvements in selected outcomes. Overall, the perceptions of this model of care were positive and the approach warrants further exploration.

Keywords: nurse-run clinic, nursing clinic, chronic kidney disease, qualitative research

In Canada the incidence of end-stage renal disease (ESRD) has increased steadily, at more than 7% per annum, over the past decade (Canadian Institute for Health Information [CIHI], 2006). ESRD occurs mainly as a result of chronic progressive kidney diseases (CKD), increasingly due to diabetes (CIHI, 2006). People with ESRD have a markedly reduced survival rate and quality of life (Molzahn, Northcott, & Dossetor, 1997; Molzahn, Northcott, & Hayduk, 1996) and very high treatment costs (Goeree et al., 1995). Since CKD is under-recognized and under-treated in the community, opportunities exist to prevent ESRD.

CKD is also associated with cardiovascular disorders, resulting in increased morbidity and mortality, but several interventions of proven efficacy can slow progression of kidney disease and reduce the morbidity and mortality associated with cardiovascular disease (Barrett, 2003). The challenge is to identify people who will benefit from these interventions and apply them consistently. In the current system, patients see physicians intermittently, and this system is not well designed for chronic disease management. However, a nurse supported by a nephrologist,

running a multiple risk factor intervention and disease management clinic may be effective in reducing or delaying the onset of advanced kidney disease, cardiovascular events, and death. To examine this hypothesis, the Canadian Collaborative Group for the Prevention of Renal and Cardiovascular Endpoints Trial (CanPREVENT) was designed as a randomized controlled trial, and a pilot test was conducted in five centres. In this article, we describe the nature of the care provided in the centres and the experiences of patients, nurses, and physicians with the clinic after nearly 3 years of operation.

Research Questions

The research questions for this sub-study of the CanPREVENT project were as follows: *What is the nature of the care provided by nurses and physicians to those in the intervention group of the CanPREVENT study? How do the nephrologists and nurses work together to provide care to those in the study? How do patients, nurses, and physicians describe their experience with the clinic?*

Literature Review

Frequently, CKD goes unrecognized in the early stages. As a result, many of its complications are left untreated and result in progression of the disease and further complications. While the benefits of treatment may be great, the regimen and care needs are complex, posing many challenges for those delivering care (Barrett, 2003).

Earlier intervention is necessary, as many people with CKD die or experience cardiovascular events before they reach ESRD. Current management of CKD is sub-optimal; CKD is under-recognized and frequently under-treated (Coresh et al., 2001). Hypertension is poorly controlled generally (Joffres et al., 1997). For example, Tonelli et al. (2001) report that Canadians attending nephrology offices with CKD are commonly under-treated with regard to blood pressure, lipid control, and aspirin administration.

It has been suggested that nurses be involved earlier in a multiple risk factor intervention approach to CKD (McLaughlin, Manns, Culleton, Donaldson, & Taub, 2001; Zabetakis & Nissenson, 2000). A recent randomized trial of a clinic focusing on intensified multiple risk factor intervention versus usual care showed clearly improved outcomes in diabetics within 4 years (Joss, Paterson, Deighan, Simpson, & Boulton-Jones, 2002). Similar benefits of clinic-delivered multiple interventions were seen in a before-after study with diabetics who had advanced CKD (Gaede et al., 2003). Almost 80% of people with CKD attending a pre-dialysis clinic expressed a willingness to consider a strict diet, taking up to six extra medications a day, and making six extra clinic visits a year if this would

delay the onset of ESRD by even a few weeks (Trivedi, Pang, Campbell, & Saab, 2002). Protocol-guided care, coordinated by nurses and focusing on illness management and prevention, may offer the best chance to maximize uptake of effective therapies for people with CKD.

Patients with advanced CKD are increasingly cared for in hospital-based multidisciplinary clinics. These clinics, staffed by specialized nurses and nephrologists, with variable involvement of other health professionals, have been associated with improved outcomes (Levin et al., 1997; Mosley, 2000). However, one trial that failed to show a benefit left it to primary care providers to implement suggested interventions (Harris, Luft, Rudy, Kesterson, & Tierney, 1998).

Care in specialized clinics has been found to reduce hospitalizations and costs for those with heart failure (McAlister, Lawson, Teo, & Armstrong, 2001a). Processes of care, hospitalization, quality of life, and functional status have also been shown to be generally improved by approaches similar to those used for coronary heart disease (McAlister, Lawson, Teo, & Armstrong, 2001b). It has been found that patients have a greater response to non-medical interventions (fluid/diet restrictions and regular self-weighing) with intensive counselling by a nurse who is part of a multidisciplinary team (Jaarsma & van Veldhuisen, 2007).

Nurses, collaborating with physicians, already effectively deliver protocol-based care in nephrology settings (Breiterman-White & Becker, 1997). Nurse case managers in disease management programs are seen to play an important role for people with CKD (Bolton, 1998; Holland, 1998; Sidorov et al., 2002). In the present study we explore the nature of care provided to people with early CKD (stages 1 to 3) and describe the experience with nurse-run, physician-monitored clinics.

Methods

Intervention

The intervention consisted of a protocol-guided, multiple risk factor clinic based in a hospital and run by a registered nurse supported by a nephrologist. Patients in a control group received usual care from their primary care physician. The philosophy of care for the intervention group involved collaboration and partnership with patients and families to improve health and enhance quality of life.

An orientation program was offered to nurses, Web-based resources were developed, and regular teleconferences among the nurses were held. A series of medical protocols were developed regarding: managing blood pressure; controlling lipids with diet and statins; disrupting the renin-angiotensin system with angiotensin converting enzyme inhibitors; using angiotensin II receptor blockers for diabetics; treating anemia; using

acetylsalicylic acid to prevent atherothrombotic events; and controlling calcium/phosphorus with diet, phosphate binders, and activated vitamin D. In addition, emphasis was placed on managing weight, controlling glycemia in diabetics, exercise, restricting dietary sodium, and smoking cessation.

Most nurses worked half-time and the intention was that they would be responsible for a group of 50 patients in the intervention group; a few nurses also worked with the 50 control-group patients, in order to create full-time positions. Three of the five centres exceeded the target enrolment so those nurses may have cared for up to 60 patients. Some nurses also had responsibilities with other research studies in their centres.

The qualifications and care provided by nurses in the clinics could not be standardized. A standard job description was developed for the nurses when the study was initiated. Recruitment of each nurse was the responsibility of the centre and was governed by institutional policies and practices. It was assumed that individual nurses, with their unique skills and knowledge based on education and experience, would use a range of interventions and strategies. These interventions could foster patient self-management, facilitate adherence to treatment regimens, and improve outcomes. It was anticipated that health promotion and illness prevention activities (unrelated to renal disease) would also be offered.

Participants

Five centres (located in Vancouver, British Columbia; London, Ontario; Greenfield Park, Quebec; Halifax, Nova Scotia; and St. John's, Newfoundland and Labrador) participated in this pilot study. Seven nurses (because of turnover) and five nephrologists were interviewed. The nurses' credentials ranged from diploma to master's degree in nursing and most had extensive nephrology nursing experience. Purposive sampling was used to select five patients from the intervention group at each participating centre. A total of 23 patients who were considered to be good informants were interviewed; at the most recently established centre, only three patients were interviewed because the centre had fewer patients and saturation had been reached. The participating patients ranged in age from 58 to 78 years and were 52.2% male.

Data Collection

Telephone interviews were conducted with intervention group patients approximately 9 months after their first visit to the clinic and with physicians and nurses after approximately 9 to 12 months' experience at the clinic. All interviewees were asked to describe their experience with the intervention. All interviews were semi-structured and were audiotaped; they ranged from 30 to 90 minutes in duration. At his request, one

patient was interviewed on two occasions. The tapes were all transcribed verbatim.

To augment the findings, charts of randomly selected patients who had been receiving care for at least 9 months were reviewed. These charts were not necessarily those of the study participants. Forty charts (10 from each of 4 centres; for the Quebec centre, analysis in French is still in process) were examined. Copies of the clinic charts were sent to the investigator after all identifiers had been removed.

Data Analysis

Transcripts were read multiple times by the investigator and research associate and themes were identified. The research team reviewed the transcripts and agreed that the themes reflected the data. To analyze chart data, the researchers employed an inductive approach using content analysis.

Rigour of the analysis was ensured through transcript review by several members of the research team. An audit trail was maintained in order to record the context and background of the decisions regarding data analysis. Ideas, decisions, actions, and responses were recorded and monitored by the researchers. Triangulation of findings was facilitated through the use of different data sources.

Findings

The themes pertaining to nature of care were as follows: patient-centred care, health promotion, teaching, dealing with problems, time, protocols, consultation and referrals, clinic logistics, paperwork/documentation, physician-nurse collaboration, challenges and recommendations, and outcomes. Each of these areas is described below.

Patient-Centred Care

It was evident from the descriptions of nurses, physicians, and patients that care was patient-centred. The nurses made many efforts to accommodate patients' schedules, often coming in early, staying late, changing appointment times, and, on rare occasions, making a home visit if the patient was too ill to attend the clinic. They usually collected the blood samples themselves to save the patients the wait in the lab (and in some instances travel to the lab). It was not unusual to find it noted in the chart that the nurse "went the extra mile"; for example, one nurse picked up a forgotten 24-hour urine sample from a patient's home while he was having breakfast.

In a number of instances, the nurses worked diligently to tailor the patients' care to their needs. One nurse commented:

I can't get her back into this clinic because it's too far for her to come, so I've had to do a lot of phone calls for her, but we've made some major changes in her blood pressure and improvements...there's still areas to work on but...I think that she really appreciates the calls and the concern and she's been very receptive to the follow-up that I've been trying to give her.

Patients made similar observations:

I know I can ask my nurse any question. If anything was to come up, I could ask her the question and she's going to find out the answer, to the best of her ability, to help me out. If you've got the faith in your nurse, I think that's the best.

Health Promotion

General health promotion strategies were used by all nurses in caring for the intervention group patients. Nurses and physicians addressed general health concerns to the best of their ability, rather than referring patients back to primary care physicians:

...just being able to see the patient and not just focusing on maybe one aspect of their health but really focusing on all aspects, because, you know, in the end they all come together to affect their general health.

One nurse contrasted this type of care with that given in dialysis units, where “you never had the whole picture like you do in this study.”

However, health promotion often posed challenges for nurses:

Challenges would be in areas of maybe assisting people with behaviour change, dealing with dietary issues and smoking cessation, which hasn't been a frequent problem, honestly...and being able to give appropriate advice on exercise patterns and supporting people through those lifestyle management choices.

There were many notes in the charts about the nurses encouraging health promotion strategies such as exercise for weight loss, smoking cessation, and, for patients with diabetes, regular monitoring of blood glucose. A few diabetic patients commented that no one had ever checked their feet until they began attending this clinic, and no one had ever told them about the importance of wearing well-fitting shoes.

Teaching

Patient education was a key focus of nursing care for people in the intervention group.

In terms of that side of my role, it was to explain to the patient what it was that we were doing and [the] risk factors that we were looking at.

We talk about the small changes that could be made in people's activities and...in their diet. And we talk about their blood pressure and I explain that it can cause problems down the line. It's not just something a pill's going to treat, but the impact of having high blood pressure — we talk about that a little. We talk about kidney disease and how it might be related to their diabetes or their blood pressure. And I have pamphlets that I give them to take home as well. We go over their BMI... And I discuss over-the-counter medications that could possibly be harmful for their kidneys.

While the teaching seemed to be a routine part of the job for the nurses, it was very important to the patients:

What I like about it is [the nurse] does a little bit of health teaching as she's doing the blood pressure and weighing you and all these things.

A patient who was still trying to absorb the diagnosis of kidney disease gave an example of being educated about the condition by the nurse:

The last time I was [at the clinic, the nurse] had a nice little chart that showed what my kidney levels should be as far as deterioration from being 100% with age.

Dealing with Problems

In providing care to the patients, the nurses often focused first on specific problems that had been identified in the assessments. Frequently these problems related to high blood pressure, uncontrolled blood glucose, or lack of adherence to the treatment plan:

For the most part it was blood pressure-related problems for those people. They were either not on something or their family doctors felt their BP was fine but when they were here it was high.... We would hook them up and...record them for the 24 hours...[referring to ambulatory blood pressure monitoring over 24 hours]. And then they would be initiated on whichever blood pressure drug that Dr. X chose. And then we would always bring them back for re-check.

If there are things that I need to follow up on — it might be blood pressure or follow-up blood work or just to see how the patient is doing with whatever things we had decided on — I may do follow-up phone calls or a follow-up visit, where I'll meet with the patient again before their next 4-month visit.

A physician commented on the work of a nurse in regulating the blood glucose of diabetic patients:

[The nurse will] work with them to establish what their pattern of sugars are. She may give them feedback/advice on her own, and then sometimes she'll e-mail me data and ask questions.

Time

Nurses, physicians, and patients all commented on the value of nurses' time in the intervention. "We have the luxury of having more time to focus on their other parameters that are actually quite normal," said one nurse, while a physician stated:

[The nurse] spends an hour with each patient. I think that's something people don't see these days. It's unheard of — an hour in the health-care system. Nobody gets that kind of treatment.

During their time with patients, the nurses were able to focus on health promotion and teaching to an extent that is rare in most health-care settings. They were also able to deal with psychosocial issues that could have had an impact on the person's care. One nurse joked,

I should have been a social worker, because I had a man whose wife died and I had somebody else who had an overdose.

A few patients commented on how much they appreciated the emotional support they received from the nurse, especially when they first learned that they had kidney problems. Patients noted that the nurses responded to their concerns quickly, which was greatly appreciated.

Protocols

Both nurses and physicians described the work entailed in implementing the medical protocols. Two of the nurses expressed some frustration with the protocols because of the lack of specific guidance. One commented:

Well, the protocol is loose, very loose. I do other trials where you have definitive guidelines, and this is sort of like, well, do it however your site wants to do it, site-specific. And so I find that a bit challenging.

In contrast, a physician said:

When you start doing this kind of study, everything becomes protocolized, which is great, but some things are difficult to protocolize — even medicine, not every single decision in medicine is evidence-based.

Some nurses and physicians worked on specific standards of care to address this concern, while others were able to establish other arrange-

ments or communicated to clarify issues when the protocols did not address the concern.

Consultation and Referrals

Each of the centres had different resources available. In some centres it was difficult to access a dietitian unless specific criteria were met. In these cases it was the nurse who conducted the dietary assessment and teaching. This entailed additional learning for the nurse, but also pride in the ability to provide this care when necessary. The nurses recognized the value of the multidisciplinary team and negotiated the involvement of others. Referrals to other professionals and to outside agencies such as diabetic resource clinics were common. Social workers and physiotherapists were involved at times. Referrals to medical specialists were fairly common.

The nurses regularly wrote to general practitioners and specialists to update them and facilitate communication and collaboration within the team. Communication with other professionals was often time-consuming for the nurses:

That was literally a day's work — talking to Dr. X, talking to the patient, talking to the specialist, getting the results, then re-talking to the patient and explaining to him.

A patient commented:

Everybody exchanges information — the kidney doctor, my family doctor, and the clinic. So everybody's informed [of] exactly what's going on. So that's good.

Clinic Logistics

In describing their experiences with the clinic, both nurses and physicians discussed the logistics of organizing their clinic's activities and data collection. This was quite time-consuming in the initial stages of the study but less so at the time of the interviews:

It's running pretty well... I think [with] a lot of these patients cholesterol and dietary control had come up and we were scrambling and doing things at the 8-month visit that we should have been doing at the first-month visit.

Their comments reflect the time needed to establish a new clinic, organize routines, and learn based on the types of patients being seen.

Paperwork/Documentation

The nurses spent considerable time documenting the care that was provided. Much of this documentation was for the purposes of the research and would not normally be part of routine care:

It almost takes up your full day just getting everything prepared for one visit and then actually having the visit and then...charting it up when they're finished.

I spend a fair amount of time...seeing intervention patients for their... 4-, 8-, [or] 12-month visit.... I'll follow up with a letter to the family doctor.

Similarly, patients commented on the amount of study documentation and number of questionnaires:

I've answered a lot of questionnaires for them...and I have some information here in front of me...there's a schedule here of everything that they've done.

Some of the nurses remarked that some of the data collected were not necessarily useful to them and the time might have been better spent.

Nurse-Physician Collaboration

The nurses and physicians spoke positively about the nature of their relationships and their collaboration. They did not view this as unusual or extraordinary. Both nurses and physicians were satisfied with the collaboration, and the nurses reported feeling that they were supported in the provision of care and could contact the physicians as necessary with questions. Many did so through e-mail or telephone, so meetings were not required on a regular basis.

Some physicians explained that they were perhaps more receptive than their colleagues to working collaboratively with nurses:

I've worked a lot with nursing, dietitian, case management coordinators, NPs...so I'm much more willing to have them as part of the clinic than some physicians are — they don't want to give up their doctor roles.

Nurses and physicians saw themselves as part of a team. One physician said, "We've really moved to a team approach. And then the physician is supposed to sort of provide guidance or help but not necessarily do all of the day-to-day care." Another physician stated that nurses and physicians contributed in different ways:

I think we've more or less evolved the relationship quite easily.... It just sort of happens. There's parts of it that she does a lot better than I do, and

she can spend more time with some of the patients when they require it than I...sometimes have. So that's good.

In each of the centres, nurses and physicians developed strategies for handling prescriptions when the physician did not actually see the patient. One physician said, "We've got a system now that if they need prescriptions, rather than me writing them out or doing anything I'll phone them in." Another physician telephoned in prescriptions after receiving an e-mail request from the nurse. Yet another "may write prescriptions in between when I'm over at the clinic area and leave them in the patient's file, and then the nurse will activate those if necessary."

Challenges and Recommendations

All participants were asked if they had suggestions for improving the operation of the clinic. Most of their recommendations related to administrative or organizational aspects. Both nurses and physicians found it challenging to establish the structure and organization of the clinic, given that it was a new setting/environment. The physical location was often far from the physician's office and other clinic/hospital facilities. There were logistical issues such as a permanent location and parking facilities:

The biggest problem we face is that our clinic is downtown, which means that driving in and parking and just the location...becomes a bit of a problem. Parking's at a premium.

One nurse said, "If I could change something, I would like to have a permanent spot for the clinic," while another nurse wished "that the blood-taking station was right next door and the line-up wasn't 45 minutes, so my patients [wouldn't be] hungry" (because of the need to fast for some lab tests before coming to the clinic).

A nurse suggested getting

organized with work sheets at the very start...and get the standards of care that we got here so that they [have] something besides the protocol for guidance.

Both nurses and physicians brought up the need for organization given the volume of forms to be completed, protocols to be implemented, and care to be provided. "The first challenge," said one physician, "is to set up teamwork. It sounds basic to nurses but not to physicians." A difficulty in some centres was the lack of a full-time secretary to assist with sending faxes, typing letters, and making follow-up phone calls to set up meetings with patients.

The nurses indicated that they did not always have ready access to the resource materials needed to address the variety of concerns or issues

confronting them. Although a Web site with resource materials had been established for the use of nurses, it was not available until several months after the commencement of the study, so nurses did not have access to the online resources or discussion forum from the start. One nurse said:

I think the Web page [with resources for nurses and patients] is underutilized right now... If [only] there had been time in the organizational phase to get all of that done so it was there and the nurses were using it right from the outset.

Outcomes

It was evident that there were high levels of satisfaction with the clinic. One physician said, "I'm happy to see it is working." Another stated, "It has convinced me that we should be doing more of this. I can follow a large number of patients this way. I'm happy with the results, because there are no catastrophes." However, one physician was tentative about the outcomes:

It's an unblinded trial to some degree, so maybe...patients' self-reported outcomes will...look more impressive than they would if the intervention were blinded.... I'm not so sure...there'll be definitive clinically important differences.

All nurses and physicians described successes in the management of patients. A physician said, "We've had some successes with blood pressure control and that type of thing," while one of the nurses offered more detail:

These patients in the clinics are being extremely well looked after. And we've had the occasion now to see a few things that have been picked up and corrected in our intervention patients that gives us great pleasure...in terms of picking up a colon cancer that might have been missed, and having a patient whose BP was in the 220/100 and something range prior to the study...[and] now is almost at target range, and the patient came in the other day and she said, "I could kiss you guys. I feel so much better."

Patients also reported positive outcomes, such as feeling better, losing weight, having lower blood pressure, and having better control of blood glucose. A number of them commented that problems not identified by their family physician were identified in the clinics, something for which they were grateful. Patients' reported satisfaction with care was consistent across all centres, and their positive comments pertained to both nursing and medical care. One patient commented:

[The nurses are] very caring and follow-up is exceptionally good... I'm contacted before my visit to make sure I don't forget... or if I have to bring anything along for that particular session.

Discussion

Nurses often do not have the opportunity to use their full scope of practice. Like Attridge, Budgen, Hilton, Molzahn, and Purkis (1997), we found that nurses, when given opportunities to provide more autonomous care, are able to meet the challenge. With the support of the nephrologists, they implemented the medical protocols and addressed a wide range of health issues. The qualitative reports suggest positive experiences and outcomes. Other research related to the quantitative outcomes of the intervention will be of interest. For example, data pertaining to morbidity, mortality, biochemical and physiological parameters, quality of life, and cost-effectiveness are being collected as part of the overall trial and will be reported at a later date.

It appears from both the interview and chart data that the intervention was implemented as designed. Not only were medical protocols used as recommended but nursing interventions included patient-centred care, health promotion, teaching, and nursing time. One surprising finding was the lack of evidence of family-centred care. It seems that patients did not usually bring family members to their visits or teaching sessions.

Issues emerging from the clinics include a number of logistical and organizational challenges, some related to the fact that this was a trial. It is often difficult to plan health-care interventions outside of the established structures of the health-care system. Different physical locations and supports were negotiated at the various centres. However, when the situations were less than ideal, nurses were affected. Greater attention to planning structures and processes of care in advance might facilitate better use of nurses' time.

One question that may emerge is the optimum number of patients that can be cared for by a nurse in a similar clinic. This is difficult to assess given the considerable work of documentation and data collection, particularly during the randomization phase of the study. For example, at the baseline, 12-month, and 24-month visits, the nurses were required to complete 57 pages of case report forms. Despite this administrative and research work, nurses working half-time could effectively manage 50 to 60 patients during the study randomization and implementation phases. Questions arise regarding cost-effectiveness of this type of care, and more data will be required to address those questions.

The intervention used in this clinic for the management of early CKD seems to have been positively received by the participants and a

number of positive outcomes were reported for individual patients. Nurse-run clinics have also been found to be effective in other settings (e.g., Attridge et al., 1997; Gorenber & Cohen, 1994; McEvoy & Vezina, 1986).

The study has a number of limitations. Findings from qualitative research are not generalizable to other settings or populations. Patients were selected for interviewing because they were seen to be good informants; their experiences may not reflect the experiences of others in the same situation. Interviews took place at only one time point and it is possible that the experiences of nurses, physicians, and patients change over time. This intervention is not necessarily the same as other nurse-run clinics, so caution should be used in interpreting the findings.

Conclusion

The nature of care provided in this illness management clinic included patient-centred care, health promotion, teaching, dealing with problems, time, protocols, consultation/referrals, logistics, paperwork/documentation, and physician-nurse collaboration. Challenges and outcomes were also described as part of the experience. Patients were actively engaged in self-management and reported high levels of satisfaction with care as well as improvements in selected outcomes. There were positive perceptions overall about this model of care and the approach warrants further exploration.

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Les femmes des milieux ruraux, la technologie et l'auto-prise en charge des maladies chroniques

**Clarann Weinert, Shirley Cudney
et Wade G. Hill**

L'objectif de cette étude était de déterminer les différences intervenant dans l'état psychosocial de 3 groupes de femmes des milieux ruraux atteintes de maladie chronique, qui participaient à une intervention par ordinateur. Elles étaient réparties en 3 groupes : intervention intense, intervention moins intense et groupe témoin. Au départ et ensuite, on a mesuré le soutien social, l'estime de soi, l'autonomisation, l'auto-efficacité, la dépression, le stress et la solitude. Les résultats de l'analyse de covariance (ANCOVA) ont fait apparaître des différences entre les groupes pour ce qui est du soutien social et dans tout le groupe en ce qui concerne l'auto-efficacité. Les résultats étaient différents pour un sous-groupe vulnérable, des différences significatives intervenant entre les groupes en ce qui concerne le soutien social et la solitude. On en a conclu qu'une intervention effectuée par ordinateur peut améliorer le soutien social et l'auto-efficacité et réduire la solitude chez les femmes des milieux ruraux, en renforçant leur capacité d'auto-prise en charge des maladies chroniques et d'adaptation à ces dernières.

Mots-clés : rural, maladie chronique, intervention par ordinateur

Rural Women, Technology, and Self-Management of Chronic Illness

**Clarann Weinert, Shirley Cudney,
and Wade G. Hill**

The objective of this study was to determine the differences in the psychosocial status of 3 groups of chronically ill rural women participating in a computer intervention. The 3 groups were: intense intervention, less-intense intervention, and control. At baseline and following the intervention, measures were taken for social support, self-esteem, empowerment, self-efficacy, depression, stress, and loneliness. ANCOVA results showed group differences for social support and self-efficacy among the overall group. The findings differed for a vulnerable subgroup, with significant between-group differences for social support and loneliness. It was concluded that a computer-delivered intervention can improve social support and self-efficacy and reduce loneliness in rural women, enhancing their ability to self-manage and adapt to chronic illness.

Keywords: rural, chronic illness, computer-based intervention, psychosocial outcomes

Adapting one's life to accommodate the challenges of a chronic illness and perfecting one's self-management skills require constant effort and adjustment, especially in the psychosocial realm. The meaning of this statement is clearer if it is expressed by someone who faces the challenge on a daily basis:

When we have an illness that continues, we have no choice but to change. [But] I like to continue to grow and change at MY pace. When you have an illness, I think it forces you to change and grow in different ways than what we would choose normally. It is not necessarily bad, but it is against our normal will. (Kralik, 2002, p. 152)

Learning to adjust, with some equanimity, to lifestyle changes imposed by long-term illness is a challenge. For rural women with chronic conditions who live in relative isolation and have limited access to support systems and health services, appropriate self-care is vital. These women often have difficulty finding the support and assistance they need in order to adapt to the alterations in physical functioning, the loss of control over life circumstance, and the attendant emotional strain (Emery, 2003).

Technology-based interventions can offer some of the health information and social support that rural women need to face the daily chal-

lence of living with a chronic condition. Such interventions have the potential to improve the women's ability to self-manage and ultimately better adapt to their chronic condition.

Background

The growing use of telecommunication technologies to provide health services for geographically isolated individuals with chronic conditions is one of the most promising developments in health care. Since chronically ill people who live in rural areas often do not have ready access to health-care providers, telehealth interventions offer great promise (Glueckauf, Pickett, Ketterson, Loomis, & Nickelson, 2003).

In recent years the Internet has become more widely accessible. In the United States in 2003, the rate of Internet penetration in rural areas was 54.1%, similar to that in urban areas (54.8%) (Cooper & Gallaher, 2004). According to the 2006 Pew Project report (Fox, 2006), 80% of adult Internet users in the United States have sought health information online. The primary consumers of online health information are women (Fox & Fallows, 2003), particularly those aged 30 to 64 with a college degree (Fox, 2005). Some 85% of women who go online have searched for at least one health topic, compared to 75% of men (Fox & Fallows, 2003). Regardless of gender, having access to free health information online can be empowering for people with chronic illnesses, making it possible for them to investigate strategies for managing their condition (Fox, 2006).

In addition to seeking health information, individuals go online to give and receive emotional support. In the United States, more than half (54%) of all Internet users, or about 63 million people, have accessed a Web site that provides support related to a specific condition or personal situation (Fox & Fallows, 2003). Lieberman et al. (2003) found that rural women with breast cancer were willing to commit to an online support group. Sharf (1997) found that the nature of messages posted by women with breast cancer in a computer-mediated support group included shared information, social support, and personal empowerment. Klemm, Reppert, and Visich (1998) report that, for a similar group, information exchange, personal opinion, support, and personal experience accounted for almost 80% of messages posted. The opportunity to talk with other people who have a chronic illness or to hear their personal descriptions of their coping strategies can have positive effects (Gustafson et al., 1998), including better health outcomes, greater efforts to improve functioning, and increased resistance to psychosocial dysfunction.

The influence of psychosocial factors such as social support, self-esteem, empowerment, self-efficacy, depression, stress, and loneliness on

the adaptation to chronic illness has been examined from many perspectives. Finfgeld-Connett (2005) holds that access to social support results in improved mental health and an increased sense of personal competence and empowerment — ultimately leading to diminished distress and an overall perception of well-being. Gray (1998) concurs that social support can help to overcome stress. There is general agreement that self-efficacy is related to health and psychosocial well-being in a variety of circumstances, including chronic illness (Bandura, 1993). The fact that self-efficacy beliefs are modifiable (Meichenbaum, 1994) makes them an excellent target for interventions (Fry & Debats, 2002). Higher levels of self-esteem and reduced depressive symptoms related to appropriate social support have also been demonstrated in studies with people who have multiple sclerosis (Foote, Piazza, Holcombe, Paul, & Daffin, 1990). It is clear, then, that interventions providing support have the potential to increase self-esteem and decrease depression.

The lessening of depressive symptoms is important, because depression often accompanies chronic illness (Rouchelle, Pounds, & Tierney, 2002) and can affect quality of life, physical activity levels, self-efficacy for illness management and self-care, and ability to communicate effectively with health-care providers (Piette, Richardson, & Valenstein, 2004). Depression undermines confidence, concentration, energy, and motivation — essential ingredients in the effective adaptation to chronic illness (Simon, Von Korff, & Lin, 2005). Social support has been shown to have an efficacious impact on depression across a range of chronic conditions (Simon, 2001), indicating the need for interventions that provide appropriate support.

Depression can also be linked to loneliness (Adams, Sanders, & Auth, 2004), a little understood risk factor for broad-based morbidity and mortality (Cacioppo, Hawkey, & Berntson, 2003). Loneliness as a symptom is often subsumed under depression instead of being recognized as a distinct problem (Grenade & Boldy, 2005). Loneliness appraisal has validity because feelings of emotional loneliness can affect perceived self-efficacy, and vice versa (Fry & Debats, 2002).

According to Bandura (1982), self-efficacy plays a role in loneliness because it influences our perceived ability to alter our thinking and emotions in psychosocially healthy ways. Compared to men, interestingly, women are more aware of their self-efficacy or lack thereof (Smith et al., 2000), which may in turn contribute to a greater sense of loneliness and psychosocial distress in women (Fry & Debats, 2002). Conversely, women have stronger self-efficacy beliefs in the interpersonal, social, and emotional domains, which may serve to buffer loneliness and psychosocial distress (Fry & Debats, 2002). Understanding the linkages among social support, self-esteem, empowerment, self-efficacy, depression, stress, and

loneliness, and the linkages between these indicators and problem-solving in chronic disease self-management, can be useful for improving individual health outcomes.

For more than 10 years, the computer-based research project Women to Women (WTW) has been providing a virtual self-help group and health education to chronically ill women in the rural inter-mountain region of the western United States, to help the women hone their self-management skills and better adapt to their chronic conditions. In the present study, the primary concept of interest in the WTW program was psychosocial adaptation. Based on the literature and on the experience of the investigators, seven empirical indicators of psychosocial adaptation were selected for investigation — social support, self-esteem, empowerment, self-efficacy, depression, stress, and loneliness — the theory being that women who report improvement on these indicators will be in a better position to successfully manage and adapt to their chronic illness. It was expected that, immediately following the intervention, the intervention group would show more improvement than the control group on each of the indicators.

In this article we will examine the change, from pre-intervention to immediately post-intervention, for each of the seven indicators and examine the differences among groups in terms of the post-intervention scores. We will also discuss the feasibility and efficacy of computer-based interventions for bridging geographical distance and the application of such interventions to rural nursing practice.

Method

Design

Following approval by the University Institutional Review Board for the Protection of Human Subjects, rural women were recruited through newspaper solicitation, announcements in newsletters published by voluntary agencies, and word of mouth. A total of 233 women participated in the WTW project between February 2002 and February 2005. Original sample-size estimates were based on an a priori power analysis that yielded at least 60 participants for each of three groups, after accounting for attrition. This article reports on the data for those women who completed the intervention and the questionnaire that immediately followed it ($n = 183$), representing a 21% attrition rate.

After completing a telephone screening interview and the baseline mail questionnaire (measures of social support, self-esteem, empowerment, self-efficacy, depression, stress, and loneliness), the women were randomized into three groups: *intense intervention*, *less-intense intervention*, and *control*. The methods are described in detail elsewhere (Hill, Weinert,

& Cudney, 2006; Weinert, Cudney, & Winters, 2005; Winters, Cudney, Sullivan, & Thuesen, 2006).

During the 22-week intervention, the *intense intervention* group participated in an online, asynchronous (any time of the day or night), peer-led support group (Koffee Klatch). This forum was *for* and *by* the women, and although it was monitored by a research team member who was an advanced practice nurse, the monitor did not take part in the conversations. In addition, approximately every 2 weeks the research team posted an independent-study online health-teaching unit on five selected topics: Web Skills, Living with Chronic Illness, Nutrition, Women's Health, and Family Finance. These units, prepared by the research team, were supplemented by asynchronous, expert-facilitated discussions (Health Roundtable). For example, the leader for the unit on Women's Health used the following discussion starters: *What problems do you have that are specifically related to women's health? What strategies and solutions have you used to address these problems?* Throughout the process, the women's health practitioner on the research team was available daily to interact online with the participants regarding their health issues. A similar format was followed for the other four units, with the appropriate research team expert participating.

The *less-intense intervention* group also participated for 22 weeks. These women completed the self-study health-teaching units but did not have access to the supportive discussion forums (Koffee Klatch and Health Roundtable). The sole task of the *control* group was to complete the mail questionnaire.

Data Generation

Multiple types of data were generated over the 2 years that each participant was engaged in the larger WTW study. The data analyzed in this report are from the questionnaire administered at baseline and week 23 and from the women's online exchanges during the 22-week intervention. The quantitative data were displayed using SPSS for Windows Version 11.0.1 and analyzed for item frequencies and measures of central tendency using descriptive statistics and ANCOVA for the inferential aims. The qualitative data embedded in the women's messages were coded, cleansed of identifying information, stored verbatim in the end-user database, and downloaded into NUD*IST software. The messages were analyzed using techniques that blended deductive, inductive, and integrative analytic processes. In the deductive phase, data were coded and sorted into categories. In the inductive phase, data were examined for emerging themes, patterns, or recurring regularities. In the integrative phase, relationships between and among themes were sought and the

pieces were woven into a meaningful conceptual pattern related to the experience of women living with a chronic illness in a rural setting.

Empirical Indicators of Psychosocial Adaptation

Chronic illness may co-exist with health in a given individual. Therefore, successful adaptation to the illness and planned health maintenance are critical factors in improving the quality of life of a chronically ill person. People with chronic conditions should be encouraged to pursue activities that educate, guide, and motivate them to make health-enhancing choices (Fries, 1997) that will lead to optimal self-management. Social support, self-esteem, empowerment, self-efficacy, depression, stress, and loneliness can influence the success of health-enhancing activities and can thus be viewed as indicators of the potential for better self-management of chronic illness.

For this study, the empirical indicators of psychosocial adaptation were defined as follows. Social support is the provision of intimacy, facilitation of social integration, opportunity for nurturing behaviour, reassurance of self-worth, and availability of assistance (Weiss, 1969). Self-esteem is the extent to which one values, approves of, or likes oneself (Baumeister, Campbell, Krueger, & Vohs, 2003). Empowerment is the ability to understand and control personal, social, economic, and political forces so as to take action to improve one's life situation (Wallerstein, 2002). Self-efficacy is the belief that one can affect one's health through personal behaviour (Fries, Koop, Sokolov, Beadle, & Wright, 1998). Stress is mental, emotional, or physical tension or strain that adversely affects one's sense of well-being (Pollachek, 2001). Depression is characterized by depressed mood, negative self-concept, disturbed, vegetative functioning, agitation, slowed activity levels, distractibility, and indecisiveness (Radloff, 1977). Loneliness is characterized by the absence of human intimacy and dissatisfaction with being alone (Hall & Havens, 1999).

Measures

The instruments selected as measures of the empirical indicators are not rural-specific but have been used with a variety of populations and in research on chronic illness. They were chosen based on the strength of their psychometric properties, conceptual fit, and prior use by the research team, and also because there is evidence in the literature that they are amenable to change based on a support/education intervention. The measures were as follows: (for social support) Personal Resource Questionnaire 2000 (Weinert, 2003); Rosenberg Self-Esteem Scale (Robinson, Shaver, & Wrightsman, 1991); Diabetes [Chronic Illness] Empowerment Scale (Anderson, Funnell, Fitzgerald, & Marrero, 2000); Self-Efficacy Scale (Sherer, Maddix, Mercandante, Prentice-Dunn, Jacobs,

et al., 1982); (for depression) CES-D (Devine & Orme, 1985); Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983); and UCLA Loneliness Scale (Robinson et al., 1991). Table 1 provides psychometric information for each instrument.

All the scales in the questionnaire were Likert-type scales in which the respondent circles a number. The following examples reflect the nature of the items: Chronic Illness Empowerment Scale — “In general, I believe that I know which of my chronic illness goals are most important to me” (1 = strongly agree; 5 = strongly disagree); UCLA Loneliness Scale — “How often do you feel isolated from others?” (1 = never; 4 = always); Personal Resource Questionnaire — “I have people to share social events and fun activities with” (1 = strongly disagree; 7 = strongly agree).

Results

The participants were chronically ill, rural, mostly Caucasian women with a mean age of 51.8 years ($SD = 2.17$) and an average of 14.5 years of education. Of the women, 82.5% were married and 61.9% were employed outside the home. They lived in rural areas of Montana, Idaho, North Dakota, South Dakota, or Wyoming (at least 25 miles from a town/city of 12,500 people), on farms or ranches or in small towns. An indicator of their geographic dispersion is the distance travelled for health care. The median distance (one way) was 8 miles for emergency care and 32 miles for routine/specialist care. Demographic details are presented in Table 2.

To evaluate the effect of the intervention on the seven indicators for the total sample, ANCOVA was conducted. The independent variable, group membership, had three levels: *intense intervention*, *less-intense intervention*, and *control*. Means for each psychosocial variable were compared at the 23-week measurement, controlling for scores at baseline. ANCOVA results (see Table 3) were significant only for social support $F(2, 185) = 3.38$, $MSE = 454.0$, $p = 0.03$ and self-efficacy $F(2, 185) = 3.19$, $MSE = 500.9$, $p = 0.04$, indicating that some differences were observed among the three groups following the intervention. For social support, the adjusted mean was highest (84.6) for those in the *intense intervention* group, followed by the *less-intense* (82.9) and *control* (79.3) groups. Similarly, for self-efficacy, adjusted means were highest for the *intense intervention* group (114.1), followed by the *less-intense* (112.2) and *control* (109.0) groups. Follow-up tests were conducted to evaluate pairwise differences among these adjusted means. Holm's sequential Bonferroni procedure was used to control for type I error across the three pairwise comparisons. The findings indicate that for both social

Table 1 Psychosocial Concepts, Indicators, Items, Reliability, Validity (Hill, Weinert, & Cudney, 2006)

Concepts	Indicators	No. of Items	Reported α	Study α	Validity
Social support	PRQ2000 (Weinert, 2003)	15	.87-.92	.90	Construct divergent
Self-esteem	Self-Esteem Scale (Robinson et al., 1991)	10	.77-.88	.87	Convergent discriminant
Empowerment	Diabetes Empowerment Scale (Anderson et al., 2000)	10	.91	.96	Concurrent
Self-efficacy	Self-Efficacy Scale (Sherer et al., 1982)	23	.71-.86	.88	Construct criterion
Depression	CES-D (Devine & Orme, 1985)	20	.84-.90	.90	Convergent discriminant
Stress	Perceived Stress Scale (Cohen et al., 1983)	14	.84-.86	.90	Convergent discriminant
Loneliness	UCLA Loneliness Scale (Robinson et al., 1991)	20	.94	.94	Convergent discriminant

Table 2 Group Characteristics		
	Participants (n = 189)	Group %
<i>Age</i>		
30–39	16	8.5
40–49	52	27.5
50–59	88	46.6
60–69	33	17.5
<i>Ethnicity</i>		
Caucasian	178	94.2
Hispanic or Latino	1	0.5
American Indian or Alaskan Native	6	3.2
Other	4	2.1
<i>Marital Status</i>		
Married	156	82.5
Divorced	19	10.1
Separated	1	0.5
Widowed/never married	12	6.3
Living together	1	0.5
<i>Education (number of years of school completed)</i>		
12 or less	48	25.4
13–15	76	40.2
16–18	60	31.7
19 or more	5	2.6
<i>Income</i>		
Less than \$15,000	30	15.8
\$15,000–\$24,999	30	15.8
\$25,000–34,999	34	18.0
\$35,000–44,999	26	13.8
\$45,000–54,999	30	15.8
\$55,000–64,999	18	9.5
\$65,000–74,999	10	5.3
\$75,000–84,999	6	3.2
\$85,000 or more	5	2.6
<i>Employment (outside home)</i>		
Yes	117	61.9
No	72	38.1

Table 3 ANCOVA Results for Psychosocial Variables — Total Group and Vulnerable Subgroup								
Psychosocial construct/ group	Total Group			Vulnerable Subgroup				
	Adj. mean	F	MSE	p	Adj. mean	F	MSE	p
<i>Social support</i>								
Intense	84.6	3.38	454.0	0.03	77.9	5.34	725.9	0.01
Less-intense	82.9				77.9			
Control	79.3				68.0			
<i>Self-esteem</i>								
Intense	32.5	2.28	38.7	0.10	28.1	0.38	4.54	0.68
Less-intense	31.0				28.0			
Control	31.0				27.3			
<i>Empowerment</i>								
Intense	29.4	0.111	10.79	0.89	27.3	0.78	58.5	0.47
Less-intense	29.6				27.2			
Control	28.8				30.1			

<i>Self-Efficacy</i>	Intense	114.1	3.19	500.9	0.04	102.5	1.87	347.0	0.16
	Less-intense	112.2				101.8			
	Control	109.0				95.3			
<i>Depression</i>	Intense	14.8	0.78	58.5	0.46	22.8	0.27	29.1	.768
	Less-intense	15.2				21.2			
	Control	16.6				23.7			
<i>Stress</i>	Intense	23.1	1.35	48.4	0.26	29.0	0.84	33.6	0.44
	Less-intense	23.7				29.0			
	Control	24.8				31.1			
<i>Loneliness</i>	Intense	41.8	1.53	67.2	0.22	47.5	4.12	190.2	.021
	Less-intense	41.1				45.4			
	Control	43.1				51.5			

support and self-efficacy the only significant group difference was that between the *intense intervention* and *control* groups and no differences were found for the other comparisons.

Identical procedures were used to evaluate the effect of the intervention on the vulnerable subgroup, which was constructed by using scores for the women in the highest 50th percentile for depression, stress, and loneliness ($n = 64$). ANCOVA results (see Table 3) were again significant for social support $F(2, 60) = 5.34$, $MSE = 725.9$, $p = 0.01$; however, self-efficacy did not appear to be different for this subgroup $F(2, 60) = 1.87$, $MSE = 347.0$, $p = 0.16$. For self-efficacy, the means appear to have even greater descriptive differences than for the overall group, suggesting that this loss of statistical significance is related more to a loss of statistical power with the smaller group than an actual null finding. Differences were also observed for loneliness $F(2, 60) = 4.12$, $MSE = 190.2$, $p = 0.02$ in this vulnerable subgroup, while this was not the case for the overall sample. For social support, the adjusted mean was highest but identical (77.9) for the intervention groups, followed by the *control* group (68.0). For loneliness, adjusted means were lowest for the *less-intense* group (45.4), followed by the *intense* (47.5) and *control* (51.5) groups. Follow-up tests were conducted to evaluate pairwise differences among these adjusted means, and again Holm's sequential Bonferroni procedure was used to control for type I error across the three pairwise comparisons. For social support and loneliness, both intervention groups were significantly different from the *control* group.

Discussion

The WTW computer-based research intervention is intended to offer a program of support and health education to rural women as a means of facilitating their ability to self-manage and adapt to chronic illness. Psychosocial adaptation was considered an indicator of healthy adaptation to chronic illness, and the seven indicators of psychosocial adaptation (social support, self-esteem, empowerment, self-efficacy, depression, stress, and loneliness) were of interest.

Social Support

The women in the *intense intervention* group participated for 22 weeks in a peer-led support group. They had an opportunity to exchange ideas about various health topics in a forum that included health-care experts. Thus it was expected that these women's sense of social support would increase significantly, compared with the *less-intense intervention* and *control* groups. This expectation was fulfilled, even for more vulnerable women, whose social support scores were significantly higher than those of

women in the *control* group. This result indicates that social support can be provided effectively through a virtual support group whose members may be located great distances from one another in rural areas.

The following comment by a participant indicates that social support is an important factor in rural women's ability to adapt to their illness:

There is no outside support. All we can do, since I think we're in WTW because we are isolated, is support each other... and I think we do a fantastic job of that!...and try to remain strong and focused, personally.

Another woman echoed this sentiment: "Our mutual support may be the greatest gift we have or can give." Effective social support has long been recognized as a buffer against the emotional problems that can develop due to the rigours of dealing with a chronic condition, culminating in the promotion of overall psychosocial adaptation (Earl, Johnson, & Mitchell, 1993).

Self-Efficacy

The *intense intervention* group also significantly increased their perceived self-efficacy — that is, their confidence in their own ability to achieve goals. As one woman so aptly put it:

I am pleased this week to become an active self-manager by setting goals for myself, listing ways to reach them, and making action plans. I find that these activities give me power over my illness, and at least I feel like I am doing what I can do to divide and conquer.

This was a rewarding outcome because individuals with a strong sense of self-efficacy are generally better poised to manage their health condition and to adapt creatively to the many demands of living with a chronic illness.

Self-efficacy among rural women with a chronic illness can take on special meaning:

Many women in rural [states] live with chronic illnesses day after day. The program has taught me much about coping with my own chronic condition, but it has also opened my eyes to the obstacles we all must deal with as we find ourselves having to rely on others for a little help now and then. You've asked questions that really made me stop and think about myself and that was tough to do.

The emergence of self-efficacy as an indicator of psychosocial adaptation is also consistent with the literature. According to Lorig and Holman (2000), changes in self-efficacy are associated with positive changes in health status and lead to improved emotional well-being. This observa-

tion is particularly important because self-efficacy is amenable to enhancement through well-designed self-management programs.

The apparent null findings for self-efficacy among the more vulnerable subgroup were not surprising, as the sample size and resulting statistical power dropped significantly. However, descriptive mean differences are consistent with findings for the overall sample, suggesting that self-efficacy was in fact different for the vulnerable group as well. This consistency suggests that the intervention was effective in helping the women gain confidence in their ability to carry out the tasks associated with the management of their illness, even in rural settings that are devoid of resources. One woman gave voice to this conclusion:

The WTW project is so important to the health and well-being of all women living in rural...states. Very few of us are able to travel to...larger specialty clinics to ask the questions that I have found answers to on the web sites suggested by you and other members of this great team.... It's programs like this that...have made all of us more informed and a lot wiser. Thanks again.

The fact that loneliness decreased in the most vulnerable women, who initially scored high for depression, stress, and loneliness, was another benefit of the intervention — as is evident in one woman's expression of reassurance: "You are not alone!" However, the reduction in loneliness was coupled with apparent changes in self-efficacy. This is particularly interesting, because strong self-efficacy beliefs are thought to be linked to psychosocial well-being, and feelings of emotional loneliness may serve to decrease one's perceived self-efficacy (and vice versa) (Fry & Debats, 2002).

It was anticipated that there would be a positive change in all of the psychosocial scores for the *intense intervention* group when compared to the *control* group. Statistically significant differences were not demonstrated for all of the measures. However, there was an encouraging positive trend in the psychosocial scores for the *intense intervention* group: all scores showed improvement after the 22-week computer-based intervention.

Lessons Learned

Several key lessons derived from this phase of the WTW project serve as the foundation for future endeavours. Though effective, the current intervention and research design are complex and therefore costly in terms of time, money, and staff resources. To reduce the complexity and to enhance transferability, foster real-world application, and lower overall costs, we have proposed several changes to the next phase of the project.

A two-group rather than three-group design is adequate. The three-group design was used to evaluate the strategy of having the participants complete the online health-teaching units on their own without expert input or group discussion. Women in this group did well in self-study mode; thus women will work on the health-teaching units independently, and there will be periodic rather than sustained interface with the content experts.

Based on our work and that of Lorig, Sobel, Ritter, Laurent, and Hobbs (2001), it seems feasible and wise to shorten the intervention from 22 to 11 weeks, with similar intensity (4–5 hours per week). We have shifted our focus from more long-term effects to the immediate and short-term impact of the intervention and will administer measures at only three time points.

The women enthusiastically engaged with the program and highly valued the experience of participating in the project. Clearly, the peer-led support group component was effective and well liked, and we do not intend to change the virtual support group aspect of the intervention. However, blending two forums into one (eliminating the health-teaching unit discussions) will streamline the intervention by requiring the women to participate in just a single discussion group.

Another significant change is the plan to redesign the health-teaching units with a focus on the process of developing self-management skills. In the revised health-teaching units, instruction in self-management skills will be in the foreground, while specific health-related content will be integrated within this context.

From a technical perspective, we met few obstacles. The women generally found that learning WebCT (the online educational platform) was a simple process, and technical support can be provided effectively via the toll-free telephone line. The participants made a total of 131 telephone calls — 43% of the women called only once, 51% called from two to seven times, and 6% called more than seven times. The most common problem, accounting for 32% of all telephone calls, related to hardware, followed closely by issues with the WebCT, at 31%. Problems connecting and logging on to the Internet accounted for 18% of calls and problems accessing hyperlinks 4% of calls.

Implications

Geographic and social isolation pose challenges for rural-dwellers and their health-care providers. A sense of isolation can lead to a variety of social ills and destructive avenues of relief, such as alcohol and drug abuse, suicide, domestic upheaval, and poor lifestyle choices. Clearly, finding an efficacious modality for working with isolated rural-dwellers, such as a computer-based intervention, is critical in the face of the short-

age of rural health-care providers and the incidence rates for chronic conditions.

As we move forward to explore application of the principles of the WTW intervention to clinical practice, demonstrating its impact on social support and self-efficacy is an important prerequisite outcome. It is our belief that technology-based interventions have great potential for improving the psychosocial status of rural women with a chronic illness, enhancing their self-management skills and their ability to adapt to their illness. This belief is exemplified in the words of one of the participants:

As we wrap up this part of the program I can honestly say that my nutritional choices are improving. (The clerk at our little grocery store even noticed that one.) I have been given some great computer help and even told my husband last week that I'd really like to have one of my own when this project is no longer at the touch of my fingers. WTW has given us some great medical sites that I've found very informative. The sites for finance and government programs really came in handy. We are right at retirement age and have really pored over all the options available on the web. I knew this would be a worthwhile program, and it certainly has been, but what I didn't expect was to gain this wonderfully supportive extended family that has a way of making you feel so good. That's what friends do and that's what you have all become to me. "I'm so glad we had this time together."

Interventions such as this one can counter the great distances identified as the all-pervasive factor in the limited self-management ability of rural women with chronic conditions (Winters et al., 2006).

The relationships among the factors that influence the adaptation process, including self-care, need to be more fully understood before we can provide a sound conceptual framework to guide the intervention and its applications. Building on our work (Weinert et al., 2005) and the work of others (Chen, 2005; Lorig & Holman, 2003; Pollock, 1993; Roy & Andrews, 1999; Stuijbergen, Seraphine, & Roberts, 2000), a new, more comprehensive model has been developed: the WTW Conceptual Model for Psychosocial Adaptation to Chronic Illness. The central theme of this new model is that the process of psychosocial adaptation is key to developing self-management skills and achieving an acceptable quality of life while living with a chronic illness.

Nursing's quest for strategies that positively influence psychosocial adaptation to chronic illness is of particular urgency because of the broad social consequences, the aging of rural populations, the limited access to health care in rural areas, and the prevalence of chronic illness. Inadequate psychosocial adaptation at the individual level may lead to inappropriate attempts to find relief from the burdens imposed by chronic illness. On

the other hand, the use of creative, computer-based interventions can foster a sense of social connection, heighten the perception of social support and self-efficacy, provide health information, and promote health-seeking behaviour — all of which can enable individuals to better self-manage and adapt to their health conditions. The result is much like the pebble in the pond — creating far-reaching health benefits for rural populations despite the burden of living with a chronic health condition.

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Knowledge Translation

Promoting Self-Care through Knowledge Translation: A Way to Reach People with Early-Stage Dementia

Alison Phinney

I have been conducting research among people with dementia for over 10 years now, and I am always struck by their thirst for knowledge about what I have learned from my research. Eager to share their own experiences of living with dementia, study participants also want to know how others are getting along, asking, “Is there anything you have heard from other people that might help me?”

Given the current enthusiasm for knowledge translation, it is timely to consider how to bring new knowledge to the people most immediately affected by dementia — those with the illness themselves. In the following few paragraphs, I will attempt to show that there is a growing population of people with early-stage dementia who could benefit from this kind of approach. In addition, I will present an overview of the research that would be of immediate benefit to this population in supporting their efforts at self-understanding and self-care. Finally, I will describe some of the guiding principles underlying knowledge translation strategies to engage with people with early-stage dementia.

Dementia is an umbrella term for a number of diseases characterized by progressive cognitive impairment resulting in functional disability. The most common of these diseases are Alzheimer disease and vascular dementia, which together account for about 85% of all dementia cases (Canadian Study of Health and Aging Working Group, 1994). The word *dementia* usually conjures an image of someone with profound disability living in a nursing home, but in fact at least 50% of people with dementia live in their own homes, usually for many years. The reported median lifespan for people with dementia ranges from 3.3 to 10.7 years after disease onset (Wolfson et al., 2001; Xie, Brayne, & Matthews, 2008), although that lifespan may be shifting with the advent of drug treatments intended to delay the onset or worsening of symptoms. The new med-

ications being developed tend to be most effective for those with mild impairment, a fact that has contributed to the increasing pressure to diagnose earlier in the disease trajectory (Alzheimer's Association, 2008). There is now an identifiable population living with what is usually referred to as early-stage dementia. These often relatively young people experience memory loss and some difficulty with everyday activities, but for the most part they are able to manage their symptoms and to continue living a meaningful life.

There is a growing body of knowledge about how people with dementia manage as well as they do. Those in the earlier stages of dementia may be very aware of their failing memory and its impact on their daily activities and social interactions (e.g., Clare, 2003; Harris & Keady, 2004; Harris & Sterin, 1999; Nygard & Ohman, 2002; Phinney & Chesla, 2003), and there is increasing emphasis in the literature on how they cope and adapt to these changes. When asked to express their own views on what is happening to them, people with dementia often downplay their difficulties and try to project a positive outlook, while at the same time identifying a variety of active coping strategies such as staying active, working harder, asking for help, and avoiding difficult situations (e.g., Clare, 2002; Menne, Kinney, & Morhardt, 2002; Nygard & Ohman, 2002; Pearce, Clare, & Pistrang, 2002; Phinney, 1998; Phinney, Chaudhury, & O'Connor, 2007; Preston, Marshall, & Bucks, 2007; Van Dijkhuizen, Clare, & Pearce, 2006; Werezak & Stewart, 2002). Overall, the findings from recent research tell us that while the disease itself presents many challenges, people in the early stages of dementia demonstrate considerable expertise in terms of how they understand and manage the effects of the illness in their everyday lives.

Researchers are beginning to disseminate this information through journal articles, books, and conference presentations, in an effort to reach clinicians, service providers, and, to a lesser extent, family caregivers, providing them with knowledge they can use to better support their patients, clients, and loved ones. However, at the same time, there is increasing eagerness within the research community to go directly to those living with the disease, reaching out to people with dementia to include them in the knowledge translation process so they might benefit more directly from the knowledge being generated.

This approach makes good sense given the extent to which people with early-stage dementia tend to "fly under the radar." These people typically do not seek out services (Toseland, McCallion, Gerber, & Banks, 2002), and their family members may not take on the role of caregiver until much later in the illness trajectory (O'Connor, 2007). This suggests that knowledge translation to benefit people with early-stage dementia will not readily occur through their contact with the health-care system

or through family caregivers; if it is to be effective at all, knowledge translation will have to be person-centred and community-based.

There is as yet little documentation of this work, with most efforts being at the planning or early implementation stage. While there is a clear need for further research, at this point it is worth identifying some of the principles guiding our own work in this area, drawing from a framework for knowledge translation that focuses on interactions between researchers and “user groups” (Jacobson, Butterill, & Goering, 2003).

The first principle is to take into account the fact of people’s cognitive impairment, recognizing that certain adaptations will be necessary to support new learning (Davis, 2005), such as providing information along different channels (written text, spoken word, visual cues, etc.) and reducing demands on recent memory (chunking information, use of repetition, etc.). We also want to explore how to draw on “care partners” in an appropriate way, identifying, for example, what friends and family members can do to help the person with early-stage dementia to become effectively involved in knowledge translation.

The second principle is to recognize that knowledge translation is not merely the passing on of new information. We believe, based on what has been learned from support groups and information forums for people with early-stage dementia (e.g., Morhardt, Sherell, & Gross, 2003; Murray Alzheimer Research and Education Program, 2007), that it is important for people to learn from each other and to engage in conversation about new research — not to just receive the information, but to talk about it and consider how it might apply to their own lives. The goal of this “dialogical” approach to knowledge translation is the creation of a community of researchers and people living with early-stage dementia who meet in a supportive group environment to learn about recent research and to exchange ideas about how to take it up in everyday life and how to then bring the reality of everyday life back into new research.

The third principle is to acknowledge that the emerging advocacy community can be an effective ally for researchers committed to engaging people who have early-stage dementia in the knowledge translation process. Knowledge translation is concerned not only with individuals acquiring the information and tools they need to support their own self-management efforts, but also with empowering them, as a group, to be informed about and supportive of each other’s efforts and to demand effective services. For example, Canadians have taken key leadership roles in the Dementia Advocacy and Support Network International (DASNI). These are people who have a diagnosis of dementia themselves and are stepping forward to share their experiences of living with

the disease with those who need to hear this voice — practitioners, researchers, policy-makers, and, perhaps most importantly, other people with dementia. DASNI and other emerging networks (e.g., the Scottish Dementia Working Group) are a critical link for researchers wishing to share the results of their work directly with the communities most immediately affected.

Together, these three notions of adaptation, dialogue, and advocacy serve as guiding principles for an emerging model of knowledge translation that can be used to foster self-understanding and self-care among people with early-stage dementia. Further research in this area will provide insight as to the particular strategies that are most effective for making new research knowledge useful and practical for this growing population.

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Happenings

Nursing the System in Chronic Disease Self-Management

Carol Jillings

“Nursing took the lead” was the first comment that Maylene Fong¹ made when asked to describe the evolution of the Vancouver Coastal Health Authority’s Chronic Disease Management/Self-Management Support Learning project.

When the case management model in use appeared not to be meeting the needs of chronically ill patients, members of the multidisciplinary team began to consider ways to enhance client self-management (in the context of a chronic care model). A first step in effecting this change was to acknowledge that health authority staff from all disciplines would require an educational component, to enable them to move away from traditional approaches to care that were grounded in the medical model and in concepts of acute and episodic care.

The Particulars

Beginning in July 2006, the goal of this project was to develop a curriculum that would provide health professionals with the knowledge, attitudes, and tools to support clients in chronic illness management. A multidisciplinary team of experts from the Vancouver Coastal and Fraser health authorities and the Universities of British Columbia and Victoria worked collaboratively to develop e-learning modules, face-to-face workshops, a toolkit of resources, and an online discussion platform to support staff from medicine, nursing, social work, dietetics, and rehabilitation sciences in the adoption of a new approach to care and in the development of the requisite skills for its implementation. With guidance from the project advisory committee, this team developed and used a logic model for the project, which guided the development of competency statements, the curriculum itself, the learning activities, and the evaluation of outcomes. The entire educational process evolved between May

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2007 (pilot workshops) and March 2008; content and strategies for face-to-face educational sessions were continually refined based on the outcomes of the pilot workshops and the input of the learners.

Challenges

Concepts of collaboration, partnership, and client-directedness were at the core of this paradigm shift. One early challenge was to acknowledge and address the tension that arose between “deliverables” and the philosophy of client-centred care; for example, the label “noncompliant” (traditionally affixed in situations where clients do not produce the outcomes mandated or expected by health professionals) was inappropriate within the self-management rubric. Other implementation issues ranged from the practicalities entailed in the development of technical platforms for e-learning and online discussion to the time and energy requirements of learners engaged with the curriculum and the various learning tools.

Insights

An early pilot project within this innovation involved a group of diabetic clients who, with members of the multidisciplinary team, structured their diabetes education classes in a collaborative fashion. Members of the group *learned from each other* through goal-setting and through co-analysis of barriers and facilitators in diabetes management. Allowing clients to act as the experts in this context was a huge learning step for the health professionals engaged in the education process, and the insights gained formed the basis for the design of a workshop for self-care facilitators. This workshop, whose curriculum was based on research evidence from the implementation of chronic disease management models in other jurisdictions, was useful to health professionals in developing the attitudes, skills, and strategies needed to support client self-management.

Commitment

Ms. Fong made the point that management support within the health authority was critical to the success of the project. From inception through to evaluation, it was essential that care managers and senior administrators be aware of the philosophy underlying self-management and the concomitant learning needs of staff. In her role as a clinical nurse specialist, Ms. Fong was able to act as the point person for project implementation, ensuring that resources were available for staff to develop and test new strategies for goal-setting and co-management with clients. She also made it clear that traditional models of care — “medical,” “acute” —

were not being abandoned but, rather, were being augmented by self-management support.

This project is one of many across the country, all derived from the observation that chronic illness cannot be effectively managed within an interventionist framework. As is clear from the research reported in this issue of *CJNR*, chronic illness is multifaceted and complex and is not amenable to “magic bullet” approaches that lack grounding in a philosophy of client self-management. Furthermore, our disease-specific traditions of management (and indeed research) may have outlived their efficacy, as we increasingly realize that common themes and issues permeate the illness experiences of clients. As we incorporate the knowledge gained through research into program development and implementation, the implications for both health and research policy will need to be considered, debated, and discussed in the academic and public domains. Nursing leaders are in an ideal position to support and champion new approaches to the care of chronic illness because of their unique vantage point within the multidisciplinary context: they are able to appreciate the complexity of illness management from client and systems perspectives and to discern the implications for staff development and program delivery.

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Recherches concernant les populations marginalisées : les préoccupations d'ordre éthique liées à l'ethnographie

Patrick O'Byrne et Dave Holmes

L'augmentation des taux de maladies transmissibles sexuellement (MTS) observée récemment chez les personnes de sexe masculin ayant des relations sexuelles avec des personnes de même sexe et l'augmentation simultanée de l'utilisation du crystal meth dans les fêtes des circuits gay mettent en évidence le besoin croissant de recherches sur les pratiques de loisirs faisant intervenir le sexe et les drogues. En fait, alors qu'il existe des preuves épidémiologiques corrélant ces pratiques, les taux de MTS n'ont pas diminué. Les auteurs fournissent un cadre éthique destiné à la recherche qualitative, qui « déborde du cadre » des méthodes épidémiologiques classiques de recherche en santé en matière de sexualité. À ce jour, la majeure partie des recherches sur les fêtes des circuits gay ont été menées selon des méthodes d'enquête; toutefois, aucun ouvrage n'aborde les préoccupations d'ordre éthique qui sont liées à l'observation naturaliste visant à mieux cerner l'environnement sexualisé des fêtes des circuits gay. Cette étude a permis d'établir que même si les risques éthiques sont inhérents, les avantages pour la société et pour le groupe étudié l'emportent largement sur ces risques.

Mots-clés : qualitative, ethnographie, éthique, fêtes gay, sexualité

Researching Marginalized Populations: Ethical Concerns about Ethnography

Patrick O’Byrne and Dave Holmes

Recent increases in the rates of sexually transmitted infection (STI) in males having sex with males and simultaneous increases in the use of crystal meth within gay circuit parties (GCP) highlight the growing need for research on leisure practices involving sex and drugs. While there is epidemiological evidence correlating these practices, STI rates have not decreased. The author provides an ethical framework for qualitative research that “colours outside the lines” of traditional epidemiological methods for research on sexual health. To date, the majority of GCP research has used survey methods; however, no literature addresses the ethical concerns of naturalistic observation that is aimed at understanding the sexualized environment of GCPs. This review found that while ethical risks are inherent, the benefits to society and to the group under study significantly outweigh the risks.

Keywords: culture, qualitative, ethnography, ethics, gay circuit party, sexuality

Introduction

Recent increases in sexually transmitted infections (STI) and in HIV among males having sex with males (MSM) (Health Canada, 2004) and the simultaneous rise in the use of crystal meth (crystal methamphetamine) at gay circuit parties (GCP) (Gahlinger, 2004) constitute both a public health problem and a clinical nursing concern. Governments are now restricting the purchase of the precursors required to produce crystal meth (i.e., Sudafed[®]), but this intervention has been thwarted by numerous Web sites providing instructions on how to make these chemicals (see Fester, 2005).

Considering the failure of current public health measures, it is critical that researchers undertake projects that address both STIs and crystal meth. Ethnography appears to be an appropriate methodology, not only because the GCP subculture constitutes a community but also because the proposed research question concerning the behavioural components of crystal meth and GCPs requires an exploratory, qualitative design. According to the ethics guidelines of the Canadian Tri-Council (1998), projects that “alleviate human suffering” and “dispel ignorance” have the potential to benefit society by improving health and welfare (p. 12).

However, the “morally acceptable ends” of improving the circumstances of an identifiable group must be achieved through “morally acceptable means.” Since ethics review boards are generally familiar with the traditional epidemiological public health methodologies, the purpose of this article is to provide an ethical analysis of the means and ends of *marginal ethnography*, rejecting the “colonial” assumption that research guidelines for one marginalized population can readily be used by another (Ethnoracial MSM Research Working Group, 2006; Thoms, 2007). We will address concerns related to naturalistic observation exclusively. To complete the review, we will provide a background of the GCP, followed by a comparison of research methods used for GCPs and for other marginalized populations (i.e., criminal behaviours) and, finally, an analysis of *marginal ethnography* using the Tri-Council guidelines.

Background

Before we delve into the ethical concerns of undertaking ethnographic research at a GCP, a brief overview of these events is needed. First, the GCP is difficult to define because the absence of a rigid definition is part of its attraction. It is forever changing, and continually providing new forms of excitement; the only characteristics that remain constant are that it is an annual gathering of predominately gay men, it takes place in the same city each year, and it features a disco theme. Second, although GCPs are generally held with the purpose of HIV/AIDS education and prevention, risky anonymous sex and drug use do occur (Husbands et al., 2004; Kurtz, 2005; Mansergh et al., 2001; Mattison, Ross, Wolfson, & Franklin, 2001). It should also be noted that while these multi-day gatherings of tens of thousands of MSM (up to 25,000), in enormous venues with intricate light shows, unique dress codes, disc jockeys, and various live performances, resemble underground raves, GCPs are legally sanctioned (Ghaziani & Cook, 2005). Third, in addition to their physical attributes, GCPs have an even larger psychological and sociocultural definition (Mansergh et al., 2001; Mattison et al., 2001). In 1977, Corbett Reynolds — the man considered the founder of GCPs — created a gay space to celebrate being gay (Bérubé, 2003). In the 1980s, as anti-gay discriminatory laws were being abolished and gay men were provided with areas to congregate and express a gay lifestyle (Bérubé, 2003), GCPs began to emerge worldwide. Over time, these parties came to represent freedom to the gay community (Ghaziani & Cook, 2005).

Diverse Forms of Ethnography

Traditionally, ethnography has been a top-down research method. It arose within anthropology and was developed for the purpose of studying cul-

tures other than those of direct European heritage. It was exemplified by the work of ethnographers such as Bronislaw Malinowski and E. E. Evans-Pritchard during the late 1800s and early 1900s (Bailey, 1997; Creswell, 1998; Denzin & Lincoln, 2003b). As with most research of that time, it was based on the colonial assumption that white, heterosexual, European cultures are superior to all others. With time, these methods evolved beyond their colonial roots and expanded to include the study of not only traditional “minority” cultures but all marginalized subpopulations. A major event in the use of ethnographic methods of direct observation and interviews within the realm of human sexuality was the publication, in 1970, of Laud Humphrey’s *Tearoom Trade*, which was covert research into the practices of MSM in public bathroom settings. However, despite the fact that later the same year Humphrey was presented with the C. Wright Mills Award by the Society for the Study of Social Problems and his findings were considered important discoveries in the field of human sexuality, shortly thereafter *Tearoom Trade* was viewed negatively by both the scientific community and the popular press because of its covert basis (Nardi, 1996).

When an established research design is employed in a novel context, ethical concerns demand that — as with covert observation or data collection related to criminal behaviours — a thorough ethical analysis be conducted. The goal is to locate ethical concerns that were identified by researchers prior to commencing a project as well as those that arose during the process. In drawing on similar types of covert research done on criminal behaviours, researchers should avoid returning to the “colonial roots” of ethnography by oversimplifying and taking a judgemental attitude towards those precise differences that distinguish one culture or subpopulation from another. Although many ethnographic studies have been published, few have addressed ethical concerns and none have specifically addressed ethical concerns about ethnographic research at GCPs. Nevertheless the literature describing ethnographic studies and the naturalistic observation of human sexuality, illicit drug use, and other sensitive topics is an excellent starting point. In total, 10 articles were found (Buchanan et al., 2002; Clarke, 1996; Gatter, 1995; Goodwin, Pope, Mort, & Smith, 2003; Madden, Quick, Ross-Degnan, & Kafle, 1997; Mansergh et al., 2001; Mulhall, 2003; Pepler & Craig, 1995; Platzer & James, 1997; Schiller, Crystal, & Lewellen, 1994). In research into criminal or potentially criminal behaviours in this area, the investigator should also review relevant *Criminal Code of Canada* sections and recent Supreme Court of Canada rulings, to gain a legal understanding of the GCP context.

Ethical Principles of Marginal Ethnography

Ethnography raises ethical concerns because it is a methodology involving *human beings* and because of the unequal power distribution between that which sees and that which is seen — the observer and the observed (see Foucault, 1977, on hierarchical observation). Moreover, the associated risks are increased in marginal research because of the political nature of the subject matter and the possible vulnerability of the group under study (Garrett, Baillie, & Garrett, 2001). The following sections address the ethical issues entailed in researchers entering a GCP and the potential social repercussions of studying a subculture that engages in practices that may be deemed immoral, risky, or dangerous by societal standards. In analyzing the associated risks of such a methodology, we apply the Canadian Tri-Council's (1998) eight research ethical principles from a participant-centred perspective. This inclusion of the research participant's perspective follows a feminist approach to ethics, in which principles are more than abstractions; they must make sense within the context of the situation, the experience of the participants, and the unique interests of those involved (Keatings & Smith, 2000). It is an ethical analysis of intellectual understanding and emotional awareness (Garrett et al., 2001). Where possible, the present analysis will be guided by research that includes input from MSM. The principles addressed are human dignity, free and informed consent, respect for vulnerable populations, privacy/confidentiality, justice/inclusiveness, minimizing harm, maximizing benefit, and balancing harm/benefit (Tri-Council, 1998).

Respect for Human Dignity

The principle of respect for human dignity assumes that capable and competent individuals are free to determine the course of their lives, and that each individual should be allowed to pursue this path (Keatings & Smith, 2000). It decrees that morally acceptable ends must be achieved through morally acceptable means and that it is unethical to use a human being as an object or as a means to an end (Tri-Council, 1998). The concept of a morally acceptable end prevents researchers from undertaking research for personal reasons or for the sake of knowledge acquisition alone. Research must benefit the group(s) under study, and the benefit must not be obtained using methods that violate other ethical principles. In the case of ethnographic research on GCPs, the object is to understand increasing STI rates. Since this is a morally acceptable end, the question becomes, Are the means to the end justifiable? The answer to this question requires an evaluation of the methodology, and since the subsequent ethical principles are built on the principle of human dignity

(Tri-Council, 1998), they will now be applied to the issue of *marginal ethnography*.

Respect for Free and Informed Consent

This principle states that individuals are capable of making, and have the right to make, informed choices. Practically, this means that researchers must ensure that informed consent is obtained (Tri-Council, 2002). The measure of free and informed consent has three components: (1) the individual is able to appreciate the consequences of his or her decisions, (2) all relevant information has been given to the individual, and (3) the individual is free from coercion and undue influence.

In addition, since the requirements of consent for observation differ in public versus private spaces (Interagency Advisory Panel on Research Ethics, 2003), it must be determined whether GCPs are public or private (Madden et al., 1997). The *Criminal Code of Canada*, section 197(1), defines a public place as “any place to which the public have access as of right or by invitation, express or implied” (1985). Case law (*R. v. Labaye*, 2005) subsequently redefined public space when two owners of swingers’ clubs were charged with keeping a common bawdy house. The Supreme Court of Canada (2005) modified the definition of public space by ruling that these clubs were private places because, in order to enter, an individual had to undergo an interview, purchase a membership, and be issued a pass-code to a door marked “Privé” (Private). While GCPs do charge an entry fee, there is neither a screening process nor a membership requirement (Bad Boys Club Montreal [BBCM], 2005). Therefore, under Canadian law they are public places. However, this does not guarantee researchers full access, nor does it guarantee that attendees will be willing research participants. Since a GCP is presented as a leisure activity, a researcher interfering in the festivities by observing, questioning, or directly interacting with attendees would constitute a “downer.” However, as part of the entrance requirement attendees must consent to be photographed and documented at the event. The photographs are then used for promotional purposes and made available on Web sites and in magazines such as *Circuit* (BBCM, 2005). Therefore, non-scientific observation at GCPs is quite common.

Nonetheless, even though these parties are public and legal, there is concern that research results will be published (Madden et al., 1997). Therefore all information regarding the final outcomes of a study must also be disclosed, to ensure that consent is completely free and informed. While it could be claimed that the results need not be published, it might also be argued that failure to publish might constitute an ethical violation (Goodwin et al., 2003). The potential benefits from the acquired knowledge would be negated if any new data were kept from the public,

policy-makers, and frontline workers, and consequently not used as a basis for change. However, publication of the results does not negate all ethical concerns about free and informed consent, because, if the results implicate the GCP as a location of drugs, unsafe sex, and transmission of disease, there could be social and political repercussions (Dodds, Keogh, & Hickson, 2005). Knowing this, GCP organizers may be unreceptive to researchers. It is therefore imperative that researchers reveal the purpose of their study to GCP organizers before “entering the field,” thus giving the organizers time to decide prior to data collection. For such consent, however, the three aforementioned rules (regarding capability, information, and absence of duress) must be rigorously applied. Thus, giving decision-making power to the organizers is one way of upholding the Tri-Council principle that research risks and benefits be measured and evaluated from the perspective of the study participants. Such a collaborative and open approach may also serve to establish trust in the research process.

However, full disclosure may be neither necessary nor possible, depending on the design of the study, because researchers must also remain sensitive to the Hawthorne effect — behaviour changes when an individual is aware of being watched (Madden et al., 1997). If the participants in the study are cognizant of the research process, there is decreased probability that they will engage in exactly those behaviours that ethnographic research endeavours to capture (Pepler & Craig, 1995). As a result, the Tri-Council (1998) states that naturalistic observation with low risk for harm may not require full disclosure. Informed consent may be ethically violated if investigators can demonstrate that full disclosure of the research process to the research participants would likely modify results, and if the risks associated with the study are low (Madden et al., 1997).

Respect for Vulnerable Populations

According to the Tri-Council (1998), a vulnerable population is any group that may have diminished decision-making capacity and is entitled to special protection. Examples of vulnerable populations include minors and individuals with cognitive impairment. However, individuals who are highly impaired due to alcohol or drug intoxication could be considered as such. Therefore, data collection must be undertaken with both this factor and the Hawthorne effect in mind (Madden et al., 1997), because information related to the practices of intoxicated participants could unveil information that is crucial in curbing the increase of GCP-associated STIs (Pepler & Craig, 1995).

Excluding intoxication, GCP attendees should be considered non-vulnerable based on their decision-making capabilities. However, there is

another issue relating to vulnerability. Many MSM report feeling misunderstood and isolated by mainstream society; consequently, they may be more than willing to engage in research that could increase society's appreciation of this minority culture. However, provided that the study is intended to benefit the MSM population, and not merely to gather knowledge, their participation could be justifiable (Clarke, 1996; Platzer & James, 2004). Indeed, the fact that MSM populations are eager to participate in research is no reason to believe they are incapable of rational decision-making. In fact, to deny MSM the opportunity to participate in research is to directly violate the principle of self-determination (which states that individuals are free to make their own decisions), a principle that is regularly invoked to justify research involving indigenous populations in Canada (Canadian Aboriginal AIDS Network [CAAN], 2004).

Another ethical concern is that ethnographic methods have the potential to take non-vulnerable populations and marginalize them, thereby making them vulnerable, since findings about a group can serve to place it outside the norm. Researchers might create rather than discover an at-risk population as a result of data collection, and a group could end up being marginalized due to the differences that will almost invariably be found (Schiller et al., 1994).

Respect for Privacy/Confidentiality

Respect for human dignity calls for measures to control access to and dissemination of personal information, including the assurance of anonymity (Tri-Council, 1998). The assurance of confidentiality is essential to participant trust in the research process. In *marginal ethnographic* research, issues related to privacy and confidentiality emerge during the on-site data-collection and dissemination phases; however, provided that the required steps are taken, ethical breaches of privacy and confidentiality should not occur as a result of ethnographic research at GCPs.

The most basic on-site invasion of privacy likely to occur is that the researcher will recognize a GCP attendee (Mulhall, 2003). This individual could be a colleague or social acquaintance who has not informed anyone of his sexual/leisure practices; by entering the GCP, the researcher clearly runs the risk of exposing this person. However, the size of these parties (up to 25,000 attendees) will minimize this risk, because such an "outing" could be effected by any number of attendees. On-site confidentiality concerns could also arise because, after a GCP attendee has interacted with a researcher who is studying drug use and risky sexual practices, other attendees, or the police, could identify him as someone who engages in marginal or illicit activities (Clarke, 1996). Because of this concern, it is essential that researchers undertake data collection in a way that ensures anonymity — data collected on-site should be coded

immediately following the interaction, to ensure that police and other authorities cannot obtain any incriminating information from them (Pepler & Craig, 1995). Beyond on-site ethical concerns, privacy and confidentiality issues remain during the dissemination phase. Confidentiality must be ensured, for all forms of dissemination, through the removal of any and all identifiers linking the study with a specific location, to prevent the findings from being used to target a particular community or party venue.

Respect for Justice/Inclusiveness

The principle of justice and inclusiveness dictates that burdens and gains be distributed such that no one population is unduly affected by the research (Keatings & Smith, 2000). However, in societies that consider free choice a fundamental right, risks and burdens can never be distributed equally (Garrett et al., 2001). Free and informed consent relies on the ability of individuals to appreciate the consequences of their choices, even if they do not invariably choose to avoid harmful consequences. Furthermore, the principle of self-determination dictates that members of minority groups be given the choice of whether to participate in research.

The goal here is to avoid exploiting populations who are unable to protect themselves while simultaneously guaranteeing equal opportunity for all populations to take part in research. While minorities must be protected from exploitation, they should not be underrepresented in research, which will result in insufficient evidence to establish valid differences between a specific minority group and more mainstream groups (Garrett et al., 2001). Scientific neglect of a group because of over-protection will serve to widen the knowledge gap, which will in turn further marginalize the vulnerable population (Tri-Council, 1998). Another negative outcome of excluding minority populations from research is that the design of health interventions will necessarily be based on mainstream assumptions about the minority group. For example, the potential increase in drug use and STI prevalence within the GCP subculture could be interpreted as a failure on the part of our public health-care system to ensure inclusiveness (Clarke, 1996). The GCP phenomenon should be studied in order for us to better understand the environment and subculture and thus to develop culturally sensitive initiatives (Gatter, 1995).

The marginalization of MSM based on sexual orientation makes the justice/inclusiveness principle highly relevant. While it is essential that research with this population not be neglected, it is also essential that MSM not be the only population targeted for behavioural STI-transmission research. The potential identification of GCPs as sites of increased

STI transmission must be balanced by inclusiveness; otherwise it could lead to attempts by researchers, health-care personnel, policy-makers, and community organizations to provide culturally appropriate services for GCP attendees (Gatter, 1995; Mulhall, 2003). To neglect this area of research is to risk a situation whereby health concerns related to MSM who attend GCPs are neither validated nor refuted. In fact, the current reliance on a small body of scientific research combined with information obtained from police reports to justify health interventions could constitute an ethical violation. While police reports are an essential component of our understanding of many phenomena, if they are used as an exclusive source of information (Adler & Adler, 2004) there is a risk of public health interventions being designed using non-scientific data.

Minimizing Harm

Minimizing harm is based on the principle of non-maleficence (doing no harm), which states that unnecessary risks are unacceptable. This means that research protocols must demonstrate that the objectives of the study cannot be achieved without the use of human subjects. It also means that the study must settle for the smallest sample size and the smallest number of tests possible (Tri-Council, 1998). It is essential that the methodology be thoroughly examined and understood, to avoid over-sampling or over-testing and thus minimize the risk for harm.

The greatest potential for harm in an ethnographic study of GCPs arises from the political concerns that could develop after the results are disseminated. Researchers must be careful in their portrayal of GCPs, because findings that cause negative social reactions could evoke feelings of betrayal in the GCP organizers and attendees who cooperated with the researchers. Unfavourable research results could also cause problems with respect to non-MSM populations. For example, they could intensify the level of complacency among heterosexual people who see themselves as not at risk for STIs because these are “gay diseases” (Valdisseri, 2004). In light of our current knowledge, complacency and the notion of “gay diseases” may seem wildly inappropriate. Yet it must be kept in mind that a mere 20 years ago AIDS was referred to as GRID (Gay Related Immune Deficiency) by the (US) Centers for Disease Control and Health Canada (Johansson & Percy, 1994). The stigmatization of MSM as vectors of infection, and the concomitant heterosexual complacency, may be reinforced by the fact that researchers continue to dedicate resources to the study of MSM and their role in STI transmission. However, to neglect research for these reasons when government reports indicate that MSM populations have the highest rates of STIs would amount to an ethical violation. One method for minimizing the harm that has been used in research involving Canadian indigenous popula-

tions is to take a community-based approach (CAAN, 2004). As long as the study is undertaken in the best interests of the community, this approach follows the same logic as the principles of justice and inclusiveness. Community-based approaches support and validate the need for research with specific populations, because each community is seen as unique.

Another means of minimizing harm is to require investigators, from the outset, to accept responsibility for all aspects of their work while remaining sensitive to their personal influence on their findings (Goodwin et al., 2003; Hammersley & Atkinson, 2004). According to Bourdieu (2001), personal influence can be addressed through reflexivity — a process by which researchers scrutinize and evaluate their own behaviours, beliefs, and reactions in the same way that they analyze their data. This principle debunks the myth of researchers as objective, passive observers by forcing them to acknowledge that any and all results are affected by their presence, and by highlighting the fact that turning one's gaze towards a phenomenon irrevocably alters its existence and structure (Foucault, 1990).

Maximizing Benefits

Beneficence (doing good) requires that, in addition to increasing knowledge and producing societal benefits (usually the principal focus), the research must directly and positively affect the individual participants (Tri-Council, 1998). For example, GCP research could result in the prevention of HIV transmission (as well as the transmission of other STIs). This research could also give voice to a marginalized population, from which public health initiatives that provide culturally sensitive and tailored services could be designed (Denzin & Lincoln, 2003a). Exploratory methodologies and ethnography could also be employed to acquaint mainstream cultures with the lifestyles of those who have been marginalized. MSM have traditionally been appreciative of and cooperative with respect to this aspect of qualitative research (Platzer & James, 1997). Since such methods promote contextual sensitivity, the collected data could be used to develop harm-reduction strategies for use within the GCP culture. Most of the current *in situ* HIV awareness campaigns are ineffective; however, these interventions could be modified as a result of data collected during GCP research.

Balancing Harms/Benefits

The final principle, balancing harms and benefits, calls for researchers to demonstrate that foreseeable harms do not outweigh intended benefits. As indicated by the World Health Organization ([WHO], 2002), the way to achieve maximal benefits is to include population health approaches

in the current health-care paradigm. Continued improvements in health care alone are insufficient; public health measures must also be employed (WHO, 2002). In adopting population health approaches (such as infectious disease control) the harms/benefits balance is central, because the entire notion of population health is based on it. This is a utilitarian application of ethics in which the benefit to the greatest number is the central measure of doing good, and means that an action that temporarily or partially wrongs one group or individual is justifiable provided that it has the potential to produce greater good for the whole of society (Shah, 2003) — that is, improving the health of the whole sometimes requires that the rights of the individual be sacrificed; for example, while researchers may risk evoking feelings of betrayal on the part of GCP organizers and attendees if unfavourable results are published, this ethical breach must be measured against the benefits that will accrue to society in light of the negative findings (Pepler & Craig, 1995). The danger is that the rights of minorities could be neglected more easily and frequently than the rights of other groups (Tschudin, 2003).

Applying a balance of harms and benefits to the present project, the main advantage, based on ethnographic research of GCPs, might be improved public health measures with regard to infectious diseases. Due to the long-term sequelae of drug use and STI acquisition, a decrease in incidence rates would reap the societal benefits of a decreased burden on the health-care system and a decrease in social issues associated with infectious diseases and addiction. A decrease in STI rates would also benefit the individual; for GCP attendees, this might translate as a reduction in social stigma, physical ailments, and deaths. Non-attendees could also benefit; it should be noted that part of the impetus for any research proposal involving MSM who attend GCPs is their self-definition as gay, homosexual, queer, bisexual, and heterosexual (Tong & Boyer, 2002). As a direct result of these wide-ranging, self-defined sexual orientations, analysis of the physiological sequelae of STIs in the context of GCPs must be conducted in conjunction with and be inclusive of all populations with whom these individuals may have sexual contact.

According to Garrett et al. (2001), the principles of beneficence and non-maleficence are too general to be useful. In view of the space and time limitations imposed on any researcher, doing all good must be seen as an impossible task. Therefore, doing good should go hand in hand with doing the least amount of harm possible, and any potential participants should be fully informed of this balance. Since most research involves cutting-edge topics, the true harms and benefits cannot be known in advance, hence the need for a thorough ethical analysis of the objectives, methods, and sample selection (Tri-Council, 1998). Application of the principle of non-maleficence justifies the researcher's entry into the GCP

for the purposes of health promotion and the provision of a voice to a marginalized population, because “unless someone will walk the ethical tightrope, the only source of information will be the police department, and that’s dangerous for society” (Adler & Adler, 2004, p. 101). The ethical tightrope is something that must be walked, to gain a more thorough understanding of the health beliefs and practices of GCP attendees.

Conclusion

Despite numerous public health efforts, STI rates continue to rise (Visser, 2005). Further, it has been acknowledged that when health officials undertake safer sex initiatives within GCPs, attendees rarely follow the suggested interventions (Mansergh et al., 2001). Since current research is mainly epidemiological and overlooks desire, and thus may fail to respect client choices, we recommend the use of ethnographic methods of direct observation. However, due to the sensitive nature of human sexuality and drug use, ethical concerns must be analyzed in order to minimize the possibility of harm. Such ethical concerns include an attendee being recognized by the researchers, attendees being targeted by the police as individuals who engage in marginal/illegal practices, and observational data being used to incriminate attendees. Additionally, concerns about informed consent and anxiety surrounding the dissemination of results will have to be explored. Meanwhile, these concerns should be balanced against the need for public health surveillance and control and the potential health benefits for the target group.

As for the final outcome of this ethics review, it seems evident that while *marginal ethnography* may raise ethical concerns, these are minor in nature and pale beside the potential benefits of improved public health and the promise that such knowledge will lead to greater understanding and greater sensitivity to the needs of a group situated outside the boundaries of mainstream society. However, this may not always be the case. Even though the outcome(s) of research with a marginal or sensitive population may be projected, perceived, or established as beneficial to both society and the group under study, it is essential that investigators thoroughly analyze, on a case-by-case basis, the ethical consequences of undertaking such research. Using previous research standards is a customary starting point, but investigators must proceed with caution to ensure that they do not adopt colonial attitudes that disregard the unique attributes of the culture under study and that may lead to its marginalization, or assume that research guidelines for one group are readily applicable to another. All researchers, but especially those dealing with sensitive topics such as MSM or GCPs, should be encouraged to analyze the ethics of

their research just as rigorously as they analyze the development of their methodological design and the background for the study.

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**Structure du travail en matière
de soins aux malades chroniques :
conséquences possibles sur la santé mentale
du personnel infirmier**

Marie Alderson

La présente étude avait pour objet d'enrichir l'ensemble des connaissances sur le cadre de travail des infirmières et des infirmiers, de manière à mieux comprendre leur expérience collective ainsi que l'origine de leurs problèmes de santé mentale. Une approche psychodynamique du travail a été adoptée. Les résultats montrent que la principale source d'insatisfaction par rapport au travail est leur sentiment que la direction et les autres professionnels ne leur accordent pas la reconnaissance, l'autonomie et l'autorité professionnelle qu'elles et ils méritent. Cette situation résulte en grande partie d'une organisation inappropriée du travail du personnel infirmier, dont les responsabilités ne correspondent pas à leur niveau de reconnaissance, d'autonomie et d'autorité professionnelle. L'auteure conclut qu'il faut transformer l'organisation des soins infirmiers, pour non seulement réduire le taux d'absentéisme mais aussi améliorer les soins infirmiers et en renforcer la professionnalisation.

Mot-clé : organisation du travail

Work Structure in the Chronic Care Setting: Possible Consequences for Nurses' Mental Health

Marie Alderson

The purpose of this study was to add to the body of knowledge on nurses' work environment in order to better understand their collective experience and the reasons for their mental health issues. A psychodynamic approach to work was used. The results show that the main source of nurses' dissatisfaction with their work is the perceived failure of management and other professionals to accord them due recognition, autonomy, and professional power. This situation is largely the result of an inappropriate organization of nurses' work, with nursing responsibilities unmatched by their degree of recognition, autonomy, and power. The author concludes that the organization of nursing must be transformed, not only to lower the rate of absenteeism but also to improve nursing care and enhance the professionalization of nursing.

Keywords: nurse roles, long-term care, work organization, occupational health

Background

In the mid-1990s economic constraints led many industrialized countries to restructure their health-care systems (Bergeron & Gagnon, 2003; Blythe, Baumann, & Giovanetti, 2001; Parker Shannon, 2002). Canada was no exception, embarking on a war against the deficit. It announced a 15% reduction in the amounts transferred to the provinces for their health-care systems (Turgeon & Gauthier, 2002). Since this measure meant a loss of revenue for the provinces, the government of the province of Quebec initiated an overhaul of its health and social services network by closing a number of hospitals, merging various health-care institutions, establishing walk-in clinics, and offering health professionals a retirement incentive (Bergeron & Gagnon, 2003). Efficiency became the mantra (Aiken, 2002; Aiken & Fagin, 1997). The number of hours of care set by the Quebec government as part of its restructuring program, however, was insufficient to meet the growing intensity and complexity of care required by the population. A true overload followed in the field of health care, which gradually affected the work satisfaction of nurses, increasing the rate of absenteeism and eroding the quality of care provided (Armstrong-Stassen et al., 2001; Canadian Nursing Advisory Committee, 2002; Gadbois & Parker, 2000). The restructuring of nursing

staff by reducing the nurse-patient ratio and mass hiring non-qualified employees (Norrish & Rundall, 2001) had an impact. This staffing model, also known as “skill mix,” involves the hiring of a small number of nurses to supervise a large and growing number of less-qualified employees (Scholaski, Estabrooks, & Humphrey, 1999). The drastic reduction in the number of nursing positions led to a reconfiguration of the role of nurses, which resulted in ambiguity, confusion, and stress. At the same time, it caused great concern among nurses about the quality of care being provided. Quality of care is central to the level of satisfaction among nurses. The more quality goes down in the eyes of nurses, the greater the stress experienced by nurses (McGillis Hall et al., 2001). The findings of a study by Aiken, Clarke, Sloane, Scholaski, and Silber (2002) illustrate the effects of redefined nursing staff on quality of care: in general surgery, vascular, and orthopedic units, a significant link was found between the nurse-patient ratio and the rate of mortality and adverse effects, as well as the level of satisfaction and burnout among nurses; with a nurse-patient ratio higher than 1:6, for each additional patient the risk of mortality and adverse effects increased by 7%, while job dissatisfaction and burnout increased by 15% and 23%, respectively.

The Canadian Nurses Association (2006) reports that during the period 1987–2005 more nurses were absent from work than ever before, and in 2005 an average of 16,500 nurses were absent each week due to illness or trauma, for 20 hours on average — a total loss of 340,000 hours per week or 17.7 million hours per year, the equivalent of 9,754 full-time nursing jobs.

It has also been found that the health problems invoked for absenteeism are more psychological than physical. Psychological distress is the number one cause of absenteeism by health professionals. Between 1993 and 1999, the period of health and social services reform in Quebec, the costs of salary insurance increased by 25%, primarily due to burnout and depression (Ministère de la Santé et des Services Sociaux, 2001). Similarly, a study with 2,006 nurses in acute-care and long-term-care settings in Quebec found that mental health problems were the most frequent reason for absences sanctioned by a medical certificate (Bourbonnais, Malenfant, Viens, Vézina, Brisson, et al., 2000); the number of absences due to mental illness quadrupled between 1993 and 1999 and the length of the average absence related to mental health went from 51.6 days in 1993–95 to 78.1 days in 1998–99.

Such an increase in mental health diagnoses warrants an examination of the work experience of nurses. It is known that structural and organizational changes associated with Quebec’s health-care reform have resulted in the reorganization of nursing care, including a reduced number of supervisory positions, increased workload, disrupted team

dynamics, and disrupted work policies (Bourbonnais, Malenfant, Viens, Vézina, & Côté, 2000). The consequence of this reform was that diverse work cultures, professional training programs, and different work routines had to inadvertently coexist. All of these changes threatened the nurses' sense of belonging and professional identity, as manifested in their reluctance to work together and their general lack of enthusiasm for the profession (Baumann et al., 2001; Bourbonnais, Malenfant, Viens, Vézina, & Côté, 2000; Dicaire, Pelletier, Durand, Dubé, & Lepage, 1997).

The purpose of this study was to examine the processes by which nurses' mental health is weakened; the approach used was the psychodynamics of work, addressing the following question: *What is the subjective experience of work, in terms of pleasure and displeasure, for nurses employed in long-term-care units in the province of Quebec, Canada?* The study was intended to throw light on those elements of nursing practice, as it is currently structured, that are a source of collective pleasure or displeasure for nurses, by identifying the factors that do and do not have meaning for nurses and that therefore serve to either support or threaten their mental health. The chronic care setting was chosen since nursing research on stress and burnout has been concentrated in the acute-care sector while the number of studies in geriatric and chronic care settings has been modest (Dicaire et al., 1997). The Quebec government (Gouvernement du Québec, 2000) predicts that the enhanced life expectancy, the aging of the population, and the transformation of family life will result in a constantly rising need for nursing home and chronic care. It is thus reasonable to assume that a growing number of nurses will, for decades to come, find work in nursing homes and chronic care facilities. The present study on the experience of nurses working in long-term care is based partly on this conclusion.

Theoretical Framework

The psychodynamics of work was developed in France in the 1970s by Christophe Dejours, a psychiatrist and specialist in workers' health. This approach was suitable for the present study as it permits a global analysis of the relationship between the organization of work and the mental health of workers. The psychodynamics of work refers to the organization of work as a source not only of pleasure or displeasure but also of defensive strategies as workers attempt to cope with the demands of their employment situation. This method fits with the global approach of the subjectivist paradigm. In order to analyze complex work relationships, it adopts an interdisciplinary approach to the work experience, one that draws from the sociology of work, health, and communication. It elicits the psychic charge of a nurse's work, a charge that is naturally subjective,

qualitative, and essentially defined by the significance of the work for the nurse. The elements of the psychic charge that are of interest in the psychodynamics of work are those that speak to workers as a group, even though individuals in the group may be affected to varying degrees.

Three theoretical premises (Vézina, 2000) clarify the psychodynamics of work and permit a better understanding of the dynamics between the subject, work, and society, the three forces that must be balanced if mental health is to be preserved. The first premise refers to the subject's desire to achieve. Each person has an instinctive desire for self-fulfilment; it is part of one's constant search for identity, a search that inspires and moves the person to contribute to the society or the community. The second premise refers to one's work, which always encompasses more than indicated in the written job description. Work that engages one's intelligence and creativity allows for a degree of autonomy and thus offers an opportunity for self-fulfilment and for the development of identity. The third premise is that the opinion or perception of others is essential to the development of one's identity. The formation of identity through work is based on the way people see each other, whether in terms of the group or in terms of belonging to a community. Recognition for one's work is a determining element in self-fulfilment and the development of a professional identity (Dessors, 1995). Thus, in terms of the psychodynamics of work, mental health is the result of a dynamic equilibrium between the person's desire to achieve, the social norms to which he or she must conform, and the work itself, with its requirements for productivity within a given framework (Vézina, 2000). Work is an activity that involves a triple bond: to the object of the activity, to the other people concerned, and to oneself. It is around these three dimensions (utilitarian, inter-subject, and intra-subject) that the meaning of the work for the individual who is doing it will be constructed (Vézina, 2000).

According to this psychodynamic approach to work, pleasure is a state of psychic well-being experienced when a person's work fulfils his or her desire for recognition, power, autonomy, achievement, and identity. Pleasure in one's work includes the experience of confidence, cooperation, solidarity, and sociability. The concept of psychic displeasure at work describes a state of boredom, monotony, fear, anxiety, anguish, disappointment, dissatisfaction, anger, and the absence of pleasure, cooperation, and solidarity (Dejours, 1987a).

The psychodynamics of work is a framework for action research. The goal of this approach is the appropriation of the study's conclusions by the participants themselves, as a means of transforming the work situation (Dejours, 1987b).

Method and Procedure

Method: The Psychodynamics of Work

The chosen method of inquiry is based on a qualitative design that flows from hermeneutic philosophy. The qualitative approach allows for the emergence of the internal logic of the phenomenon under study; also, the global hermeneutic approach provides access to the real meaning, as constructed by the participant. For the psychodynamician, access to the meaning of work is gained through the words of the participants, which reflect their experience (Dejours, 1993b). This method calls for the participation of researchers from different disciplines (Dejours, 1993b), thus permitting the convergence of ideas as well as the complementarity of different disciplinary viewpoints, the basis for a large part of the heuristic capacity of the psychodynamics of work. For the present study, the researcher was joined by a health sociologist and a psychoanalyst.

With this method, data collection invariably comprises two steps. The first step is the pre-inquiry, which includes meetings with institutional administrators, explanations to the head nurses and staff nurses on the units chosen for the study, and non-participatory observation by the researcher. This observation is not intended to provide a detailed description of the observed dimensions; rather, it is meant to give the observer an understanding of the situation so that, during the interviews, the statements of the participants will be fully understood by the researcher. An observation guide indicated the main dimensions to be observed: the characteristics, environment, organization, constraints, context, and climate of the work; horizontal and vertical social relationships; physical, psychological, and socio-organizational risks; and the nurses' behaviour with regard to the risks.

The second step is the actual data collection, from the group interviews to the final research report. The interview method is based on a process of taping the conversation, interpreting the content, and, finally, discerning the meaning by comparing the interpretations of the interdisciplinary researchers with those of the participants. The purpose is to develop a common and shared understanding of the collective experience of work. An interview guide suggested by the frame of reference reminds the researcher of the dimensions to be discussed with the participants so that a global understanding of the work experience can be developed. The themes were as follows: the nature and specifics of the work; the sources of displeasure at work; the risks, fears, and anxieties at work; defensive strategies; enjoyment of work; support at work; and solutions suggested by the participants. The guide and the interview process were flexible, in order to ensure spontaneous comments from the nurses, thus revealing the meaning they gave to their work experience.

Inclusion Criteria

Since results are not to be generalized, this research method does not require a representative sample. The participants in the group interviews took part on a voluntary basis, thus ensuring authentic witnessing. In order to participate, the nurses had to meet the following inclusion criteria: be a nurse working days or evenings on a long-term-care unit; understand and speak French; agree to take part in a collective interview; and agree to forego any financial remuneration for participation. Since on the one hand employment implied a willingness to participate in research and on the other hand the study concerned collective experience, no inclusion criterion specified part-time or full-time employment, on-call or regular staff, or degree of seniority.

Setting and Sample

The study was carried out in a long-term-care institution in Greater Montreal, Quebec, Canada. A total of 33 nurses volunteered to be interviewed and made up nine groups, eight consisting of nurses on day duty and one consisting of nurses on evening duty. Night nurses did not participate because of the impracticalities of night-time interviewing. The participants had between 2 and 28 years' experience; a small number had worked in an acute-care setting and the majority had long-term-care experience in the institution chosen for the study. The great majority had a college diploma; almost all were married and had children. Nearly all were born in Quebec with French as their mother tongue. All but the oldest participants had been on-call nurses before joining the regular staff. The youngest participants worked part-time and also on call. A great many of the day nurses had previously worked evenings and nights. Most of the nurses who worked evenings had chosen that shift; their previous experience included day duty.

Procedure

For each group, the researcher conducted three 2-hour interviews — two to collect data and one to validate, with the participants, the interdisciplinary interpretations of the data. Audiotapes of the interviews were copied for the sociologist and the psychoanalyst. The researcher's content analysis and written interpretations were submitted to these two collaborators, who, after individually analyzing the tapes, confronted the researcher's subjectivity, thus prompting a rich exchange of ideas. The interpretations to which the majority gave consent were then returned to the nurse participants in preparation for the validation interview with them. After completion of the third interview with all nine groups, the researcher wrote the preliminary report, using material common to all

groups. This report was given to the nurse participants for their approval and comments, which were then incorporated into the final report.

Results

Responsibility versus Recognition, Autonomy, and Power

The analysis and gradual clarification of the relationship between pleasure/displeasure and the organization of work resulted in the emergence of a "common feeling." This common feeling fell under three themes (recognition, autonomy, and power), which are summarized below.

In this particular chronic care setting, the principal source of displeasure appeared to be the nurses' perceived lack of professional recognition, autonomy, and decisional power (Alderson, 2001). The nurses perceived themselves as having more responsibility than recognition, autonomy, or power. While autonomy and power are closely linked, clinical studies have found differences between the two concepts. Autonomy refers to freedom of action within the limits set by the structure of the workplace. For example, when a nurse writes a nursing care plan, she is "autonomous" if she is free to carry out the plan in the sequence of her choice. The notion of power goes further, to include the dimensions of responsibility and accountability. To return to the same example, the nurse has real power if she not only has the freedom and the responsibility to prepare the care plan but also is accountable for the choices she has made. Power appealing to an individual's creativity and ingeniousness implies the freedom and ability to contribute to the institution's success in achieving its goals. Autonomy without power is a trap. The participants pointed out that the responsibilities they were expected to assume in primary nursing must necessarily be accompanied by professional autonomy and decisional power. In the absence of recognition, autonomy, and power, the nurses viewed their responsibilities not as a source of professional pride but as a source of anxiety.

Lack of Recognition by Management, Other Professionals, and Peers

The nurses' perception of a failure, on the part of management, to recognize their particular competencies reveals their conviction that nursing's contribution to the institution's reputation is not acknowledged: "We don't want them to say thank you; we want them merely to recognize that we are a part of the institution and that we contribute significantly to its excellent reputation." The recognition of nurses by other health professionals, including doctors, is scarcely greater: "The physicians are more likely to listen to others than to us"; "The goals of the other professionals take precedence over ours."

It was much the same with peers, especially among nurses on different shifts: "I wouldn't say that solidarity among nurses is strong"; "If a nurse finds herself facing a serious problem, she is deserted by her colleagues." The heavy workload and resultant lack of discussion were often blamed for the absence of group work and common goals: "There's no time or place for nurses to talk to each other. As a result, it's very difficult to act as a group." The nurses therefore knew that they were partly responsible for their lack of enjoyment of work. In the absence of confidence, solidarity, and cohesiveness, they remained silent, lamenting the failure of any collective attempt at change.

Lack of Managerial Support for the Search for Identity

In their quest for professional identity, the nurses deplored the absence of managerial support and consideration for the nurses' needs, the lack of any effort to improve working conditions, the lack of transparency with regard to reorganization of the workplace, and the lack of any real attempt to consult nurses or have them participate in decisions about their work: "I'd say that we are perhaps consulted, in that we can express ourselves at meetings and give our opinion about various things, but we're rarely listened to, or even heard." As an example of a recent lack of consultation, the nurses cited management's decision to introduce a homelike atmosphere on the units, a change that would affect the nurses' work: "They didn't consult us. They simply informed us that the patients would now be able to have visitors 24 hours a day." The nurses were also disillusioned with how the concept of primary nursing was understood, with management providing no explicit definition of the roles, responsibilities, and tasks of the various members of the nursing team: "We have four different categories of nursing personnel: orderlies, nursing assistants, diploma nurses, and baccalaureate nurses — but we all end up doing the same thing." This resulted in role ambiguity, overlapping responsibilities, and conflicting interpersonal relationships. The nurses felt that their work was seen as insignificant and that their nursing skills were underestimated and underused: "My tasks are not those of a nurse; I feel undervalued." They said they lacked a sense of professional achievement and complained about their interchangeability with less-qualified personnel: "I have the feeling that I'm using 50% of my nursing knowledge... that I'm working as an orderly"; "My frustration is linked to the fact that management keeps me from assuming the role for which I was prepared." The nurses also said that the increased workload prevented them from enjoying the satisfying feeling that comes from work well done: "We carry out our nursing tasks without any sense of satisfaction, because we have to rush through them"; "Because of time constraints, we can't perform those tasks that are specifically nursing — establishing a relation-

ship with patients and families, making nursing assessments, revising nursing care plans, writing monthly reports." These frustrations served to restrict the nurses' enjoyment of their work, remove meaning from their work, shake their sense of professional identity, and threaten their mental health.

The Helping Relationship: A Protective Factor

The findings demonstrate that nurses' burnout and mental health problems are caused not by their helping role, attachment to patients, or grief over the death of a patient, but, rather, the way in which their work is structured: "The real source of burnout is the way the work is organized"; "The relationship we have with patients motivates and sustains us; if we didn't have the opportunity to connect with the patients, I don't know how we could endure what we sometimes have to." Investment in the helping relationship with patients and families emerged as the strategy chosen by the nurses to compensate for the frustration, dissatisfaction, and displeasure they experienced. It was in the nurse-patient relationship that the nurses perceived their real role in long-term care; it was there that they found meaning in their work, a sense of professional self-esteem, and the recognition that they considered indispensable. The helping relationship was at the heart of the nurses' psychic balance; it opened the door to meaning and enjoyment at work.

In short, it might be said that the participants experienced displeasure because their desire for professional recognition, autonomy, and power in the discipline for which they were trained was not being fulfilled. They felt that their skills, knowledge, and abilities were underused, that their mental potential was not being recognized. The image projected by the work they did compromised their identity, self-esteem, and sense of worth. However, the participants were able to sublimate their frustrations to their helping and supportive relationship, which is founded on caring.

Solutions Proposed by the Participants

Creation of a framework for discussion. For all participants, the primary solution was to create a framework for discussion with respect to their practice, to allow them to talk about their feelings, bringing about more favourable conditions for working collectively and regaining a degree of control over their work situation.

Enhanced recognition. Among other solutions suggested by the nurses was that management acknowledge their important role in fulfilling the institution's mission and upholding its reputation, by organizing the work such that it supported their skills and expertise while keeping the workload at a level that allowed them to perform their tasks properly; according them more autonomy and power; embracing organizational

transparency; and instituting a bona fide consultation process regarding their work and the decisions that affected their practice.

Reorganization of primary care. Given that the provision of quality care was central to their enjoyment of work, the nurses wished to retain this dimension as well as its underlying conditions. They also wished to retain the primary care model, which they considered a guarantee of quality. However, they expressed a need for a redefinition of the roles, tasks, and responsibilities of various health-care workers, such that those tasks that are not specific to nursing be assigned to other employees and that all nursing-specific tasks be assigned to nurses. They recommended that nursing assistants meet at certain times during the day to perform those tasks that do not require the presence of a nurse. This organization would enable nurses to focus on nursing tasks, such as charting, preparing and administering drugs according to the medical prescription, conducting evaluations, and forming helpful and supportive relationships with patients and their families.

With regard to nursing staffing practices, the nurses saw the prevailing situation as threatening to compromise the quality of care. They expressed a desire for head nurses to listen more attentively to their needs, be more supportive, resolve problems and conflicts more appropriately and effectively, and reinforce their leadership both on the unit and within the institution. Many nurses said they favoured a return of the annual evaluation process, stating that without an official evaluation process their expertise and skills would never be officially or explicitly recognized.

Discussion

Implications for Nursing

The findings suggest that the subjective rationality of work (linked to nurses' sense of achievement) is frequently sacrificed to the objective rationality of work (linked to production). This state of affairs leads to a loss of meaning in nurses' work and mental health problems for those who do that work every day. Aiken et al. (2001) report that recent health-care restructuring in the United States, Germany, England, and Scotland, as well as in the province of Ontario, is based on the industrial model of growth and productivity rather than addressing the situation of practising nurses. The levels of dissatisfaction found by Aiken et al. (2001) are akin to the sources of displeasure brought to light in the present study; this dissatisfaction is related to organizational shortcomings such as lack of nursing staff, lack of participation in decision-making, lack of recognition for nurses' contribution to patient care, lack of control over work hours, and lack of managerial attention and action regarding nurses' con-

cerns and career perspectives. The conclusion of a literature review by Cummings (2003) is consistent with the findings of the present study, citing decreased work satisfaction and increased emotional exhaustion¹ as the two main effects of restructuring on the health and well-being of nurses. These effects are largely the result of heavy workloads, nurses' loss of control over their practice, and reduced quality and quantity of time spent with patients (Cummings, 2003). Kiesners and McGillis Hall (2005) also report that nurses have insufficient time to talk with their patients.

The results also show that a helping relationship with patients and families enables nurses to reinforce their identity and preserve their mental health. This is an important finding in terms of knowledge about the determinants of mental health. Indeed, the findings suggest that investing in the relationship with patients and families is a means of transforming workplace tensions into a source of enjoyment and identity development. Jackson (2005) also reports that emotional proximity with patients and their families, the opportunity to comfort them, and the ability to meet their needs are major sources of satisfaction for nurses. The ability to spend time with patients and their families and the opportunity to offer personalized care contribute to a sense of accomplishment among nurses (Jackson, 2005). The present findings clearly demonstrate the importance of the patient-nurse relationship and its positive effects on nurses. It is essential that management create working conditions that promote this relationship.

The present results suggest avenues for developing models, theories, and transactions to help harmonize both the organization of the workplace and nurses' health, ambitions, and desire for self-fulfilment. They support the development of an appreciation of nursing personnel as a resource to be valued rather than as an expense to be controlled (Koehoorn, Lowe, Rondeau, & Schellenberg, 2002). They confirm the unfavourable influence of economic logic on nursing care. Economic logic has the effect of modifying values so that productivity takes precedence over holistic nursing imbued with caring, the very heart of the professional ideal for nurses. The results show that if authorities really wish to resolve the problem of nurse absenteeism they will grant nurses recognition in the form of professional autonomy and real power over nursing care. Management must cultivate collegial rather than hierarchic relationships. Increased nurse participation at the decision-making level is strongly recommended. The organization of nurses' work should allow nurses to use their specific skills and competencies and thus to feel productive and fulfilled. Overall, the findings indicate that shared governance would allow for collective autonomy and participation in decision-

¹One of the components of professional burnout, according to Maslach (1976).

making while also addressing the need for job satisfaction. This view is expressed by Kelly and Joël (1995) and by Moloney (1992). Many authors have recommended that nurses be involved in the restructuring of services (Aiken, 2002; Aiken & Fagin, 1997; Blythe et al., 2001; Johnston, 1998; Norrish & Rundall, 2001; Rosengren, Engstrom, & Axelsson, 1999; Scholaski, Aiken, & Fagin, 1997; Wunderlich, Aloian, & Davis, 1996). The positive impact of participatory strategies is expressed in terms of job satisfaction and organizational efficacy (Kusserow, 1988; Murray & Leatt, 1992), autonomy, sense of responsibility, and identification with the work setting (Macy, Peterson, & Norton, 1989; Skelton-Green, 1996; Spector, 1986). Marmot and colleagues (Bosma et al., 1997; Bosma, Stansfeld, & Marmot, 1998; Kuper & Marmot, 2003; North, Syme, Feeney, Shipley, & Marmot, 1996) report that the benefits of a setting that allows nurses to control their own work include physical health and well-being as well as decreased absenteeism and increased productivity. The American literature also discusses constructive work settings, called magnet hospitals, which represent the “gold standard” in nursing care. Nurses who work in these hospitals have lower rates of burnout (Aiken, Clarke, & Sloane, 2000; Aiken & Patrician, 2000; Aiken & Sloane, 1997a). Two of the organizational characteristics common to these settings are a decentralized structure and participatory management (Buchan, 1997, 1999; Kramer and Schmalenberg, 1991b), enabling nurses to make use of their entire skill set (Aiken, 1995). Professional autonomy is identified as one of the chief elements in clinical professional practice at magnet hospitals (Aiken, 1998; Aiken, Sloane, & Lake, 1997; Aiken, Smith, & Lake, 1994; Buchan, 1994; Chalfant, 1998; Kramer & Hafner, 1989; Kramer & Schmalenberg, 1991a). Professional autonomy is characterized as both the ability to make decisions on all clinical aspects of the nursing profession and organizational autonomy (planning and managing hospital operations) (Aiken, 1995). The freedom to make decisions positively influences the satisfaction of nurses (Kramer & Schmalenberg, 1991a) and serves to reduce burnout (Aiken & Sloane, 1997a), while also improving the quality of care (Aiken et al., 1994) and patient satisfaction (Aiken & Sloane, 1997b).

It is equally important that management provide opportunities for nurses to meet as a group to discuss their work; social exchange is the cement that holds a team together (Baumann et al., 2001). Also critical are administrative mechanisms promoting stability of the nursing team, the basis for effective group action.

Finally, the results of this study will alert health-care managers to the negative consequences of requiring several different categories of personnel to carry out similar tasks.

Contribution to Our Understanding of the Phenomenon

The originality of this study lies in its examination of nurses' work from the point of view of a paradigm, from an approach and a methodology that are different from those traditionally used in nursing research in the area of mental health in the workplace.

The results show that on-site research in the work setting, which is the basis for the psychodynamic approach to work and which originates in the actual experience of work, throws light on those phenomena that are of special interest to the nursing profession. The psychodynamic approach to work is very useful in those areas to which nursing decision-makers give priority: administration of nursing personnel, organization of nursing services, assessment of nursing interventions, and organization of intra- and interdisciplinary work. Because they concentrate on everyday work situations, studies using the psychodynamic approach obtain, from the participants themselves, viable solutions to workplace problems. The results of such research provide data that managers can use in their decision-making. In addition, the psychodynamic approach leads directly to the formulation of policies concerning nursing practice and the administration of nursing services.

During the interviews, the participants said how good it felt to talk with and listen to their colleagues. Through the act of "venting" and sharing their negative work experiences, many of the nurses discovered that they were not alone in what they were going through. This brought out feelings of empathy and solidarity, leading several participants to state that they would support each other from that point on. These results corroborate Trudel's (2000) conclusion that people really need to talk about what they experience at work.

Limitations of the Study and of the Psychodynamic Approach

One limitation of the study was the imposition, by the institution, of time constraints on the nurse participants. Another was the small size of the sample — three or four nurses per group, except for the evening group, with six nurses — thus limiting the opportunities for conversation among the participants. Because the interviews took place during working hours, some nurses were obliged to remain on the unit in order to ensure the availability of services.

Inherent in the psychodynamics of work is the impossibility of generalizing and reproducing the results. The approach allows for the transfer of conclusions from one setting to another on the condition that the workers in the recipient setting recognize themselves in the results and appropriate the results.

The psychodynamics of work does not always lead to immediate and rapid organizational change (Trudel, 2000). Concrete improvements may be spread out over time, depending not only on the determination of workers to bring about change but also on management's willingness and ability to let the workers reconcile their needs and ambitions with their work; the after-effects of a psychodynamic study depend on the quality of the social dialogue within the institution and on the degree of confidence that exists among all concerned (Vézina, 2000).

Implications for the Future

Nursing as a discipline and nursing as practice evolve within historico-political events and are part of the social movement of the society; they develop according to the rhythm of those great currents of thinking that lead to the evolution of knowledge (K  rouac, Pepin, Ducharme, Duquette, & Major, 2003). In this spirit, it is appropriate to consider nurses' work as a social construction intimately linked to the socio-historical process of the moment (Billiard, 1993), such as the supremacy of the economic logic underlying the reform of health and social services. According to Carpentier-Roy (2001), social finality has a place alongside economic finality. We must rethink nursing practice so that it will be experienced by nurses as an opportunity for personal growth as well as serving society.

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Book Review

Handbook for Synthesizing Qualitative Research

Margarete Sandelowski and Julie Barroso

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Reviewed by Souraya Sidani

This handbook presents guidelines for synthesizing findings of qualitative research. After discussing the importance of such synthesis for building knowledge, in the second chapter the authors introduce definitions of and types of qualitative research synthesis. They view the synthesis as a study comprising a series of steps, starting with the formulation of a problem and a statement of purpose. In chapter 3 the authors focus on the steps of retrieving all research reports and determining their relevance to the study domain. In chapter 4 they describe strategies for appraising individual study reports and for conducting a comparative appraisal. Comparative appraisal consists of displaying key elements of the studies included in the synthesis and comparing them in order to determine whether they confirm, extend, refute, or complement each other. In chapter 5 Sandelowski and Barroso discuss issues encountered in appraising the quality of qualitative studies and present a typology of findings that can be used to classify results. In chapters 6 and 7 they describe the process of implementing the two types of qualitative research synthesis, metasummary and metasynthesis. In chapter 8 the authors review strategies for maintaining validity of qualitative research synthesis and in chapter 9 they review content and format for presenting the results of the synthesis.

Sandelowski and Barroso are to be commended for addressing a controversial topic, and for refining the types of qualitative research findings and procedures for conducting a synthesis of these findings. They clarify the arguments advanced by proponents and opponents of the qualitative research synthesis, thereby facilitating our understanding of the rationale underlying the two types of synthesis. Conceiving the synthesis as a study that is conducted in steps, similar to those entailed in a meta-analysis, helps us to view the process as a systematic one with a well-defined sequence of steps. The book is structured accordingly, starting with the formulation of a researchable problem, moving on to the conduct of an extensive search of the relevant literature, then to an appraisal and synthesis of findings across studies, and ending with

dissemination of the results. This sequence is logical. The information relative to the implementation of each step in the synthesis process is presented briefly, with a focus on issues to consider and tips for undertaking some of the steps. The tips are summarized in point form or in tables, and are illustrated with the authors' work. The directions for comprehensively searching published and grey literature, and the decision tree and audit trail to guide and document decisions regarding the relevance of study reports, will be useful for scholars planning to conduct a qualitative or quantitative research synthesis. The authors provide the reader with an extensive list of additional resources useful for an in-depth understanding of the issues and procedures.

This handbook takes a general, broad approach to the presentation of strategies for conducting a qualitative research synthesis. Sandelowski and Barroso provide the reader with an example to illustrate each strategy they discuss, tabulated information highlighting key points or illustrating application of the strategy, and an exhaustive bibliography. While the book lacks details on the implementation of each step, this is consistent with the authors' approach of offering guidelines rather than using a cookbook means of conducting a synthesis. While this methodological flexibility is consistent with the iterative and interpretive nature of qualitative research and with the diversity with which qualitative research is carried out, it can lead to confusion and variability in the synthesis process. Therefore, it appears that the best means of learning how to conduct a synthesis is by doing it!

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