Volume 46 Nº 1

CJNR

March / mars 2014

CONTENTS / TABLE DES MATIÈRES

Self-Management and Patient-Centred Care /
Autogestion de la santé et soins axés sur le patient

Ingram School of Nursing, McGill University

CJNR 2014, Vol. 46 Nº 1, 3–7

EDITORIAL

uLearning for Nursing Professional Development: Paving the Road Ahead

Antonia Arnaert, Norma Ponzoni

The practice of nursing and the development of the profession have always required that one stay current with the evolving standards of practice, yet in today's ever-advancing and hectic clinical environments it can be a Herculean effort to do so. Staying informed requires that one constantly receive updates on new protocols, guidelines, and evidence-based clinical approaches. Health-care institutions have a vested interest in supporting nurses' professional development, to achieve a competitive advantage over other organizations. Excellence of staff practice, the provision of high-quality services, and the promotion of patient safety, as well as a heightened institutional profile in the community, are outcomes that can be tied to investments in staff development.

Traditionally, professional development has consisted mainly of face-to-face instruction — often a challenging and costly endeavour in terms of program development, accessibility, and the regular updating that is required. Access to continuing education is a challenge not only for nurses working in remote regions. Even in urban areas, shift work and the difficulty in leaving busy practice units at fixed hours serve to limit access to in-service education programs. Arguably the most cost-effective and efficient way to address these constraints is ubiquitous learning, or uLearning, a future-oriented and innovative educational strategy for making professional development readily available.

uLearning — an extension of ubiquitous computing — incorporates the use of advanced computing and communication technologies such as sensors, mobile phones, RFID (radio frequency identification devices) tags and cards, wireless communication equipment, and wearable computers, for the purpose of creating environments of *omnipresent* education, enabling anyone to learn anywhere and at any time.

"Anywhere and any time learning" often confuses users of uLearning environments: it is so broad and all-encompassing that its potential for learning in various contexts of daily life can be hard to fully appreciate. We prefer the less abstract definition offered by Yahya, Ahmad, and Jalil (2010): "uLearning is a learning paradigm which takes place in a ubiquitous computing environment that enables learning the right thing at the right place and time in the right way" (p. 120). The main purpose of uLearning, therefore, is to help learners obtain the information they are seeking at any given moment. In fact, uLearning puts the learner's needs and the dynamics of learning ahead of the technology that supports it. The arrival of ubiquitous computing does not mean that people's fundamental way of processing and assimilating information has changed, but uLearning allows us to develop ways to better serve the ever-changing learning needs of individuals.

uLearning can be seen as an extension of distance education — the provision of learning opportunities when content and learners are separated by time and distance. Distance education includes both paper-based and electronic delivery methods. Some speak of transitioning from conventional to electronic learning (eLearning), from eLearning to mobile learning (mLearning), and, most recently, the shift to uLearning (Yahya et al., 2010). Yet nurses and other health professionals are only beginning to adopt eLearning, a term that often encompasses Web-based learning, online learning, distributed learning, computer-assisted instruction, or Internet-based learning, which are static modes of content delivery that allow interaction with subject matter (Ruiz, Mintzer, & Leipzig, 2006). However, users of eLearning have the ability to incorporate forums for learning and exchange. These environments facilitate various levels of interactivity with the content and between learners, which allows for a constructivist approach to learning in which the learner is actively engaged. The true potential of this learning space, created by and among learners, is co-construction of knowledge and creation of online or virtual communities of practice (Boulos, Maramba, & Wheeler, 2006; Bristol & Zerwekh, 2011).

Today, the Internet, also called Web 2.0, incorporates online collaborative tools, such as blogs, wikis, mash-ups, podcasts, social network sites, online worlds, open-source systems, and a host of other current and emergent entities. These are the existing media that people use to work together on the Internet in order to facilitate peer support, collaboration, and dialogue among individuals located in different physical areas even at great distances from one another (Hanson, Thackeray, Barnes, Neiger, & McIntyre, 2008). Virtual collaborations can have a social purpose but can also be used by groups of professionals. Of particular interest for nurses is the potential for communities of practice that promote networking, fruitful exchange, and opportunities for peer learning between practitioners near or far (Boulos et al., 2006; Ruiz et al., 2006). These collaborations, in addition to letting nurses select the information they would like to review, have the effect of making eLearning more learner-centred, allowing for personalized sessions and for nurses to have control over the pace of their learning.

Most current eLearning applications are limited to enabling learner interaction with content despite the inherent ability of technology to facilitate a second level of exchange — that between learners. At present, learning management systems (LMSs) hosting online content are most often passive online repositories of information, with instructors simply slotting in their prepared materials. Practically speaking, the natural tendency of instructors, when information technology (IT) was first widely introduced in education, was to directly apply conventional pedagogical practices to online, electronic delivery systems and call them LMSs. There are at least two forces that likely account for the relatively unsophisticated use of the technology, one related to the course creator and the other to the limitations of proprietary software (programs licensed by a copyright holder under very strict conditions) that support LMSs. Firstly, the instructor who creates a course may not be aware of the benefits of an interactive approach to pedagogy, or may not have the technological expertise to incorporate various features that promote interactivity between learners. Very few instructors are "digital pedagogues" (teachers who use technology in a fluid manner) or are sophisticated users of digital media in their teaching and learning. The simple act of using electronic elements in one's online teaching does not mean that one is practising digital pedagogy. Essentially, this demands that we use digital media to rethink the power relations between learners and instructors and create more collaborative and less hierarchical spaces for learning (Milton, 2013).

Turning to the second group of limitations, for years proprietary software was the norm in eLearning and its vendors "locked in" customers to specific systems, thereby limiting technological interoperability with other systems or eLearning components (Pankaja & Mukund Raj, 2013). The imposed restrictions of propriety software limited users' ability to interact with people across systems and led to a shift from proprietary to open-source software (OSS) systems. OSS is a type of software licence that makes the source codes — scripts used for programming — available to the public with no copyright restrictions. That said, it may not be entirely free, as people with limited programming skills require administrative and technical support. OSS developers realize that one size does not fit all and have given educational providers the freedom to build a tailored and flexible eLearning platform incorporating features that suit the learning needs of users. In addition, the adaptability of OSS allows for easy and timely integration of new design features and Web developments, such as the upcoming conversion from Web 2.0 to Web 3.0, also known as the Semantic Web. The popularity of this software has generated a broad base of users and programmers who support its development and thus provides the premise for a sustainable community. It is clear that OSS systems, supported by these large communities of users, are becoming serious competitors of proprietary eLearning systems (Kertalj, Jerkovic, & Hlupic, 2006).

Despite the rapid uptake of new learning technology, the mere acquisition of equipment is insufficient to enable organizations to shift the delivery of nurses' professional development to eLearning. Too often, organizations fail in their attempts to adopt eLearning because they are not ready to take it up and to maximize the benefits and innovation that can follow. Assessment of an organization's readiness to implement eLearning is a critical element and should be circumscribed before an institution even considers introducing eLearning (Schreurs, Ehlers, & Sammour, 2008). In reality, an organization's readiness is reflected by its e-maturity, which encompasses, for example, the availability of infrastructure; its openness and commitment to investing in IT initiatives; and the attitudes and perceptions of users as well as their experience with computers and various mobile devices and their skill in navigating the features incorporated into an eLearning platform. Whatever the e-maturity of an organization, all of these factors must be assessed and taken into consideration prior to implementation and integration of eLearning.

In conclusion, the use of technology to facilitate teaching and learning is here to stay. uLearning, with its networking and collaborative possibilities, offers nurses a tremendous opportunity to share knowledge and expertise with their peers in virtual communities of practice. These communities represent a more engaging and learner-centred environment for professional development, making this method of content delivery more effective compared to traditional approaches. In light of this new reality, the nursing profession should fully embrace uLearning, to capitalize on all that existing and future computing and communication technologies have to offer in order to promote high-quality services for those entrusted to our care.

References

Boulos, M. N. K., Maramba, I., & Wheeler, S. (2006). Wikis, blogs and podcasts: A new generation ofWeb-based tools for virtual collaborative clinical practice and education. *BioMed Central (BMC) Medical Education, 6*(41), 1–8.

Bristol, T. J., & Zerwekh, J. (2011). *Essentials of e-learning for nurse educators.* Philadelphia: F. A. Davis.

Hanson, C., Thackeray, R., Barnes, M., Neiger, B., & McIntyre, E. (2008). Integrating Web 2.0 in health education preparation and practice. *American Journal of Health Education, 39*(3), 157–166.

Kertalj, K., Jerkovic, H., & Hlupic, N. (2006). *Comparison of e-Learning management systems*. Paper presented at 5th WSEAS International Conference on E-ACTIVITIES, Venice, November 20–22. Retrieved March 8, 2014, from https://www.zpr.fer.hr/zpr/Portals/0/Predmeti/UIS/Comparison%20of%20eLMS.pdf.

Milton, M. (2013). Digital literacy and digital pedagogies for teaching literacy: Pre-service teachers' experience on teaching rounds. *Journal of Literacy and Technology, 14*(1), 72–97.

Pankaja, N., & Mukund Raj, P. K. (2013). Proprietary software versus open source software for education. *American Journal of Engineering Research, 2*(7), 124–130.

Ruiz, J. G., Mintzer, M. J., & Leipzig, R. M. (2006). The impact of e-learning in medical education. *Academic Medicine, 81*(3), 207–212.

Schreurs, J., Ehlers, U. D., & Sammour, G. (2008). E-learning readiness analysis (ERA): An e-health case study of e-learning readiness. *International Journal of Knowledge and Learning, 4*(5), 496–508.

Yahya, S., Ahmad, E. A., & Jalil, K. A. (2010). The definition and characteristics of ubiquitous learning: A discussion. *International Journal of Education and Development Using Information and Communication Technology, 6*(1), 117–127.

Antonia Arnaert, PhD, MPA, is a CJNR *Editor and Associate Professor, Ingram School of Nursing, McGill University, Montreal, Quebec, Canada. Norma Ponzoni, RN, MSc, MEd, is Faculty Lecturer, Ingram School of Nursing, McGill University.*

CJNR 2014, Vol. 46 Nº 1, 8–10

COMMENTARY

Limitations of Nursing Education in Promoting Client-Centred Care and Self-Management

Diane Duff

For the past 18 months I have been a member of the Nova Scotia Nursing Education Review Steering Committee. Our review of nursing education has included extensive stakeholder input. The refrain from leaders in the health-care system is that nursing graduates are not "practice-ready." While the axiom that university nursing graduates can "theorize but not catheterize" is sometimes true, there is a greater disconnect than simply their lack of confidence and skill in working with tubes and handing out medications in a timely manner; they are also expected to be leaders in advancing client-centred care and in providing self-management support.

Part of the responsibility for the gap between education and practice lies squarely with nursing education. Professors tend to shy away from the "swampy lowlands" of practice; it is easier to teach from the "high, hard ground" (Schön, 1987, p. 1) of the university classroom using case studies that have a "right" answer, presenting ideal models of care, and delivering known content with scads of slides than to wade into the weeds with our students, integrating knowledge through problem-solving, discussion, and debate. While expert clinicians are needed to help students bridge "*abstract knowledge* and theory . . . into the productive thinking required to use in practical situations" (Benner, Hooper Kyriakidis, & Stannard, 2011, p. 12), we have largely delegated this essential clinical work to part-time instructors and preceptors. In addition to teaching foundational knowledge, we must create opportunities and tools for "situated learning in simulation, skill labs and clinical practice . . . for students to learn how to use knowledge" (Benner et al., p. 12) and to actively engage with patients in ways that address the "messy, confusing problems that defy technical solution" (Schön, p. 1).

Educating students to meet the current needs of the health-care system is relatively easy through increased use of simulation and extended periods of consolidation with preceptors. It is much more difficult to educate for the future. The Registered Nurses' Association of Ontario (2002) defines client-centred care as "an approach in which clients are viewed as whole persons; it . . . involves advocacy, empowerment and respecting the client's autonomy, voice, self-determination, and participation in decision-making." Self-management requires informed, "activated" patients who manage their own care decisions. Supporting self-management requires skill in case management, active listening to identify patient concerns, use of motivational interviewing, and collaborative problem-solving to create step-by-step written action plans (Glasgow et al., 2002). In the current "nurse du jour" environment, where nurses are assigned to care for any patient on any given shift, client-centred care and self-management are not priorities. Nurses are simply coping with increased acuity of care in a fragmented health-care system. Therefore, students have little opportunity to actively engage in client-centred care or in the promotion of care self-management in practice outside of the classroom.

Inherent in discussions about nursing education over the last few decades is the notion that if we create a different kind of nursing graduate we will transform the health-care system. If we teach students to practise from the stance of client-centred care and towards the goal of patient self-management we will transform the system, one graduate at a time. Enough graduates practising differently and demanding system change will create "the moment of critical mass, the threshold, the boiling point" that will, in turn, cause system change (Gladwell, 2000, p. 12).

Client-centred care and self-management models that support patients and their families require health-care-system supports. Education alone is not enough to transform practice. Experienced nurses, nurse leaders, nurse researchers, and nurse educators need to work together to address the reality that "we in nursing . . . are too lost to find our first steps . . . when keeping our heads above water consumes so much of our time and energy" (Clarke, 2013, p. 7). Otherwise, we will continue to burden new graduates not only with expectations of "road-readiness" but also with the expectation that they transform the health-care system while navigating their own transition to professional practice.

References

Benner, P., Hooper Kyriakidis, P., & Stannard, D. (2011). *Clinical wisdom and interventions in acute and critical care: A thinking-in-action approach* (2nd ed.). New York: Springer.

Clarke, S. P. (2013). Patient- and family-centred care: A long road ahead. Editorial. *Canadian Journal of Nursing Research, 45*(4), 5–7.

Gladwell, M. (2000). *The tipping point.* New York: Little, Brown.

Glasgow, R., Funnell, M., Bononi, A., Davis, C., Beckham, V., & Wagner, E. (2002). Self-management aspects of improving chronic illness care breakthrough series: Implementation with diabetes and heart failure teams. *Annals of Behavioral Medicine, 24*(2), 80–87.

Registered Nurses' Association of Ontario. (2002). *Client-centred care.* Toronto: Author. Retrieved March 12, 2014, from http://rnao.ca/bpg/guidelines/client-centred-care.

Schön, D. (1987). *Educating the reflective practitioner.* San Francisco: Jossey-Bass.

Diane Duff, RN, PhD, is Director, School of Nursing, St. Francis Xavier University, Antigonish, Nova Scotia, Canada.

CJNR 2014, Vol. 46 Nº 1, 11–25

Development and Validation of a Self-Care Ability Measure

Souraya Sidani, Diane Irvine Doran

Self-care is an outcome of nursing care that is instrumental for promoting recovery and preventing complications following hospitalization. The Therapeutic Self-Care (TSC) measure was developed to assess self-care ability in acute-care settings. Its content was derived from a conceptualization of self-care generated from an extensive literature review. Clinical experts considered the 13 items of the TSC measure as relevant, supporting its content validity. Findings of 1 study indicate that the items are internally consistent and loaded on 1 factor. The TSC scores correlate with relevant concepts. The TSC measure quantifies patients' perceived ability for self-care, operationalized in behaviours related to taking medications, recognizing and managing symptoms, carrying out activities of daily living, and managing changes in condition. It can be used to guide and evaluate nursing care.

Keywords: self-care, measure, acute care, content validity, internal consistency reliability, construct validity, conceptualization

Résumé

Élaboration et validation d'un instrument de mesure de la capacité d'autogestion des soins

Souraya Sidani, Diane Irvine Doran

L'autogestion des soins est un résultat de soins infirmiers déterminant pour le rétablissement du patient et la prévention des complications après une hospitalisation. Dans le but d'évaluer la capacité d'autogestion dans un contexte de soins actifs, nous avons élaboré un instrument de mesure appelé Therapeutic Self-Care (TSC). Son contenu est dérivé d'une conceptualisation de l'autogestion fondée sur une vaste synthèse de la recherche sur le sujet. Des experts cliniques ont confirmé la pertinence de ses 13 items et corroboré la validité de son contenu. Une étude a montré que les items ont une cohérence interne et sont représentés par un seul facteur. Les scores corrèlent avec les concepts pertinents. L'instrument quantifie la capacité d'autogestion des soins telle que perçue par le patient, opérationnalisée notamment dans les comportements touchant la prise des médicaments, la reconnaissance des symptômes et leur gestion, l'exécution des activités de la vie quotidienne et la modification de l'état de santé. Il peut servir à guider la prestation des soins infirmiers et à évaluer celle-ci.

Mots clés : autogestion des soins, mesure, soins actifs, validité de contenu, fiabilité de la cohérence interne, validité conceptuelle, conceptualisation

Development and Validation of a Self-Care Ability Measure

Souraya Sidani, Diane Irvine Doran

Introduction

Within the context of current changes in the health-care system, self-care, or self-management, represents an important component and outcome of nursing care (Dodd & Miaskowski, 2000). The emphasis on responsible cost-containment imposes a reduction in the length of hospital stays for patients presenting with acute illnesses or exacerbation of chronic diseases and comorbid chronic conditions. Nurses attending to patients admitted to acute-care units for the management of acute and chronic conditions are in a position to plan, initiate, and implement interventions as well as coordinate services to promote patients' ability to care for themselves at home after discharge. Nurses need to assess patients' perceived self-care ability in order to determine the effectiveness of the interventions they provide to enhance this outcome and the patients' readiness to engage appropriately in self-care activities once discharged home. Whereas self-report instruments are available to assess self-care ability, their content is usually disease-specific; it covers self-care activities that patients with particular conditions such as type 2 diabetes and heart failure are expected to perform. The Therapeutic Self-Care (TSC) measure is a generic measure of self-care ability that can be administered to patients admitted to hospital with a variety of acute medical and surgical conditions. Its development and initial psychometric evaluation are described in this article.

Background

Self-care is viewed as a process underlying the performance of health-related activities. The process involves the recognition of changes in a health condition that require remediation and the selection of and engagement in activities to address these changes (Sidani, 2011). The ultimate goal is to maintain an acceptable level of functioning, thereby preventing illness or complications and promoting health and well-being. The self-care process is initiated by the individual independently or in collaboration with nurses.

Self-care forms an active element of nursing interventions, including self-management education and cognitive-behavioural therapy (e.g., Grady, 2008; Kendall et al., 2007; Sit, Yip, Ko, Gun, & Lee, 2007). The interventions consist of providing persons with information and opportunities to apply strategies and activities aimed at enhancing their capacity to engage meaningfully in health-care decision-making and their ability to follow treatment recommendations. In acute-care inpatient units, nurses assume primary responsibility for patient education. As part of discharge planning, education involves informing patients about their condition and its treatment and instructing them in self-monitoring to identify changes in their condition and symptoms indicative of post-acute complications. Specifically, self-care education focuses on the following: appropriately interpreting the meaning of changes in overall status and in symptoms, carefully assessing the suitability of alternative strategies or activities for managing changes in status and symptoms, selecting and properly carrying out self-care strategies or activities, and engaging in the recommended activities to maintain physical and psychosocial functioning over the post-acute recovery period. Patient education during hospitalization is expected to enhance ability to engage in self-care at home post-discharge. Improvement in self-care ability is critical for the successful management of the presenting acute condition and possible comorbid conditions following discharge. Successful management of acute and comorbid conditions contributes to the prevention of complications, uneventful recovery, and preservation of acceptable levels of functioning; in turn, these benefits reduce the burden of illness on patients, such as increased time off work, and on the health-care system, such as inappropriate health-care utilization (Doran et al., 2006; Kreulen & Braden, 2004; Sidani, 2011).

As an outcome of nursing care and a mediator of recovery from acute conditions or exacerbations of chronic diseases, patients' self-care ability should be systematically assessed within the inpatient context. Assessment of patients' perceptions of their self-care ability, done at discharge, is useful in determining the effectiveness of educational interventions delivered by nurses to promote their capacity to manage the post-acute condition at home. Multiple self-report instruments are available to measure self-care ability and actual performance (Sidani, 2011). Most were developed to assess sets of self-care activities or behaviours that a particular patient population is expected to perform (Vrijhoef, Diederiks, & Spreeuwenberg, 2000). For instance, some instruments assess the extent to which healthy individuals engage in health promotion behaviours, including exercise and healthy eating, such as the Personal Lifestyle Questionnaire by Nicholas (1993). Others operationalize self-care as the performance of usual activities of daily living such as the Inventory of Adult Behavior (Kreulen & Braden, 2004). Several measures focus on self-care activities specific to patients with different diseases. They capture the use of strategies or the implementation of treatment recommendations for the management of chronic conditions such as asthma and chronic pulmonary disease (Rootmensen et al., 2008), diabetes (Toobert, Hampson, & Glasgow, 2000), heart failure (Baker et al., 2005; Riegel, Lee, Dickson, & Carlson, 2009), arthritis (Lorig et al., 1996), and hypertension (Chen, Tsai, & Lee, 2009). These measures are not relevant for assessing the self-care ability of patients admitted for the medical or surgical management of a variety of acute and chronic conditions. The self-care activities that they capture are not expected of patients in the post-acute recovery period. For instance, patients recovering from surgery cannot reasonably be expected to engage in exercise programs following discharge. A generic measure of self-care ability is needed to enable nurses to assess this outcome, prior to discharge, as a means of documenting the effectiveness of nursing care or educational interventions in preparing patients to manage their condition at home.

The TSC measure is a generic measure of self-care ability as perceived by patients admitted for the medical or surgical management of acute conditions. The conceptualization of self-care ability that guided its development is reviewed. The development and content of the measure are described. The results evaluating its content validity, internal consistency reliability, and construct validity are summarized.

Conceptualization of Self-Care Ability

The conceptualization of self-care is derived from the results of a concept analysis (Sidani, 2011) clarifying the distinction between two interrelated concepts: self-care behaviour and self-care ability. Self-care behaviour refers to the actual performance of activities for the purpose of maintaining healthy functioning and treatment recommendations for managing an illness or disease. Self-care ability reflects the capacity to engage in self-care behaviour. It rests on an adequate understanding of the health condition, identification of alterations in functioning, and knowledge of activities that are appropriate in promoting health and in addressing changes in functioning. Self-care ability denotes perceived capabilities for recognizing changes in functioning, assessing the appropriateness of strategies or activities to manage these changes, selecting relevant activities, and performing the selected activities. Accordingly, the operationalization of this concept focuses on perceived ability to engage in self-care activities.

In the context of acute illness or acute exacerbation of chronic conditions treated in acute-care inpatient units, patients are expected to acquire the ability to (1) recognize symptoms or changes in condition, particularly those indicative of complications; (2) identify, select, and implement relevant strategies or activities to successfully and promptly manage the changes; (3) carry out the recommended treatment regimen; and (4) resume usual activities. Four categories of factors have been hypothesized to influence self-care ability. The first is cognitive factors such as cognitive function and knowledge of the illness condition, its treatment, and self-care strategies (e.g., Zambrowski, 2008). The second comprises psychosocial factors, of which perceived self-efficacy and social support are consistently reported to be associated with self-care (e.g., Jenerette & Murdaugh, 2008). The third entails physical factors, primarily movement or disability levels (e.g., Zambrowski, 2008). The fourth is demographic factors, notably age and gender (e.g., Rodeman, Conn, & Rose, 1995). Perceived self-care ability facilitates engagement in self-care behaviours. Performance of these behaviours contributes to the prevention of complications and the promotion of uneventful recovery, and subsequently maintenance of physical and psychosocial functioning (Kimberly, 1997; Leveille et al., 1998).

Development of the Therapeutic Self-Care Measure

The conceptualization and operationalization of perceived self-care ability presented above guided development of the TSC measure. Development of the measure proceeded according to four steps, reflecting the deductive approach to item generation.

The first step consisted of delineating the target population and the context in which self-care is assessed. The focus was adults admitted to hospital for the surgical or medical management of acute conditions or exacerbations of chronic diseases.

The second step involved identifying the aspects of self-care and specific activities that are relevant to the target population and are to be captured. Pertinent information was obtained from empirical and experiential evidence. Adults admitted for the surgical or medical management of an acute condition are expected to have the ability to manage the symptoms and changes in condition associated with their illness and its treatment, to recognize and prevent complications, and to maintain or improve physical and psychosocial functioning (Jenerette & Murdaugh, 2008; Kreulen & Braden, 2004). Nursing care is directed at assisting hospitalized patients to acquire the knowledge needed to improve their ability to engage in relevant self-care activities in the post-discharge period. Activities relevant to this period include implementing the treatment recommendations, monitoring and recognizing symptoms and changes in condition, managing these symptoms and changes, and carrying out usual activities of daily living (Barroso, 1995; Jaarsma et al., 2000). The TSC measure was designed to assess patients' perceived ability to engage in self-care at home post-discharge. Hospitalized patients often do not have an opportunity to perform self-care behaviours to their full extent; however, they should acquire the ability to do so once they are on their own, at home. High levels of self-care ability translate into appropriate performance of self-care activities (Orem, 2001). Consistent with the identified self-care activities relevant to the post-discharge period, the TSC measure captures the categories applicable to different acute conditions, as follows: taking medications as prescribed, recognizing and managing symptoms, carrying out activities of daily living, and man-

Table 1 ***Results of Item Analysis***

Category / Item	***Mean***	***SD***	**Item-Total *r***	**Factor Loading**
Taking medications				
Knowing medications to take	4.5	1.2	.49	.56
Understanding purpose of medications	4.6	1.1	.58	.68
Taking medications as recommended	4.9	0.9	.59	.63
Recognizing and managing symptoms				
Recognizing symptoms	4.5	1.0	.51	.56
Understanding reasons for symptoms	4.4	1.1	.60	.65
Knowing how to manage symptoms	4.1	1.3	.68	.72
Carrying out treatment recommendations to manage symptoms	4.1	1.3	.70	.75
Carrying out treatment recommendations to avoid symptoms	4.1	1.3	.67	.74
Carrying out activities of daily living				
Getting help, as needed, to carry out activities of daily living	4.7	1.0	.50	.56
Performing activities of daily living	3.5	1.5	.47	.52
Taking care of self	3.9	1.4	.57	.61
Managing changes in condition				
Getting help in case of emergency	4.8	0.9	.51	.57
Adjusting activities of daily living in relation to symptoms	4.1	1.3	.61	.64

aging changes in condition. The specific activities within each category are presented in Table 1.

The third step was generating items to assess the 13 specific activities. The item statement illustrated knowledge about or ability to engage in relevant behaviours. The language was simplified and lay words were used to clarify the meaning of some terms. The activities were described in general terms to make them relevant and applicable to patients with different conditions. For instance, *knowing how to control symptoms* was stated as "I know what to do to control changes in my body (symptoms)" and *taking medications* was stated as "I am able to take the medications as prescribed."

The last step in developing the TSC measure was selecting the dimension to be assessed and the respective response options. To be consistent with the operationalization of self-care ability, the dimension measured by the TSC is level of self-care ability as perceived by patients.

A numeric rating scale was used, anchored with *not at all* (0) and *very much so* (6). High scores indicated high levels of self-care ability.

Content Validity

An adapted group cognitive interview technique (Oremus, Cosby, & Wolfson, 2005) was used to examine the relevance of the self-care activities captured by the TSC measure in the context of acute-care inpatient settings and to validate their applicability to patients admitted for the management of different conditions. The group sessions were conducted with staff nurses employed in general medical and surgical inpatient units. Nurses are in a position to judge the relevance of the self-care activities captured by the TSC measure to different inpatient populations (Schilling et al., 2007). They plan and implement interventions to enhance self-care ability and can use the measure to assess self-care ability of patients assigned to their care.

Research Methods

Five group sessions were held with nurses working in university-affiliated and community hospitals. Each session was attended by three to six nurses, for a total of 35. The small number of nurses in each session promoted meaningful participation of individual nurses and group agreement on the relevance and applicability of the self-care activities (Krueger & Casey, 2009). The sessions were semi-structured. After describing the task at hand, the moderator read an item of the TSC measure and requested participants to reiterate, in their own words, the content (i.e., specific self-care activity) conveyed. This step is a means for exploring comprehension of the item. The moderator then engaged the nurses in a discussion of the activity's relevance in capturing patients' self-care ability at discharge and its applicability to a variety of inpatient populations.

The study protocol was approved by the university's Research Ethics Board. With participants' consent, the group sessions were audiorecorded and transcribed verbatim. The transcripts were content analyzed to determine nurses' qualitative judgement of the items' relevance in reflecting self-care ability related to activities in which patients with various acute conditions are expected to engage at home post-discharge. The content analysis was done first at the level of each group session and then across all sessions.

Results

In general, nurses found the three activities operationalizing the self-care category of *taking medications* as prescribed to be relevant and applicable to patients receiving surgical or medical treatment for different acute conditions and exacerbations of chronic conditions. They agreed that the items' content is clear, simple, and easy to understand. Nurses indicated that the five activities pertaining to *recognition and management of symptoms* are relevant and applicable. The items' content was judged as comprehensible; however, they suggested use of the word "manage" instead of "control" with respect to symptoms. Nurses considered the three activities representing the self-care category of *carrying out activities of daily living* to be relevant and applicable. Finally, they agreed that the two activities reflecting the category of *managing changes in condition* to be relevant and applicable and the respective items easy to understand.

Overall, the results of the cognitive group sessions indicate that nurses were in agreement about the relevance of the activities in assessing the self-care ability of patients at discharge from hospital. The findings validated the content of the 13 items forming the TSC measure. Based on nurses' feedback, the word "control" was changed to "manage" in the respective items. The revised 13-item scale was subjected to psychometric testing.

Psychometric Evaluation

The initial psychometric evaluation of the TSC measure focused on examination of its internal consistency reliability, factorial structure, and construct validity. The psychometric properties were evaluated in a study of the effects of changes in nursing staff-mix complement (i.e., introduction of registered practical nurses and patient care assistants) and the nursing care delivery model (i.e., introduction of care leader role to coordinate patient care) on nurses and patient outcomes (Irvine Doran, Sidani, Keatings, & Doidge, 2002). Significant associations between the TSC and relevant concepts (i.e., receipt of patient education, physical and psychological factors) were evidence supporting construct validity.

Study Design

A cross-sectional design was used. Eligible patients completed the TSC measure and items assessing related concepts (receipt of patient education, physical and psychological factors) within 24 to 48 hours prior to discharge. This time frame for assessing self-care ability is consistent with its conceptualization and is appropriate to determine whether patients have the capacity to engage in self-management at home post-hospitalization. Staff nurses helped the research assistants to identify eligible patients and to explore patients' interest in the study. The research assistants described the study to interested patients, addressed their questions, obtained their written consent, and made arrangements for data collection prior to the expected day of discharge. The study protocol was approved by the Research Ethics Board at the participating site and the University of Toronto.

Setting and Sample

The study was conducted on medical, surgical, and cardiac inpatient units in a tertiary-care hospital located in a large city. Patients were eligible if they were at least 21 years of age, English-speaking, and cognitively intact (as ascertained by nursing staff), were admitted to a general medical, general surgical, or specialized (e.g., cardiology, oncology, orthopedic) unit, and had a hospital stay of more than 48 hours. A total of 396 patients completed the questionnaire. The sample size exceeded the 10 cases per item required for internal consistency and factor analysis (Streiner & Norman, 2008).

Variables and Measures

Demographic characteristics (age, sex, marital status, education) were assessed by means of standard questions. Self-care ability was measured using the 13-item TSC measure. Receipt of education was assessed using one item; patients reported whether or not nurses instructed them in how to take care of themselves. Physical factors included functional status and experience of a physical symptom (pain). Functional status was measured using four items adapted from Cassard, Weisman, Gordon, and Wong (1994) and inquiring about their perceived readiness to resume usual activities (e.g., return to work, activities of daily living such as bathing, and visits with family and friends); the items were internally consistent (Cronbach's alpha = .89) in this study. The physical symptom was pain, which was assessed using a one-item numeric rating scale. The psychological factors related to the four states of anxiety, depression, confusion, and anger. They were measured using items developed by Sutherland, Lockwood, and Cunningham (1989).

Analysis

Descriptive statistics were used to describe the patients' demographic profile, responses to the TSC items, and levels for relevant concepts. To test internal consistency reliability, the corrected item-to-total correlation coefficient and the Cronbach's alpha coefficient were computed. Inter-item correlation coefficients were reviewed for redundancy ($r > .85$) among items. Item-to-total correlation coefficients > .30 and alpha coefficient ≥ .70 supported the TSC measure's internal consistency reliability. Factorial structure was examined using exploratory factor analysis. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was ≥ .60, indicating suitability of the data for factor analysis. The principal axis factoring method was used for factor extraction. A factor was accepted if it met the following criteria: (a) eigenvalue > 1.0, (b) percentage of variance in items' responses accounted for by a factor of ≥ 10%, (c) loadings ≥ .30 on a factor and a difference > .20 for loadings on other factors, and (d) interpretability of a factor that is consistent with the conceptualization of self-care underpinning the TSC measure (Streiner & Norman, 2008). Statistically significant correlation coefficients of the hypothesized direction (i.e., positive or negative) provided evidence of construct validity. Pearson's *r* coefficient was used when the variables were continuous and Hη coefficient was used when one variable was dichotomous and the other continuous.

Results

On average, participating patients (*n* = 396) were middle-aged (53.6 ± 16.8). Slightly more than half were women (52.4%) with at least a high-school education (58.8%). Most were married (65.5%). About half of the patients were admitted for surgery (52%) and the remainder for general medical (26%) and cardiac (22%) conditions.

Table 1 presents the results of the TSC item analyses. Patients who completed the TSC items selected the full range of response options, suggesting that the TSC numeric rating scale is acceptable. The mean item scores were relatively high. Upon discharge, patients reported high levels of perceived ability to take medications as prescribed and to recognize and manage symptoms, and slightly lower levels of perceived ability to carry out activities of daily living and to manage changes in condition. There was no evidence of item redundancy, as none of the inter-item correlation coefficients was over .85. These coefficients varied between .08 and .72, with a mean of .38. The 13 items were internally consistent: the item-to-total correlation coefficients were over .30, ranging from .47 to .74; Cronbach's alpha was .89. Results of exploratory factor analysis supported a one-factor model. The factor had an eigenvalue of 5.29 and accounted for 41% of the variance in item responses. The factor loadings varied from .52 to .75.

The findings provide initial evidence of construct validity. A small but statistically non-significant difference in the TSC total scores was observed between the group of patients who reported having received instructions for self-care and the group who did not. The correlation coefficient was .19, implying that those who received education had higher levels of self-care ability. The association between perceived self-care ability and functional status was positive and moderate ($r = .36$; $p < .05$), indicating that patients with high levels of functioning had high levels of self-care ability. Negative relationships were found between self-care ability and the physical symptom of pain ($r = -.23$) and the psychological symptoms of anxiety ($r = -.21$), confusion ($r = -.27$), depression ($r = -.28$), and anger ($r = -.26$; all p's $< .05$). These findings show that experience of the symptoms at high levels of severity is associated with perception of low self-care ability.

Discussion

Whether hospitalized for the medical or surgical treatment of acute and/or chronic conditions, adult patients should have the ability to manage their conditions once discharged home. Appropriate self-care is instrumental in promoting recovery, preventing complications, and avoiding re-admission (Sidani, 2011). Assessment of patients' self-care ability prior to discharge from acute care is important for evaluating their capacity for engaging in activities aimed at managing their condition at home during convalescence. The TSC measure was developed to measure self-care ability as perceived by patients with different acute conditions requiring medical and/or surgical treatment. The results of this study confirm the measure's internal consistency reliability as well as content and construct validity.

The content validity of the TSC measure was maintained throughout the systematic process followed in its development and through a careful review by nurses responsible for delivering interventions targeting self-care and for evaluating the effectiveness of interventions in improving self-care ability. The content of the measure was derived from a comprehensive and clear conceptualization of self-care ability generated from an extensive analysis of the literature. The analysis identified four categories of self-care that are relevant to hospitalized patients: taking medications as prescribed, recognizing and managing symptoms, carrying out activities of daily living, and managing changes in condition. The content of the 13 items captured specific activities representative of these categories and reflected the individuals' perceived ability to perform each activity. Nurses providing care on inpatient medical, surgical, and specialized units confirmed the relevance and applicability of the self-care activities making up the TSC measure to patients hospitalized for a variety of conditions. The suitability of the TSC's items for patients is also inferred from the responses of participating patients. Specifically, participants of different age groups, educational levels (including non-high-school graduates), and health conditions completed the measure. Issues with comprehension of item content were not reported.

The results of internal consistency and factor analyses converged in supporting the accuracy of the items in capturing patients' self-care ability and the unidimensionality of the measure. Accordingly, a total scale score can be computed as the mean of the items' scores to quantify self-care ability. The possible range for the total scale score is 0 to 6, with higher scores (over 3, which is the mid-point of the numeric rating scale) indicating higher levels of self-care ability. However, additional analyses (e.g., confirmatory factor analysis to explore higher-order factor structure) are needed in order to examine the viability of generating scores that would quantify patients' ability to engage in activities within the four self-care categories: taking medications, recognizing and managing symptoms, carrying out activities of daily living, and managing changes in condition. Determining patients' perceived ability to engage in activities within each category would be useful for nurses in identifying self-care areas requiring interventions in preparation for discharge. The findings support the construct validity of the TSC measure. As hypothesized, patients who experienced severe symptoms reported low levels of self-care ability and those with high functional status reported high levels. The observed small magnitude of the correlation coefficients is expected with large sample sizes (Cohen, 1992). The non-significant relationship between provision of education and self-care ability requires further examination. Therefore, future research is needed to examine the association of self-care ability with the delivery of nursing interventions (such as discharge planning) aimed at enhancing overall self-care ability.

Conclusions

The TSC measure is a reliable and valid measure of self-care ability as perceived by patients about to be discharged home from hospital. Its items tap four categories of self-care that patients are expected to engage in at home post-discharge: taking medications as prescribed, recognizing and managing symptoms, carrying out activities of daily living, and managing changes in condition. The measure's content is relevant to patients receiving medical and/or surgical treatment for a variety of acute conditions or for exacerbations of chronic diseases. Therefore, it can be used in research to evaluate the effectiveness of nursing interventions and/or of overall nursing care, as well as day-to-day practice. The TSC measure is currently being used in several acute-care hospitals in Ontario. Staff nurses administer it within 24 hours prior to discharge. They view the assessment done at this time as informative of patients' readiness for discharge.

References

Baker, D. W., Asch, S. M., Keesey, J. W., Brown, J. A., Chan, K. S., Joyce, G. J., & Keeler, E. B. (2005). Differences in education, knowledge, self-management activities, and health outcomes for patients with heart failure cared for under the chronic disease model: The improving chronic illness care evaluation. *Journal of Cardiac Failure, 11*(6), 405–413.

Barroso, J. (1995). Self-care activities of long-term survivors of acquired immunodeficiency syndrome. *Holistic Nursing Practice, 10*(1), 44–53.

Cassard, S. D., Weisman, C. S., Gordon, D. L., & Wong, R. (1994). The impact of unit-based self-management by nurses on patient outcomes. *Health Services Research, 29*(4), 415–433.

Chen, S.-L., Tsai, J. C., & Lee, W.-L. (2009). The impact of illness perception on adherence to therapeutic regimens in Taiwanese patients with hypertension. *Journal of Clinical Nursing, 18*(15), 2234–2244.

Cohen, J. (1992). A power primer. *Psychological Bulletin, 112*(1), 155–159.

Dodd, M. J., & Miaskowski, C. (2000). The Pro-Self Program: A self-care intervention program for patients receiving cancer treatment. *Seminars in Oncology Nursing, 16*(4), 300–308.

Doran, D., Harrison, M. B., Laschinger, H., Hirdes, J., Rukholm, E., Sidani, S., . . . Cranley, L. (2006). Relationship between nursing interventions and outcome achievement in acute care settings. *Research in Nursing and Health, 29*(1), 61–70.

Grady, K. L. (2008). Self-care and quality of life outcomes in heart failure patients. *Journal of Cardiovascular Nursing, 23*(3), 285–292.

Irvine Doran, D., Sidani, S., Keatings, M., & Doidge, D. (2002). An empirical test of the Nursing Role Effectiveness Model. *Journal of Advanced Nursing, 38*(1), 29–39.

Jaarsma, T., Halfens, R., Tan, F., Abu-Saad, H. S., Dracup, K., & Diederiks, J. (2000). Self-care and quality of life in patients with advanced heart failure: The effect of a supportive educational intervention. *Heart and Lung, 29*(5), 319–330.

Jenerette, C. M., & Murdaugh, C. (2008). Testing the Theory of Self-Care Management for sickle cell disease. *Research in Nursing and Health, 31*(4), 355–369.

Kendall, E., Catalano, T., Kuipers, P., Posner, N., Buys, N., & Charker, J. (2007). Recovery following stroke: The role of self-management education. *Social Science and Medicine, 64*(3), 735–746.

Kimberly, O. (1997). Home-taught pediatric asthma program improves outcomes, cuts hospital, physician visits. *Health Care Cost Reengineering Report, 2*(3), 40–43.

Kreulen, G. J., & Braden, C. J. (2004). Model test of the relationship between self-help-promoting nursing interventions and self-care and health status outcomes. *Research in Nursing and Health, 27*(2), 97–109.

Krueger, R. A., & Casey, M. A. (2009). *Focus groups: A practical guide for applied research* (4th ed.). Thousand Oaks, CA: Sage.

Leveille, S. G., Wagner, E. H., Davis, C., Grothaus, L., Wallace, J., LoGerfo, M., . . . Kent, D. (1998). Preventing disability and managing chronic illness in frail older adults: A randomized trial of a community-based partnership with primary care. *Journal of the American Geriatrics Society, 46*(10), 1191–1198.

Lorig, K., Gonzalez, V., Stewart, A., Ritter, P., Laurent, D., & Lynch, J. (1996). *Outcome measures for health education and other health care interventions.* Thousand Oaks, CA: Sage.

Nicholas, P. K. (1993). Hardiness, self-care practices and perceived health status in older adults. *Journal of Advanced Nursing, 18*(7), 1085–1094.

Orem, D. (2001). *Nursing: Concepts of practice* (6th ed.). St. Louis: Mosby.

Oremus, M., Cosby, J. L., & Wolfson, C. (2005). A hybrid qualitative method for pretesting questionnaires: The example of a questionnaire to caregivers of Alzheimer disease patients. *Research in Nursing and Health, 28*(5), 419–430.

Riegel, B., Lee, C. S., Dickson, V. V., & Carlson, B. (2009). An update on the Self-Care of Heart Failure Index. *Journal of Cardiocascular Nursing, 24*(6), 485–499.

Rodeman, B. J., Conn, V. S., & Rose, S. (1995). Myocardial infarction survivors: Social support and self-care behaviors. *Rehabilitation Nursing Research, 4,* 58–63, 71.

Rootmensen, G. N., van Keimpema, A. R. J., Looysen, E. E., van der Shaaf, L., de Haan, R. J., & Jansen, H. M. (2008). The effects of additional care by a pulmonary nurse for asthma and COPD patients at a respiratory outpatient clinic: Results from a double blind, randomized clinical trial. *Patient Education and Counseling, 70*(2), 179–186.

Schilling, L. S., Dixon, J. K, Knafl, K. A., Grey, M., Ives, B., & Lynn, M. R. (2007). Determining content validity of a self-report instrument for adolescents using a heterogeneous expert panel. *Nursing Research, 56*(5), 361–366.

Sidani, S. (2011). Self-care. In D. M. Doran (Ed.), *Nursing outcomes: The state of the science* (2nd ed.) (pp. 79–130). Sudbury, MA: Jones & Bartlett.

Sit, J. W. H., Yip, V. Y. B., Ko, S. K. K., Gun, A. P. C., & Lee, J. S. H. (2007). A quasi-experimental study on a community-based stroke prevention programme for clients with minor stroke. *Journal of Clinical Nursing, 16*(2), 272–281.

Streiner, D. L., & Norman, G. R. (2008). *Health measurement scales: A practical guide to their development and use* (4th ed.). Oxford: Oxford University Press.

Sutherland, H. J., Lockwood, G. A., & Cunningham, A. J. (1989). A simple, rapid method for assessing psychological distress in cancer patients: Evidence of validity for linear analogue scales. *Journal of Psychosocial Oncology,* 7(1/2), 31–43.

Toobert, D. J., Hampson, S. E., & Glasgow, R. E. (2000). The summary of diabetes self-care activities measure: Results from 7 studies and a revised scale. *Diabetes Care, 23*(7), 943–950.

Vrijhoef, H. J. M., Diederiks, J. P. M., & Spreeuwenberg, C. (2000). Effects on quality of care for patients with NIDDM or COPD when the specialized nurse has a central role: A literature review. *Patient Education and Counseling, 41*(3), 243–250.

Zambrowski, C. (2008). Self-care at the end of life in patients with heart failure. *Journal of Cardiovascular Nursing, 23*(3), 266–276.

Souraya Sidani, RN, PhD, is Professor and Canada Research Chair, Daphne Cockwell School of Nursing, Ryerson University, Toronto, Ontario, Canada. Diane Irvine Doran, RN, PhD, is Professor Emerita and Scientific Director, Nursing Health Services Research Unit, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto.

CJNR 2014, Vol. 46 Nº 1, 26–43

Computer Intervention: Illness Self-Management/ Quality of Life of Rural Women

**Clarann Weinert, Shirley Cudney,
Bryan Comstock, Aasthaa Bansal**

The Women To Women project, a computer-based support and educational research intervention, was designed to help rural women better understand and manage their chronic illnesses. Its impact on psychosocial adaptation has been reported elsewhere. This article reports on the effect of a computer intervention on chronic illness self-management skills and quality of life. Using a parallel 2-group study design, the researchers randomized 309 middle-aged rural women with chronic conditions to either a computer-based intervention or a control group. They collected data on self-management of chronic illness and quality of life indicators at baseline and at the end of the intervention. Women in the intervention group reported significantly more self-efficacy in managing their chronic disease than those in the control group and the observed effect was of moderate size. Women in the intervention group also reported statistically significant gains in quality of life; effect sizes were small but consistent. Select chronic illness self-management skills and quality of life can be positively influenced by a well-designed computer intervention.

Keywords: computer-based intervention, chronic illness self-management, rural, women, quality of life

Résumé

L'intervention par ordinateur : l'autogestion de la maladie/la qualité de vie chez les femmes en région rurale

Clarann Weinert, Shirley Cudney,
Bryan Comstock, Aasthaa Bansal

Le projet « Women To Women », une initiative de soutien par ordinateur et de recherche en intervention éducative, a été conçu pour aider les femmes en région rurale à mieux comprendre et gérer les maladies chroniques dont elles souffrent. Son impact sur l'adaptation psychosociale a été rapporté dans une publication antérieure. L'article qui suit fait état de l'effet d'une intervention par ordinateur sur les capacités d'autogestion de maladies chroniques et de la qualité de vie. Menant une étude parallèle auprès de deux groupes, les chercheurs ont randomisé 309 femmes d'âge moyen vivant en région rurale et atteintes de maladies chroniques, les assignant à un groupe bénéficiant d'une intervention par ordinateur ou à un groupe de contrôle. Ils ont recueilli des données sur les indicateurs d'autogestion des maladies chroniques et de la qualité de vie au début et à la fin de l'intervention. Les femmes du groupe ayant eu accès aux interventions ont dit être beaucoup plus efficaces en ce qui a trait à la gestion de leurs maladies chroniques, comparativement à celles du groupe de contrôle, et l'effet observé était d'ampleur modérée. Les femmes du premier groupe ont aussi signalé des gains statistiquement significatifs quant à la qualité de vie; les valeurs des effets observés étaient faibles mais cohérentes. Une intervention par ordinateur bien conçue peut exercer une influence positive sur les habiletés d'autogestion de maladies ciblées et sur la qualité de vie.

Mots clés : intervention par ordinateur, autogestion des maladies chroniques, région rurale, femmes, qualité de vie, adaptation psychosociale

Background

Living life to the fullest is a universal goal of nearly all human beings. However, when faced with chronic illness — that is, a long-lasting health disorder that impacts physical, emotional, intellectual, vocational, social, or spiritual functioning (Mosby, 2009) — individuals may find their sense of self and security, and, ultimately, their quality of life, dramatically challenged. At the same time, they must deal with psychological/physical discomfort, prolonged medical treatment, and increasing interference in the performance of their daily activities (Livneh & Antonak, 1997). Meeting these challenges requires an ability to adapt to the illness-imposed changes, and key to successful adaptation is the ability to self-manage the health condition (Lorig & Holman, 2000).

To manage well, individuals must become experts and take responsibility for their day-to-day care. In response to this expectation, psychoeducational interventions are being designed to promote self-management practices that will facilitate adaptation (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). The goal of education programs for chronic illness self-management is to provide the problem-solving skills people need in order to enhance their quality of life (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997).

It is a particular challenge to design and provide meaningful, useful self-management education programs for women with chronic conditions who live in rural areas. The unique social and environmental characteristics that make up rural daily life require those with chronic conditions to adapt their self-management strategies to the constraints imposed by these characteristics (Hill-Briggs, 2003).

Health-Care Access for Rural Women With Chronic Illness in the United States

There are more than 28 million women over 18 years of age living in rural/frontier America who need access to quality health services, and more than four million of these are identified as having a disability (Bennett, Lopes, Spencer, & van Hecke, 2013). Limited access to quality health care is related to the geographic barriers, distance, lack of transportation, and inadequate funding that are inherent in the broad sociocultural and lifestyle factors that typify rural life (Mulder et al., 2000). Significant health disparities exist between rural and urban women, with poorer health outcomes for rural dwellers (National Center for Health Statistics, 2011). For this population, the difficulties in obtaining quality care are compounded by the long-term nature and accompanying disabilities of their conditions. Finding assistance with learning to self-manage their chronic illnesses in a resource-limited environment is an added challenge.

Chronic Illness Self-Management

Chronic illness self-management education has the potential to foster positive perceptions of self, health, and functional ability and to greatly enhance quality of life (WHOQOL Group, 1994). In their classic work, Corbin and Strauss (1988) list the tasks of managing well: medical or behavioural management of the condition; maintaining, changing, and creating new life roles; and learning to deal with the emotional sequelae. Programs that address these self-management tasks have been shown to change behaviours, health status, and health-care utilization (Barlow et al., 2002). Chronic illness self-management strategies should allow individuals to identify problems and could provide techniques to help them make decisions, take appropriate action, and alter their actions as they encounter changes in circumstances or illness (D'Zurilla, 1986).

Quality of Life and Chronic Illness

Chronic illnesses are subject to myriad consequences (Harris & Wallace, 2012). Individuals trying to cope with an ongoing illness may be frightened by symptoms that do not subside, given unfounded hope by remissions, frustrated by the illness's unpredictability, and debilitated by the illness's progression (Helgeson & Reynolds, 2002). All these challenges are assaults on one's quality of life.

There is some agreement that quality of life is a multidimensional concept, encompassing aspects of perceived psychological, social, and physical well-being (Snoek, 2000). Quality of life is defined as individuals' perceptions of their overall well-being within the context of the culture and value systems in which they live, as related to their goals, expectations, standards, and concerns (WHOQOL Group, 1994). Happiness is considered a necessary component of quality of life (Hajiran, 2006). If individuals are assisted, through effective interventions, to self-manage their chronic illnesses well, and consequently adapt effectively, it is likely that their quality of life will be enhanced. One approach to providing such interventions is through the use of health information technologies.

Health Information Technologies

Initially, chronic illness self-management interventions were designed and implemented in specific locations that required in-person contact. In recent years, however, successful outcomes have been demonstrated with computer outreach education programs for the self-management of chronic illness (Lorig, Ritter, Laurent, & Plant, 2008). Such telehealth programs are used primarily with urban residents but can also be of value to those in underserved rural communities. The increased emphasis on chronic disease management, health promotion, and disease prevention presents opportunities for growth and innovation in the delivery of health information technology (HIT) programs that fall in the nursing domain (Effken & Abbott, 2009). Thus, such programs need not be limited to those who live in physical proximity to health centres. In fact, according to the American College of Preventive Medicine (2007), health-care providers have a responsibility to offer convenient, quality programs to those with chronic illnesses who live distant from health centres, to assist them in becoming successful self-managers and achieving the best possible quality of life.

Women To Women Project

History

The vision for nurses to become involved in HIT-based interventions was realized as early as 1995 when rural nurse researchers at Montana State University developed and launched the research-based Women To Women (WTW) computer intervention (Weinert, 2000). Their approach was influenced by the pioneering work of Brennan, Ripich, and Moore (1991) with persons with AIDS and that of Gustafson et al. (1993), who designed a HIT program for women with breast cancer. The research was conducted over a 15-year period in three phases (1995–2000, 2002–05, and 2006–10) to give women the self-management education and support they needed to adapt to living with chronic illness in a rural environment.

Aims and Conceptual Base

The overall aim was to use HIT as an intervention modality to provide health information and mutual support to middle-aged rural women living with chronic illness. In Phase One of the development and implementation, the conceptual focus was *social support*. This was expanded in Phases Two and Three to a more comprehensive *adaptation to illness* model. The major constructs of the Women To Women Conceptual Model for Adaptation to Chronic Illness that ultimately evolved were (a) environmental stimuli, (b) psychosocial response, and (c) illness management (Weinert, Cudney, & Spring, 2008).

> The basic tenets of the model are that people are bombarded with environmental stimuli (such as chronic illnesses) that evoke psychosocial responses which, in turn, can be either a positive or negative influence on their perception of their ability to self-manage their health condition. Based on the literature and the experience of the investigators, the psychosocial adaptation empirical indicators, previously reported, were:

> social support, self-esteem, acceptance of illness, stress, depression, and loneliness. (Weinert, Cudney, Comstock, & Bansal, 2011, p. 84)

The empirical indicators of chronic illness management, reported on in this article, were self-efficacy, forming partnerships, and resource utilization, along with the empirical indicators of quality of life and happiness.

The Study

Purpose

In an earlier article we reported on the impact of the WTW computer-based intervention on the psychosocial response construct of our conceptual model (Weinert et al., 2011). It was found that the intervention significantly affected five of the six psychosocial domains measured. In addition, the conceptual model that guided the study included the construct of illness management, which consisted of two concepts: chronic illness self-management and quality of life. The purpose of this article is to report on the influence of participation in the WTW intervention on the women's perceptions of their self-management abilities and quality of life.

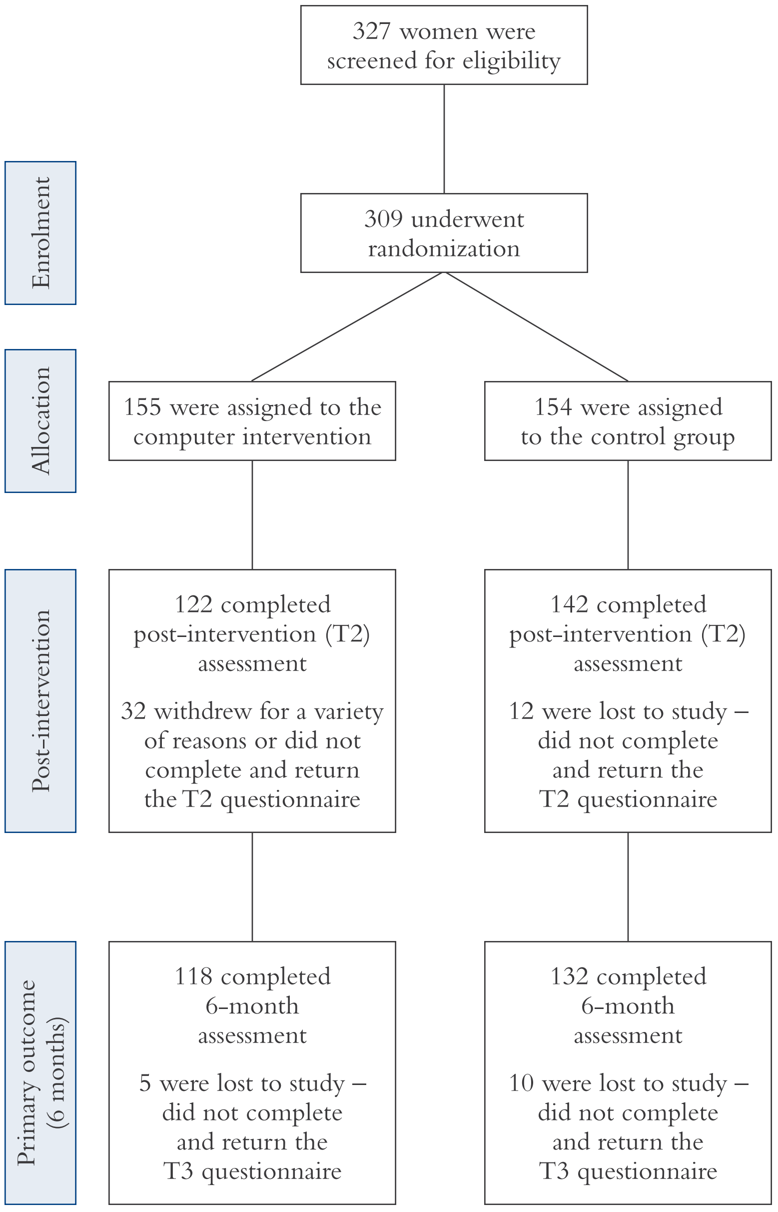
Methods

While the WTW program was carried out in three phases between 1995 and 2010, with minor evolutionary revisions in design over time, this article is based on the data generated in Phase Three. A detailed description of the intervention and protocol has been published elsewhere (Weinert, Cudney, & Winters, 2005; Weinert et al., 2011); therefore, a limited review will be presented here.

Design

From 2006 to 2010 (Phase Three), 309 women were randomized to one of two groups, intervention and control, within eight cohorts of approximately 20 women each (see Figure 1). For 11 weeks, the intervention group had 24-hour computer access, through a WebCT platform, to (a) a peer-led virtual support group (Sharing Circle) where feelings and life experiences were exchanged, support was given and received, issues were discussed related to the self-study health teaching units, and discoveries were shared related to pertinent Internet-based health information; (b) chronic illness self-management teaching units in a self-study format that incorporated the self-management skills proposed by Lorig and Holman (2000) — problem-solving, decision-making, resource utilization, forming partnerships with health-care providers, and taking action; and (c) Internet-based health information.

Figure 1 ***Randomization and Follow-up of WTW Participants***



Source: Weinert et al. (2011).

There were nine online health teaching units. The first addressed the use of Web skills and the remainder were self-management teaching units: keeping a health record; becoming a self-manager; using resources; health-care provider relationships; managing emotions, symptoms, and physical changes; maintaining wellness; managing finances; and relating to others. Each unit was presented within 1 week, with a "break" week midway in the intervention to allow for catch-up and review and a concluding wrap-up week.

The control group's sole task was to complete the mail questionnaires. Incentives for members of both groups who completed all activities associated with the study were $75 and a copy of the book *Living a Healthy Life With Chronic Conditions,* by Lorig and colleagues (2006).

Candidates

Candidates were women aged 35 to 65 with one or more chronic diseases — for example, an arthritic condition, diabetes, multiple sclerosis, cancer — living on ranches/farms or in small towns at least 25 miles from a town/city of 12,500 people or more in Idaho, Iowa, Montana, Nebraska, North Dakota, Oregon, South Dakota, Washington, or Wyoming. Recruitment was conducted through newspapers, newsletters of agencies and service organizations, and word of mouth. Prior to randomization, women were screened via a telephone interview, gave their verbal consent to participate, and completed the baseline questionnaire. Written consent was obtained after randomization. The study was approved by the University Institutional Review Board for the Protection of Human Subjects.

Measures

The task was to determine how the women's participation in the project influenced their perceived ability to self-manage their health condition and, ultimately, their quality of life. Measures that were considered amenable to change by the intervention were selected. These included three indicators related to the middle-range concept of *chronic illness self-management* — self-efficacy, client/health-care provider partnerships, and resource utilization — as well as measures for the concept of *quality of life* (Murphy, Herrman, Hawthorne, Pinzone, & Evert, 2000) and an indicator of quality of life, subjective happiness (Lyubomirsky & Lepper, 1999). A mail survey covering perceptions of illness self-management and quality of life was administered to both groups at baseline, at week 12, and at 6 months (week 24).

Self-Efficacy for Managing Chronic Disease (SEMCD) scale. To determine perceived self-management ability, *self-efficacy for managing chronic disease* was targeted. Self-efficacy is individuals' belief that they are capable of organizing and executing the courses of action required to influence events that affect their lives (Bandura, 1997). People with a strong sense of self-efficacy set challenging goals for themselves and maintain a strong commitment to these goals, thus guiding them to effective performance (Bandura, 1993). In this case, the performance was that of self-managing chronic illness. Self-efficacy was measured using Lorig's SEMCD scale (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). Participants estimated their self-management confidence on six items — for example, "How confident are you that you can do the . . . activities needed to manage your health condition . . . ?" Each item was rated from 1 *(not at all confident)* to 10 *(totally confident),* with a total score calculated as the average of the six items. The study alpha was .89.

Perceived Efficacy in Patient–Physician Interactions (PEPPI) questionnaire. The 10-item PEPPI questionnaire (Maly, Frank, Marshall, DiMatteo, & Reuben, 2003) was developed to measure confidence in ability to effectively communicate information during physician visits. A typical question was "How confident are you in your ability to get doctors to pay attention to what you have to say?" Each item was rated on a scale of 1 *(not at all confident)* to 5 *(very confident),* with the summed total score ranging from 10 to 50. The study alpha was .96.

Brief Chronic Illness Resources Survey (BCIRS). The 29-item BCIRS (Glasgow, Strycker, Toobert, & Eakin, 2000) was developed to examine participants' views of the importance of health-care resources in managing illness. Each item was rated on a scale of 1 *(not at all)* to 5 *(a great deal).* All items were averaged for the score. The study alpha was .86.

Quality of Life (WHOQOL-BREF). The WHOQOL instruments were tested and validated worldwide (Murphy et al., 2000). The WHOQOL-BREF is a 26-item questionnaire abbreviated from its 100-item predecessor. Single items addressing quality of life in the last 2 weeks and satisfaction with health in the last 2 weeks were rated on a five-point scale. The remainder of the scale contains 24 items, each rated on a scale of 1 to 5, with higher scores denoting higher perceived quality of life. The alpha for the total scale was .92. Using items from the overall scale, four subscales are calculated: psychological health (6 items), physical health (7 items), social relationships (3 items), and environment (8 items).

Subjective Happiness Scale (SHS). The SHS is a four-item measure of happiness (Lyubomirsky & Lepper, 1999) — for example, "In general, I consider myself: 1 *(not a very happy person)* to 7 *(a very happy person).*" An overall score is calculated by averaging the responses across the four items. The study alpha was .87.

Statistical Analyses

To examine differences between the intervention and control groups in terms of illness management outcome measures, we fit separate analysis of covariance (ANCOVA) models for each outcome measured at 12 weeks. ANCOVA is an efficient and powerful method for estimating the effect of an intervention in a randomized controlled study where the baseline (pre-intervention) measure of outcome is available (van Belle, Fisher, Heagerty, & Lumley, 2004). In each model, we adjusted for the treatment group as the independent variable of interest, the pre-intervention value of the outcome measure, and any baseline factor or covariate found to significantly differ ($p < 0.05$) between intervention groups using t tests for continuous measures and chi-squared tests for categorical variables. To account for potential correlation of outcome measures among participants in the same cohort, we also adjusted for an indicator of cohort as a fixed effect covariate. To assess the impact of the intervention relative to the control in an unbiased manner, we used an "intent-to-treat" approach, whereby women's scores were analyzed in accordance with the group to which they were assigned, regardless of how closely they adhered to the assigned intervention. In the absence of established minimally clinically important differences on the scales used in this study, effect sizes were evaluated using Cohen's d statistic (Cohen, 1988), where statistics below 0.3 represent small effect sizes, statistics between 0.4 and 0.8 denote moderate effect sizes, and statistics above 0.8 are considered large.

There was a differential proportion of drop-out by group, with women in the intervention group having a greater probability of dropping out than women in the control group. Missing outcome data can bias results if they are not completely independent of the outcome (Little & Rubin, 1987). We conducted sensitivity analyses to assess whether a woman's illness management, quality of life, or other characteristics at baseline had any bearing on whether she followed through with the intervention. We fit separate logistic regression models with all available demographic and illness-management variables as predictors of missing data at 12 weeks, with drop-out status indicator as the outcome. These analyses were repeated for each group separately by including an interaction term between intervention group assignment and the baseline variable. Lastly, we imputed missing 12-week outcome measures using the last-value-carried-forward — for example, baseline measures — and re-ran all primary regression models with the imputed data to assess the impact on intervention effectiveness (van Belle et al., 2004). All statistical analyses were performed using Stata, version 10 (StataCorp, 2007), and R statistical software, version 2.10.1 (R Development Core Team, 2008). Reported p values were two-sided, with statistical significance taken to be p value < 0.05 and no adjustment for multiple testing.

Results

Participant Characteristics

The group was primarily Caucasian (91%) with a mean age of 55.5 years and had dealt with one or more chronic illnesses for an average of 16.5 years. Nearly 77% (76.9%) were married and a similar proportion (77.7%) had no children in the home. Mean years of education was 14.7 and 53% were employed outside the home. The baseline demographics/characteristics are summarized, by study group, in Table 1.

Of the 309 rural women who began the study, 250 (80.9%) completed and provided data at all three time points. By the conclusion of data collection, 37 of 155 women (23.8%) in the intervention group had dropped out and 22 of 154 (14.3%) in the control group had dropped out. Attrition of these 59 participants (19.1%) was attributed to several factors: failure to return a questionnaire (29), increased family responsibilities (9), exacerbation of illness (8), non-participation in the intervention (6), inability to relate well to using the computer (4), irresolvable computer or Internet problems (2), and death (1).

Outcomes

The results for each chronic illness self-management and quality of life outcome measured at 12 weeks are shown in Table 2. In general, the direction and strength of the changes at 12 weeks persisted at the 24-week measurement.

Chronic illness self-management outcomes. Women randomized to the intervention group reported significantly greater self-efficacy (SEMCD) in managing their chronic disease at 12 weeks relative to those in the control group (0.8; 95% CI: 0.5, 1.2; $p < 0.001$). The observed difference between groups was moderately large (Cohen's d: 0.48). However, while the intervention group had higher scores for confidence in communicating with physicians (PEPPI) and the importance of health-care utilization (BCIRS), the differences were small and were not significantly different statistically from those of the control group.

Quality of life outcomes. Women in the intervention group reported statistically significant gains compared to those in the control group in three out of four domains of the WHOQOL-BREF questionnaire. Effect sizes in psychological ($d = 0.30$; $p = 0.003$), social relationship ($d = 0.24$; $p = 0.038$), and environmental ($d = 0.29$; $p = 0.010$) quality of life domains were found to be small but consistent, while the intervention effect size on the physical health quality of life domain was smaller and not statistically significant ($d = 0.19$; $p = 0.089$). Subjective happiness did not change noticeably in either group over 12 weeks, with women reporting 12-week changes of 0.1 (intervention) and 0.0 (control) points out of a possible 1 to 7 scale ($d = 0.17$; p value = 0.073).

Table 1 ***Participant Characteristics***

Characteristic	**Intervention** $N = 155$	**Control** $N = 154$	p **value**
Age, years[a]	56.1 (7.7)	55.0 (9.1)	0.25
Caucasian[b]	144 (93%)	137 (89%)	
Marital Status[b]			
Married, common law, or living together	126 (81%)	118 (77%)	
Divorced or separated	19 (12%)	24 (16%)	
Other	9 (6%)	12 (8%)	
Education, years[a]	14.8 (2.4)	14.5 (2.6)	0.33
Income[b]			
Under $15,000	18 (12%)	25 (16%)	
$15,000 to $34,999	45 (29%)	54 (35%)	
$35,000 to $64,999	59 (38%)	50 (32%)	
Over $65,000	28 (18%)	23 (15%)	
Homemaker[b]	74 (48%)	69 (45%)	
Hours/week worked outside home[a]	29.5 (14.6)	28.0 (16.0)	0.56
Years since onset of symptoms – median (IQR[c])	13 (8, 23)	13.5 (7, 23.75)	0.86
Years since diagnosis – median (IQR[c])	10 (5, 16)	9 (4, 16)	0.36
Primary health condition[b]			
Arthritis	31 (20%)	25 (16%)	
Diabetes	24 (15%)	19 (12%)	
Multiple sclerosis	24 (15%)	26 (17%)	
Fibromyalgia	22 (14%)	22 (14%)	
Lupus	11 (7%)	1 (1%)	
Cancer	6 (2%)	8 (5%)	
Other	37 (24%)	53 (34%)	
Difficulty: vision, hearing, mobility, pain, fatigue, coordination[a]	10.7 (5)	10.3 (5.1)	0.56
Computer skills[a,d]	6.2 (2.0)	5.7 (2.6)	0.03
Computer comfort[a,d]	7.3 (2.4)	6.6 (2.9)	0.02

[a] Presented as mean (*SD*); *p* value obtained from two-sample *t* test
[b] Presented as frequency (%); *p* value obtained from chi-square test
[c] IQR presented as the 25th, 75th percentiles; *p* value obtained from Wilcoxon rank rum test
[d] Rated on a scale of 0 *(no skills)* to 10 *(expert)* or, similarly, for the social relationships subscale (*p* value 0.038), 0 *(not at all comfortable)* to 10 *(very comfortable)*.

Table 2 *Impact of Intervention on Illness Management and Quality of Life Variables at 12 Weeks*

Outcome Measure	Intervention *Mean (SD)*			Control *Mean (SD)*			Intervention Effect[a]	Cohen's *d*	*p* value
	Baseline	12 Weeks	Change at 12 Weeks	Baseline	12 Weeks	Change at 12 Weeks			
Chronic illness self-management									
SEMCD (1–10)	5.6 (2.1)	6.4 (1.7)	0.7 (1.6)	5.5 (2.1)	5.5 (2.0)	-0.1 (1.4)	0.8 (0.5, 1.2)	0.48	< 0.001
PEPPI (10–50)	39.7 (7.4)	40.8 (6.9)	1.0 (5.6)	37.7 (8.7)	38.7 (7.7)	1.2 (6.1)	0.6 (-0.6, 1.9)	0.29	0.305
BCIRS (1–5)	3.0 (0.5)	3.0 (0.5)	0.0 (0.4)	3.0 (0.7)	2.9 (0.6)	-0.1 (0.4)	0.1 (0.0, 0.2)	0.18	0.305
Quality of life									
WHOQOL-BREF (4–20)									
Physical health	12.3 (3.4)	13.0 (2.9)	0.6 (2.5)	12.3 (3.4)	12.4 (3.5)	0.1 (2.2)	0.5 (-0.1, 1.0)	0.19	0.089
Psychological	13.5 (3.3)	14.0 (2.9)	0.4 (2.3)	13.4 (3.2)	13.1 (3.1)	-0.3 (2.2)	0.8 (0.3, 1.3)	0.30	0.003
Social relationships	13.4 (3.9)	14.0 (3.6)	0.5 (3.6)	13.3 (3.8)	13.1 (3.9)	-0.4 (2.7)	0.7 (0.0, 1.4)	0.24	0.038
Environment	14.8 (2.5)	15.2 (2.3)	0.2 (1.8)	14.7 (2.8)	14.5 (2.5)	-0.3 (1.8)	0.5 (0.1, 0.9)	0.29	0.010
SHS (1–7)	5.0 (1.2)	5.1 (1.1)	0.1 (0.8)	4.9 (1.2)	4.9 (1.3)	0.0 (0.8)	0.2 (0.0, 0.4)	0.17	0.073

[a] Estimate (95% confidence interval) from ANCOVA model adjusting for the outcome measured at baseline, baseline level of comfort with the computer, baseline PEPPI, and cohort number. Intervention effects are coded such that a positive value favours the intervention.

Sensitivity Analysis

More women dropped out of the intervention group (p = .024) compared to the control group, potentially impacting the reliability of the intervention effects observed and reported at 12 and 24 weeks. In separate univariate models, all baseline characteristics displayed in Table 1 as predictors of missing data at 12 weeks were assessed, both overall and separately for each treatment group. Divorcees and homemakers were almost twice as likely as the other women to drop out.

To adjust for women with missing data at 12 weeks, each of the models for the illness-management outcome measures was reassessed by imputing missing data using the last known value. For 22 women in the control group and 37 women in the intervention group, the 12-week outcomes were imputed using the outcomes measured at baseline. For five additional women in the intervention group and 10 additional women in the control group, outcome measures collected at baseline were used. Using last-value-carried-forward imputation for women who dropped out of the study, the same outcomes remained statistically significant, with p values < 0.05. However, the intervention effects presented in Table 2 were reduced by approximately 20% to 30%.

Discussion

The question to be answered was whether a HIT-based intervention can positively influence the confidence of rural women in their ability to be effective self-managers in order to adapt to living with chronic conditions. This question was important, because if the women showed a strong sense of self-efficacy in ability to self-manage their illnesses, it could be expected that they would be guided towards effective self-management behaviour (Bandura, 1993). Participants in the intervention were expected to have significantly higher scores on measures of self-efficacy, confidence in communicating with health-care providers, importance of chronic illness resources, and quality of life than those in the control group. The achievement of one of the main aims of the intervention, *to foster perceived ability to self-manage one's chronic illness,* was seen in the statistically significant improvement of self-efficacy in managing their disease. These reported effects were sustained for as long as 24 weeks.

Moderate, though not statistically significant, improvement in confidence in patient/physician interactions and perceived importance of chronic illness resources was demonstrated. The absence of a significant increase in perceived importance of resources was unexpected, since the health teaching activities of the intervention incorporated identification and utilization of health resources. It is also surprising that there was little measureable effect on overall quality of life and subjective happiness.

Because the effect size for only three of the quality of life subscales was deemed significant, one could be led to conclude that the intervention had little impact. However, a closer look may shed some light on this apparent deficiency. The four quality of life subscales were physical health, psychosocial health, social relationships, and environment. Of these, only physical health did not show significant change that could be considered least likely to be impacted by the nature of this intervention. Psychosocial health, a major focus of the intervention, was significant, with a $p = .003$, and the effect sizes were also significant for the social relationships subscale ($p = .038$) and the environment subscale ($p = .010$). Given the support component of the intervention, the impact on psychosocial health and social relationships is a logical conclusion. However, it is not as easy to understand the positive impact of the intervention on the environment subscale.

The sensitivity analysis revealed that women who were married and women who worked outside the home tended to stay with the study. Divorced women and stay-at-home homemakers were twice as likely to drop out, a phenomenon that is discussed in detail in a related article (Weinert et al., 2011).

As with any study, these results are subject to limitations. The theoretical model that evolved from and guided our research is new and not fully tested. A second consideration that may bias the findings is the rate of missing data, specifically the fact that there were more missing data for the intervention group than for the control group. Furthermore, sensitivity analyses demonstrated that women with certain characteristics had a greater likelihood of dropping out. These women may have had more severe illnesses or barriers to participating in the intervention. These limitations, and the fact that the sample was age-bound and included only rural woman from a particular part of the country, place restrictions on the generalizability of our findings.

Conclusion

The pioneering work of Lorig and colleagues (Lorig & Holman, 2000; Lorig et al., 2001, 2008) in the field of self-management interventions was designed to assist primarily urban populations in self-managing their conditions. We sought to determine whether a similar computer-based intervention could positively influence the illness management of *rural* women with chronic illnesses. Given their impressive improvement in self-efficacy in illness management and their modestly increased confidence in patient/physician interactions and social relationships, there is evidence that our intervention can enhance the abilities of rural dwellers to manage chronic illness.

As part of an examination of the impact of the WTW computer-based intervention on rural women's adaptation to chronic illness, a discussion of the constructs of adaptation within the framework of the Women To Women Conceptual Model for Adaptation to Chronic Illness has been ongoing. In a previous report, we described the success of the WTW computer-based intervention on the indicators of the construct of psychosocial response (Weinert et al., 2011). In this article, we have expanded the discussion to include the impact of the intervention on perceived ability to self-manage chronic illness and quality of life. The WTW intervention has been demonstrated to have a positive impact on psychosocial adaptation among rural women with chronic illnesses. We have now found evidence of an impact on perceived self-management ability and quality of life, but not as strong as that on psychosocial adaptation. Future research will explore the associations and interrelationships among the WTW constructs as we strive to better understand the parameters of rural women's adaptation to chronic illness.

References

American College of Preventive Medicine. (2007). Patients learn chronic disease self-management online. *Medscape Education.* http://www.medscape.org/viewarticle/558483.

Bandura, A. (1993). Perceived self-efficacy in cognitive development and functioning. *Educational Psychologist, 28*(2), 117–148.

Bandura A. (1997). *Self-efficacy: The exercise of control.* New York: W. H. Freeman.

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: A review. *Patient Education and Counseling, 48*(2), 177–187.

Bennett, K., Lopes, J., Spencer, K., & van Hecke, S. (2013). *Rural women's health.* Policy brief. Leawood, KS: National Rural Health Association. Retrieved March 7, 2014, from http://www.ruralhealthweb.org/index.cfm%3Fobjectid%3DF5A503E1-3048-651A-FE066957562D3AC7.

Brennan, P., Ripich, S., & Moore, S. (1991). The use of home-based computers to support persons living with AIDS/ARC. *Journal of Community Health Nursing, 8*(1), 3–14.

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum.

Corbin, J., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home.* San Francisco: Jossey-Bass.

D'Zurilla, T. (1986). *Problem-solving therapy: A social competence approach to clinical intervention.* New York: Springer.

Effken, J., & Abbot, P. (2009). Health IT-enabled care for underserved rural populations: The role of nursing. *American Medical Informatics Association, 16*(4), 439–445.

Glasgow, R., Strycker, L., Toobert, D., & Eakin, E. (2000). A social-ecologic approach to assessing support for disease self-management: The Chronic Illness Resources Survey. *Journal of Behavioral Medicine, 23*(6), 559–583.

Gustafson, D., Wise, M., McTavish, F., Taylor, J., Wolberg, W., Stewart, J., . . . Bosworth, K. (1993). Development and pilot evaluation of a computer-based support system for women with breast cancer. *Journal of Psychosocial Oncology, 11*(4), 69–92.

Hajiran, H. (2006). Toward a quality of life theory: Net domestic product of happiness. *Social Indicators Research, 75,* 31–43.

Harris, J., & Wallace, R. (2012). The Institute of Medicine's new report on Living Well With Chronic Illness. *Preventing Chronic Disease, 9,* 20126.

Helgeson, V., & Reynolds, K. (2002). Social psychological aspects of chronic illness. In A. J. Christensen & M. H. Antoni (Eds.), *Chronic physical disorders: Behavioral medicine's perspective* (pp. 25–46). Oxford: Blackwell.

Hill-Briggs, F. (2003). Problem solving in diabetes self-management: A model of chronic illness self-management behavior. *Annals of Behavioral Medicine, 25*(3), 182–193.

Little, R., & Rubin, D. (1987) *Statistical analysis with missing data.* New York: John Wiley.

Livneh, H., & Antonak, R. (1997). *Psychosocial adaptation to chronic illness and disability*. Gaithersburg, MD: Aspen.

Lorig, K., & Holman, H. (2000). *Self-management education: Context, definition, and outcomes and mechanisms*. Palo Alto, CA: Stanford University.

Lorig, K., Holman, H., Sobel, D., Laurent, D., Gonzalez, V., & Minor, M. (2006). *Living a healthy life with chronic conditions* (3rd ed.). Boulder, CO: Bull.

Lorig, K., Ritter, P., Laurent, D., & Plant, K. (2008). The Internet-Based Arthritis Self-Management Program: A one-year randomized trial for patients with arthritis or fibromyalgia. *Arthritis and Rheumatism, 59*(7), 1009–1017.

Lorig, K., Sobel, D., Ritter, P., Laurent, D., & Hobbs, M. (2001). Effect of a self-management program on patients with chronic disease. *Effective Clinical Practice, 4*(6), 256–262.

Lyubomirsky, S., & Lepper, H. (1999). A measure of subjective happiness: Preliminary reliability and construct validation. *Social Indicators Research, 46*(2), 137–155.

Maly, R., Frank, J., Marshall, G., DiMatteo, M., & Reuben, D. (2003). Perceived Efficacy in Patient-Physician Interactions Questionnaire. In B. Redman (Ed.), *Measurement tools in patient education* (2nd ed.) (pp. 53–55). New York: Springer.

Mosby. (2009). *Mosby's medical dictionary* (8th ed.). St. Louis: Author.

Mulder, P. L., Shellenberger, S., Streiegel, R., Jumper-Thurman, P., Danda, C., Kenkel, M. B., . . . Hager, A. (2000). *The behavioral health care needs of rural women.* Rural Women's Work Group of the Rural Task Force of the American Psychological Association and the American Psychological Association's Committee on Rural Health. http://www.apa.org/pubs/info/reports/rural-women.pdf.

Murphy, B., Herrman, H., Hawthorne, G., Pinzone, T., & Evert, H. (2000). *Australian WHOQOL instruments: User's manual and interpretation guide.* Melbourne: Australian WHOQOL Field Study Centre.

National Center for Health Statistics. (2012). *Health, United States, 2011, with special feature on socioeconomic status and health.* Hyattsville, MD: Author. Retrieved October 25, 2013, from http://www.cdc.gov/nchs/data/hus/hus11.pdf.

National Rural Health Association. (2005). *Rural/frontier women's access to health services*. Kansas City: Author. http://www.ruralhealthweb.org/go/rural-health-topics/women-s-health.

R Development Core Team. (2008). *R: A language and environment for statistical computing.* R Foundation for Statistical Computing. Retrieved March 7, 2014, from http://www.R-project.org.

Rural Assistance Center. (2010). *Rural health disparities*. Grand Forks, ND: Author. http://www.raconline.org/info_guides/disparities/.

Snoek F. (2000). Quality of life: A closer look at measuring patients' well-being. *Diabetes Spectrum, 13*(1), 24.

StataCorp. (2007). *Stata statistical software: Release 10*. College Station, TX: Author.

van Belle, G., Fisher, L., Heagerty, P., & Lumley T. (2004). *Biostatistics: A methodology for the health sciences* (2nd ed.). Hoboken, NJ: Wiley-Interscience.

Von Korff, M., Gruman, J., Schaefer, J., Curry, S., & Wagner, E. (1997). Collaborative management of chronic illness. *Annals of Internal Medicine, 127*(12), 1097–1102.

Weinert, C. (2000). Social support in cyberspace for women with chronic illness. *Rehabilitation Nursing, 25*(4), 129–135.

Weinert, C., Cudney, S., Comstock, B., & Bansal, A. (2011). Impact of a computer intervention on the psychosocial adaptation of rural women with chronic conditions. *Nursing Research, 60*(2), 81–91.

Weinert, C., Cudney, S., & Spring, A. (2008). Evolution of a conceptual model for adaptation to chronic illness. *Journal of Nursing Scholarship, 45*(4), 364–372.

Weinert, C., Cudney, S., & Winters, C. (2005). Social support in cyberspace: The next generation. *CIN: Computers, Informatics, Nursing, 23*(1), 7–15.

WHOQOL Group. (1994). Development of the WHOQOL: Rationale and current status. *International Journal of Mental Health, 23*(3), 24–56.

Clarann Weinert, SC, RN, PhD, FAAN, is Professor Emerita and Research Scientist, College of Nursing, Montana State University, Bozeman, United States. Shirley Cudney, RN, MA, is Research Assistant (now retired), College of Nursing, Montana State University. Bryan Comstock, MS, is Biostatistician, Center for Biomedical Statistics, University of Washington, Seattle, United States. Aasthaa Bansal, is a doctoral student at the Center for Biomedical Statistics, University of Washington.

CJNR 2014, Vol. 46 Nº 1, 44–65

Electronic Record Adoption and Use Among Nurse Practitioners in British Columbia

Elizabeth Borycki, Esther Sangster-Gormley, Rita Schreiber, Mindy Swamy, April Feddema, Janessa Griffith

There has been a research focus on physician adoption of electronic medical records (EMRs). However, there has been less research into nurse practitioner (NP) use of EMRs. The authors present findings on the adoption and use of EMRs by NPs arising from a survey of the patterns of NP practices in the Canadian province of British Columbia. The research reveals a high rate of NP adoption of EMRs, with 82% of respondents indicating that they were using the technology. However, only 19% of NPs were using fully electronic records while 63% were using hybrid records, with only components of the electronic record being available. Respondents were found to be using several EMR features and functions, namely patient demographics, clinical notes, medication lists, laboratory results, and patient problems. NPs' high rate of EMR adoption suggests that there is much to be learned regarding the effect of eHealth strategies on EMR adoption.

Keywords: electronic medical record, electronic patient record, electronic health record, adoption, nurse practitioner, hybrid electronic–paper records

Résumé

L'adoption et l'utilisation d'un système électronique de tenue de dossiers chez les infirmières praticiennes en Colombie-Britannique

Elizabeth Borycki, Esther Sangster-Gormley, Rita Schreiber, Mindy Swamy, April Feddema, Janessa Griffith

L'adoption par les médecins de la tenue de dossiers médicaux électroniques (DME) a fait l'objet de nombreuses recherches. Toutefois, les recherches portant sur l'utilisation de DME par les infirmières praticiennes (IP) se font beaucoup plus rares. Les auteures présentent les résultats d'une étude portant sur les tendances relevées chez les IP œuvrant dans la province canadienne de la Colombie-Britannique, relativement à l'adoption et l'utilisation de DME. L'étude révèle un taux élevé d'IP travaillant avec des DME, 82 % d'entre elles indiquant qu'elles utilisent maintenant cette technologie. Cependant, seulement 19 % d'IP travaillent avec des dossiers entièrement informatisés alors que 63 % utilisent des dossiers hybrides, la partie électronique du dossier ne comportant que certains éléments. Les personnes qui ont répondu utilisent plusieurs fonctions électroniques, notamment celles permettant la gestion des données démographiques du patient, des notes cliniques, des listes de médicaments et des résultats de laboratoire ainsi que des données sur les troubles du patient. Le taux élevé d'adoption de cette technologie chez les IP suggère la nécessité d'étudier davantage les effets des stratégies de cybersanté sur l'utilisation de DME.

Mots clés : dossier médical électronique (DME), adoption, infirmière praticienne, dossier hybride, stratégie de cybersanté

Introduction

Worldwide, electronic medical records (EMRs) are being implemented in an effort to modernize health-care delivery. EMRs allow clinicians, at the individual or clinic level, to enter and access patient data electronically and also allow for integration of decision support and regionally stored health data (Hodge, 2011). Globally, there has been significant interest in understanding the factors that promote physician adoption of EMRs as well as in documenting the rate of adoption within health care. International reports of physician adoption of EMRs have provided benchmarks and insights as to the types of eHealth and public policy strategies that can be employed by national and regional governments to increase the rate of uptake and use of this technology (Jha et al., 2009; National Physician Survey, 2010). Less attention has been given to EMR adoption rates among other health professionals — for example, nurse practitioners (NPs).

NPs are an important group of health professionals working in primary care settings. They sometimes work with physicians, and they provide health care to families and chronically ill individuals. In Canada, NPs are defined as RNs with additional education and experience "who possess and demonstrate the competencies to autonomously diagnose, order, and interpret diagnostic tests, prescribe pharmaceuticals, and perform specific procedures within their legislated scope of practice" (Canadian Nurse Practitioner Initiative, 2006, p. 26). There is very little literature on the rate of adoption and use of EMRs among NPs either in Canada or internationally. Yet in North America there are more than 170,000 NPs providing care in over 600 million patient visits per year (American Association of Nurse Practitioners, 2013). NPs would benefit from the decision support and population health management features and functions embedded within an EMR as well as the ability of EMRs to connect to electronic health record (EHR) information stored locally or regionally (i.e., EMR interoperability with a national EHR) (Canada Health Infoway, 2011).

In this article we report on NPs' adoption and use of electronic records in the province of British Columbia. To date, little research has been reported on NP adoption and use of EMRs. This study represents a new contribution to the Canadian and international literature, as it attempts to determine the extent to which NPs use electronic records in the region where they practise. Such research will inform policy-makers in those countries where NPs represent a significant portion of the health-care workforce (e.g., United States) and those Canadian health-care regions that are introducing the role.

The work reported here is part of a multi-year mixed-method study of NP role integration into the health-care system in British Columbia.[1]

We begin by providing background on British Columbia and the history of NPs as a profession in the province. We follow with a discussion of the current state of research involving nurse and NP adoption of electronic records. Finally, we discuss the implications for future research and policy initiatives involving NP use of EMRs.

Background

At 944,735 square kilometres, British Columbia is Canada's third-largest province — larger than France, Germany, and the Netherlands combined. The majority of the population live in two cities: Vancouver and Victoria. The Okanagan Valley is the most populated inland region (BC Stats, 2011). Health-care delivery takes place across a wide variety of urban, rural, and remote settings, and NPs practise in each setting. To address the unique needs of each setting, health-care delivery and management are divided into five health authorities. Additionally, a Provincial Health Authority manages and delivers province-wide programs such as cancer care (British Columbia Ministry of Health, n.d.) and a new First Nations Health Authority is dedicated to advancing the quality of care delivered to First Nations and Aboriginal people.

History of the Nurse Practitioner Role in British Columbia

In the early 1990s the British Columbia health ministry became interested in implementing the NP role as a cost-effective means to increase access to primary health care (Haines, 1993), and in 2005 legislation enabling the role was enacted. Because the role is new in British Columbia, the number of NPs is relatively small; as of 2013, there were just 226 NPs registered in the province. There are approximately 2,800 NPs in Canada (Canadian Institute for Health Information, 2013). NPs have been hired by health authorities throughout British Columbia over the past 7 years, and they practise in acute, long-term, and primary health care settings. Implementation of the NP role represents a significant shift in the delivery of primary health care, and with it a need to identify those technologies, such as EMRs, that would best support NP practice.

eHealth and Policy Initiatives Involving EMR Adoption

Worldwide, there has been considerable work undertaken by researchers and governments to accelerate EMR adoption and use by physicians. Some countries, such as Australia, Denmark, the Netherlands, New

---

[1] Funded by the Michael Smith Foundation for Health Research.

Zealand, and Sweden, have achieved nearly 100% adoption by physicians (McCarthy, How, Fryer, Radley, & Shoen, 2011). Others, such as Canada and the United States, are still striving to have the majority of physicians adopt the technology (Jha et al., 2009; McCarthy et al., 2011; National Physician Survey, 2010). In an effort to understand the links between eHealth, policy initiatives, and physician adoption and use of EMRs, surveys have been conducted at the country level and cross-country comparisons made using the survey data (Jha et al., 2009; McCarthy et al., 2011; Nohr & Boye, 2008). To illustrate, the Commonwealth Survey's focus on EMR adoption in industrialized nations has led to policy shifts in Canada and the United States in terms of developing eHealth strategies aimed at incentivizing physicians to adopt EMRs and identifying ways to measure EMR use (McCarthy et al., 2011). Some countries, including Canada, have borrowed eHealth strategies from countries that have high rates of EMR adoption, such as Denmark and Sweden. Scandinavian countries have pioneered approaches that encourage physician use of EMRs, such as ensuring that EMRs in physician offices can exchange data across a country-wide secure network. Physicians in these countries have been motivated to use EMRs because of the opportunities they afford for improving the quality and safety of patient care as well as communication between physician offices and acute-care facilities (Nohr & Boye, 2008; Protti, 2008, 2009). Such information has been used to inform Canadian work on the interoperable electronic health record and US work on regional health information exchanges (McCarthy et al., 2010; Protti, 2008, 2009).

In North America, surveys regarding EMR adoption have focused on physician adoption in Canada (National Physician Survey, 2010) and physician and nurse adoption in the United States (DesRoches, Campbell, et al., 2008; DesRoches, Donelan, Buerhaus, & Zhonghe, 2009; McCarthy et al., 2011). In response to the results, the Office of the National Coordinator for Health Information Technology (ONC) (2011) in the United States has developed an eHealth strategy whereby physicians are incentivized to use EMRs over time. In Canada, the National Physician Survey, which has been used to build knowledge about physician-related current and future health-care issues and trends, has seen the inclusion of questions specific to physician adoption and use of EMRs in recent years (National Physician Survey, 2012a); information from the survey has helped to show researchers, policy-makers, and chief information officers how EMRs are adopted by physicians over time as well as to determine strategies for promoting EMR adoption and use. Canada Health Infoway, the organization responsible for the creation of a pan-Canadian EHR and for facilitating adoption of health technologies across the country, has used information from the survey to drive its eHealth strategy (Canada Health Infoway, 2011). Despite the usefulness of this survey, no equivalent survey has been used, in Canada or elsewhere, to examine NPs' adoption and use of the technology.

EMR Strategy in British Columbia

In British Columbia, the Physician Information Technology Office (PITO) was created in 2006 to "co-ordinate, facilitate and support information technology planning and implementation for physicians, including the development and implementation in BC of standardized systems of electronic medical records (EMR)."[2] PITO is funded by the provincial government and Canada Health Infoway. Its steering committee, composed of practising physicians from the BC Medical Association and representatives from the provincial government, reports to the e-Health Steering Committee, which in turn reports to the BC Health Leadership Council (whose membership includes CEOs of the health authorities and senior executives from the health ministry). Most of PITO's programs concern physician adoption of EMRs. PITO funds physicians on a cost-shared basis: government, 70%; physicians, 30%, to purchase EMRs. Four vendors are currently approved by PITO: Intrahealth, MedAccess, Osler Systems, and Wolf (Telus Health Solutions). According to Smith (2011), "around 60% of physicians in private practice offices are using an EMR" (p. 460). In fact, 90% of large, full-service family practice clinics in the province have adopted EMR. Adoption rates are approximately 50% for small to medium-sized family practice clinics (i.e., 2–5 physicians) and between 5% and 10% for solo family physicians (Smith, 2010, p. 289). Recently, PITO extended its work to NPs by providing self-assessment, educational, and tailored practice support opportunities around electronic records. In summary, physicians in large, full-service family practices have the highest adoption rates and solo-practice physicians the lowest. EMR adoption by physicians is an important issue at the national and jurisdictional levels in Canada. For NPs it is also becoming an important issue.

NPs as Stakeholders in EMR Initiatives

Recently, NPs have emerged as important stakeholders and key users of EMRs in clinics, physician offices, and hospital ambulatory-care settings. NPs have been identified by some governments (e.g., British Columbia, Saskatchewan) as health professionals who should receive support in

---

[2] All information in this section concerning the Physician Information Technology Office is taken from the organization's Web site (pito.bc.ca/), retrieved August 8 and 11, 2012.

order to learn about the technology and use it effectively (PITO, 2012). There is little research literature specifically reporting on NPs' adoption and use of EMRs in clinics, physician offices, and hospitals in Canada or internationally. There is even less literature documenting how NPs adopt EMRs and use the technology in their day-to-day practice. Only a few countries (e.g., the United States) have undertaken nationwide studies to determine the rate of EMR adoption among nurses and how nurses are using the technology in their practice. The focus of these studies has been nurses (e.g., DesRoches et al., 2008) and not NPs, who are the predominant users of EMRs.

Much of the nursing research has been conducted in the United States, alongside studies on EMR adoption by physicians (DesRoches et al., 2008; Jha et al., 2009). In addition, research in this area is aimed at determining how nurses use EMRs (in outpatient settings) and electronic patient records (EPRs) (in hospitals). Earlier studies attempted to (a) determine the proportion of registered nurses who use minimally functional electronic records; (b) examine the relationship between nurses' beliefs about quality of/improvement in care and and electronic records; (c) assess the impact of electronic records on time spent on documentation versus patient care (DesRoches et al., 2008); and (d) document the impact of electronic records on hospital costs, staffing levels, patient mortality rates, and development of complications in patients' conditions (Furukawa, Raghu, & Shao, 2011). There has been less research on NP adoption and use of electronic records; the focus of research involving NPs has been how they use electronic records in the context of the "meaningful use" work instituted by the ONC in the United States (Maxson, Jain, Kendall, Mostashari, & Blumenthal, 2010; ONC, 2011). Meaningful use refers to the use of a certified electronic record and its components in the process of patient care in order to improve the "quality, safety, efficiency of health care," "reduce health disparities," engage patients and their families, and "improve care coordination, and population and public health" while at the same time "maintaining the privacy and security of patient health information." For the most part, this work takes the form of anecdotal reports (ONC, 2011).

In Canada, there has been little research, at the national or jurisdictional level, on NP adoption of EMRs. Even less research has been conducted to determine the nature and quality of meaningful EMR use among NPs or the clinical value associated with EMR use. Little is known about the current rate of adoption or how the technology is being used in patient care and practice management. Further, there has been little research on the requirements and needs of NPs who use

EMRs; the focus of nursing informatics survey research in Canada has been the current state of nursing informatics education and competency integration in college and university schools of nursing across the country (see Nagle & Clarke, 2004).

Methods

Participants

NPs in the province of British Columbia who (a) were registered, and (b) had previously consented to be contacted about taking part in research were invited to participate in the Nurse Practitioner Practice Patterns Survey (NPPPS) in the fall of 2011. As the researchers were interested in learning more about the adoption rate and use of EMRs among NPs, they included questions relating to the features and functions of the EMR.

Setting

The survey took place in one Canadian jurisdiction — British Columbia, the third-largest province in Canada.

Survey and Pilot Testing

The NPPPS was used to collect data for this portion of the research. Originally developed by Martin-Misener et al. (2010), the NPPPS has been used in the provinces of Nova Scotia and Ontario to collect data on NP practice. It has been used to collect data on NP characteristics, practice models, practice settings, practice populations, services provided, and barriers to/facilitators of implementing the NP role. Before the tool was used in British Columbia (and with the permission of the author), it was reviewed by three researchers to ensure that the questions were appropriate. For example, modifications were made to collect information on which health authority the NP was employed by, a section was added on reporting of codes and electronic data, and the five most common diagnoses and diseases in British Columbia were added. To investigate EMR adoption and use, questions developed by Jha et al. (2009) were added. The survey was then pilot-tested with two NPs working in the province and found to be appropriate, though long.

EMR Questions

In selecting the EMR questions to be added, the researchers reviewed several survey tools that had been used in North America (see DesRoches, Campbell, et al., 2008; Jha et al., 2009) to assess the level of EMR use among NPs and other health professionals.

Questions used to assess NP adoption and use of EMRs were drawn from a survey developed by Jha et al. in 2009 to determine the level of EMR adoption in hospitals across the United States. The focus of Jha et al.'s (2009) work was determining the degree to which base functionalities of electronic records were used; they developed their survey by "examining and synthesizing prior hospital-based surveys of electronic-records systems or related functionalities (e.g., computerized provider-order entry) that have been administered in the past 5 years" (p. 1629). The researchers shared a draft of the survey with other researchers working in the area, chief information officers, hospital leaders, and survey experts. Lastly, a consensus panel of health informatics, health services research, survey research, and health-policy experts reviewed the survey, leading to further modifications.

The researchers reviewed Jha et al.'s (2009) survey and extracted key questions that would allow for the measurement of NP adoption and use of key functions of the technology and added them to the NPPPS survey. The full survey (NPPPS, including the EMR components) was then pilot-tested with two experienced NPs for clarity, appropriateness, and usability. Permission was obtained from Jha et al. (2009) to use parts of the EMR survey tool that was developed. Ethics approval for the larger study and use of the survey was obtained from the Human Research Ethics Board at the University of Victoria.

Data Collection

Several recruitment methods were used to maximize the response rate for the online survey. Eysenbach (2005) and Jackson (2003) note that several methods of recruitment may be needed to improve online survey response rates.

The full, revised NPPPS was built into Fluid Surveys®, an online application. NPs were invited to complete the online survey in one of three ways, to maximize the response rate. NPs who had indicated their willingness to participate in research were sent a letter from the College of Registered Nurses of BC by post; the letter included a link to the online survey that could be entered as a URL in a Web browser and would direct the participant to the survey Web site. The invitation, including the survey URL, was also posted on the BC Nurse Practitioner Web site, where participants could click on the link to be automatically directed to the online survey. Finally, an e-mail with an invitation to participate and a link to the survey was sent to the University of Victoria NP alumni listserv; NPs wishing to participate were asked to click on the survey link in their e-mail to be connected to the online survey.

Findings

Responses were received from 37 of the 226 NPs registered in British Columbia. Data collected from six of these were excluded from the analyses (three did not complete the survey and three were practising outside the province). The data discussed here are based on responses from 31 NPs, or approximately 14% of NPs practising in the province. According to Eysenbach (2005), the response rate for online surveys ranges from 9% to 98%. Thus, our response rate is consistent with that reported in the literature on online surveys and similar to that reported by the 2011 National Physician Survey (18%), the primary source of data on physician EMR adoption and use in Canada (National Physician Survey, 2012b). Therefore, our response rate is within the expected range. NP demographic data and EMR use data were analyzed using descriptive statistics appropriate for use in analyzing survey data (Backstrom & Hursh-César, 1981).

Demographic Data

The respondents ranged in age from 28 to 60 years (mean = 45). Most were female (*n* = 27; 87%) and all were prepared at the master's level (*n* = 31; 100%), the standard in British Columbia. The mean number of practice years was 19 as an RN and 3.6 as an NP. They were registered as either family NPs (*n* = 27; 87%) or adult/pediatric NPs (*n* = 4; 13%). At the time of survey completion, most respondents (*n* = 21; 68%) held permanent full-time positions, while some (*n* = 6; 19%) held part-time positions.

The majority of respondents were employed by a regional health authority. Most practised in community/primary health care settings, ambulatory clinics, outpatient settings, physician offices, long-term/residential care, or hospital settings (Table 1). Only nine respondents (29%) worked in an inpatient setting and seven of these (*n* = 7; 78%) also worked in an outpatient setting.

NPs were, for the most part, co-located with other members of the health-care team. Most were co-located with physicians (*n* = 27; 87%), registered nurses (*n* = 24; 77%), and/or medical office assistants (*n* = 24; 77%).

EMR Use

Respondents were initially asked to indicate their method of record keeping — that is, whether they were using a full EMR or a hybrid EMR, whereby part of the patient record is electronic and part of it is paper-based (Borycki, Lemieux-Charles, Nagle, & Eysenbach, 2009; Urowitz et al., 2008). A total of 27 NPs responded to this question, of

Table 1 ***Practice Settings***

	***n* = 31**	**%**
Community/primary health care centre	15	48
Ambulatory clinic/outpatient department	9	29
Other (e.g., mental health centre, addictions centre, homeless shelter, hospice)	7	23
Physician office	7	23
Long-term-care/residential-care facility	5	16
Hospital (inpatients)	3	10
Home care	2	6
Aboriginal health centre	2	6
Outpost nursing health centre	1	3
Public health	1	3

Note: Multiple responses were allowed.

whom 19% (*n* = 5) were using paper charts, 63% (*n* = 17) were using hybrid records, and 19% (*n* = 5) were using fully electronic records. In other words, 82% of NPs (*n* = 22) who responded to the question were using either hybrid or full EMRs. These data are consistent with those found in prior North American research suggesting that most health professionals use a hybrid electronic record and that 50% of Canadians have at least one component of an electronic record, the remainder being paper-based (Canada Health Infoway, 2011; DesRoches, Donelan, et al., 2008; Jha et al., 2009).

Our results indicate that NPs are using a wide range of electronic records. Only 22% of respondents (*n* = 6) were using PITO-qualified EMRs. Financial and implementation support is provided for PITO electronic record products used by physicians and NPs in British Columbia. The PITO-qualified EMRs being used were Intrahealth (*n* = 1; 4%), MedAccess (*n* = 1; 4%), Osler Systems (*n* = 2; 7%), and Wolf (*n* = 2; 7%). The remaining NPs were using other electronic products. A few were using EPRs such as Cerner (*n* = 1; 4%) or Meditech (*n* = 2; 7%). The type of electronic record used may have varied by type of organization or care setting (e.g., hospital, community, clinic, physician office). For example, EMRs are used by NPs working in physician offices and EPRs by NPs working in hospital settings.

Of the respondents, 25 (80%) rated their degree of satisfaction with the EMR system used. Of these, 60% (*n* = 15) were either very satisfied or somewhat satisfied. However, 20% (*n* = 5) were very dissatisfied and 16% (*n* = 4) somewhat dissatisfied. Further study is needed to determine the underlying reasons for 36% of NPs being dissatisfied with the EMR system used.

Respondents were asked to identify the features and functions available within their EMR. Not all NPs responded to this question; therefore, the value of *n* changes. The features reported as most available were patient demographics (22/22; 100%), clinical notes (21/23; 91%), electronic lists of patients' medications (19/21; 91%), laboratory results (18/24; 75%), radiology results (16/21; 76%), and patient problem lists (16/20; 80%). A summary of the availability of features and functions is presented in Figure 1.

In addition to identifying the features and functions available within their EMR, respondents were asked if they used these features and functions. They reported using the following features and functions most of the time or some of the time: patient demographics (16/22; 73%), clinical notes (14/21; 67%), electronic lists of patients' medications (13/21; 62%), laboratory results (13/18; 72%), and patient problem lists (13/16; 81%). These results are summarized in Figure 2.

Finally, most NPs rated their electronic records as having a positive impact on the quality and efficiency of their work. In particular, 67% (16/24) felt that they had a positive effect on their communication with other health-care providers and on their timely access to medical records and 54% (13/24) believed that they improved their practice patterns.

Respondents indicated that EMRs improved the consistency of communication between practitioners, legibility of patient information, remote access or access from another health-care site, follow-up and reminders, and ease of refilling prescriptions. Challenges included slow computers, technical failures, lost or difficult-to-access data when hybrid electronic records were used, and missing or suboptimal EMR features that served to hinder NP practice.

Discussion

We have reported on the findings of the NPPPS related to the current state of adoption and use of EMRs by NPs in British Columbia. Over the past several years, there have been significant financial investments and policy changes at the national and jurisdictional levels in Canada aimed at fostering EMR adoption by health professionals, specifically physicians. These initiatives have been undertaken by national organizations such as Canada Health Infoway and local or regional jurisdictional organizations such as PITO and OntarioMD. Much of the investment and policy work has been aimed at helping physicians to select and implement EMRs in

Figure 1 ***Availability of EMR Functions and Features***

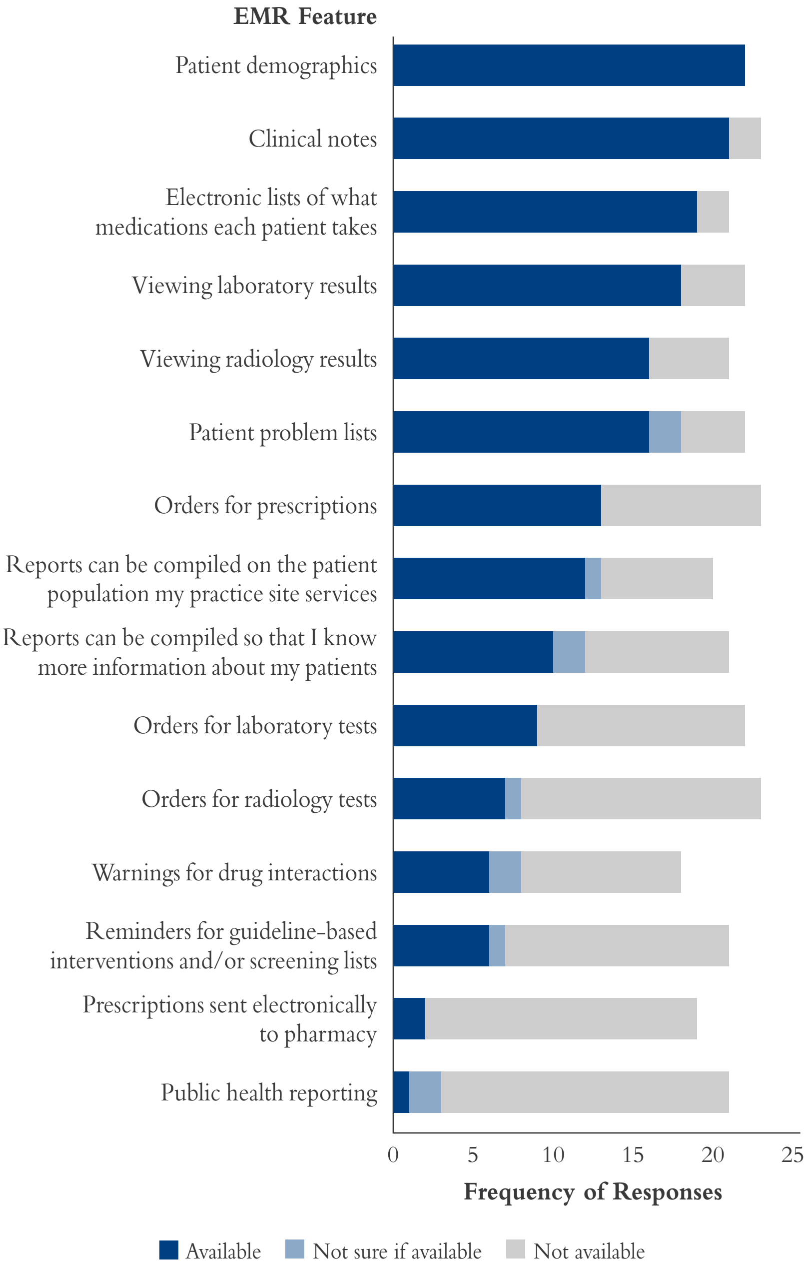
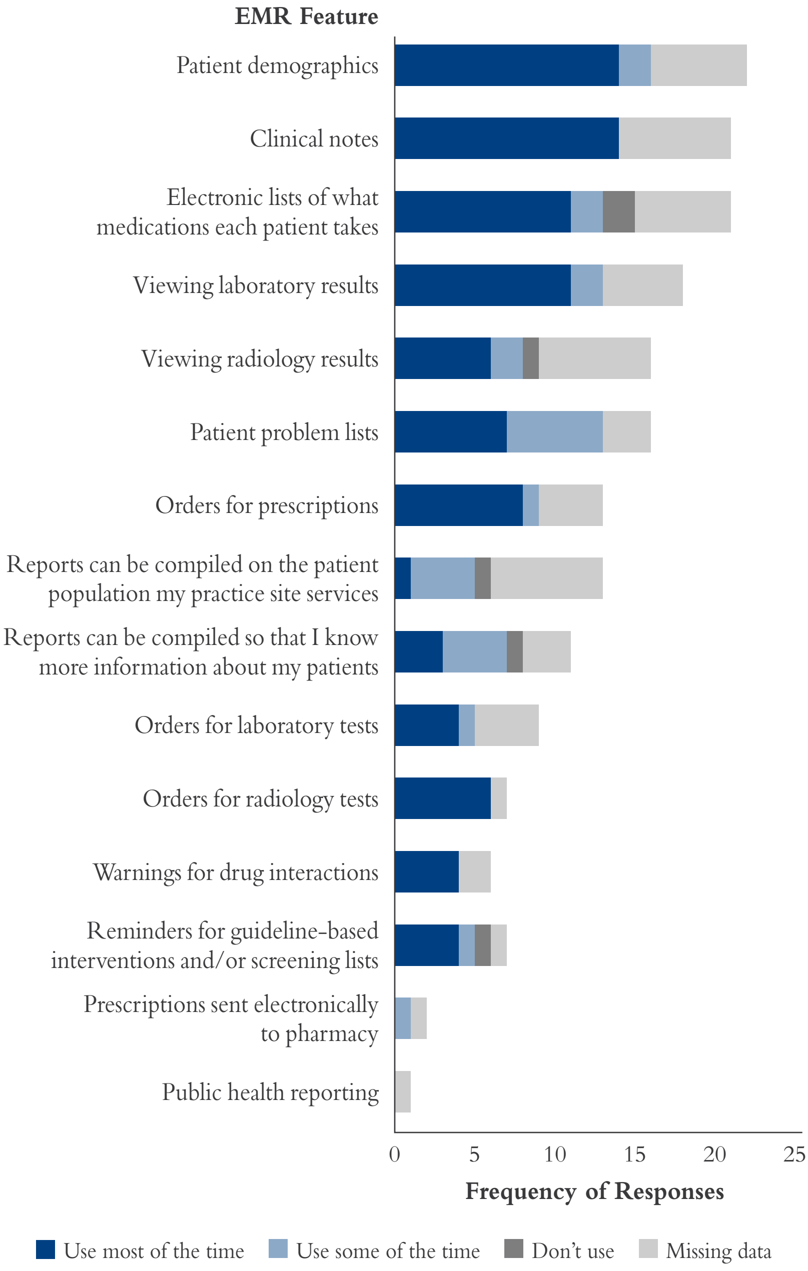


Figure 2 ***Nurse Practitioner Use of Functions and Features***



their office settings in an effort to accelerate physician adoption of EMRs. The expected outcome of this work is improvements in the quality and safety of health care. There have been several publications comparing physician adoption rates across countries (e.g., Canada, Denmark, Germany, United Kingdom, United States) and provinces (e.g., Alberta, British Columbia, Saskatchewan) in terms of progress towards 100% adoption. This work has involved physician surveys with questions added specific to EMR adoption and use (e.g., National Physician Survey in Canada). The surveys conducted allow for comparison of adoption rates and eHealth strategies across countries and jurisdictions; to date, however, the work has focused on physicians.

This study represents the first attempt to examine EMR adoption by NPs and has produced a number of new and interesting findings. NP adoption of electronic records is impressive, with 82% of respondents indicating that they were using the technology: 19% of NPs were using full electronic records and an additional 63% were using hybrid records, with not all components of the electronic record being available. These data are consistent with published reports suggesting that most North American health professionals use some form of hybrid electronic records (Borycki et al., 2009; Urowitz et al., 2008). They are also consistent with the work of DesRoches, Campbell, et al. (2008) involving physicians and nurses; these authors found that 4% of physicians were using full electronic records, 13% were using components of the EMR (part of the electronic record is electronic and part is paper-based), and 83% continued to use paper charts. This finding is consistent with that of a study conducted by DesRoches, Donelan, et al. (2008) focused on nurses. In our study, only 25% of NPs were using full electronic records, relying on both electronic and paper-based sources of information.

NPs appear to be in the very late part of the late majority stage — that is, on the verge of entering the laggard stage of the diffusion of innovation as outlined in Rogers's (1962) theory (see Table 2). According to Rogers's (2003) theory, there would still be some NPs sceptical of the innovation but most average members of the group would have adopted the technology. While NPs are on the very cusp of sinking to the laggard stage, it appears that only a small percentage have not adopted the technology — that is, those who are averse to change (Rogers, 2003). These results differ significantly from those for physician EMR use. The 2010 National Physician Survey found that only 33.6% of physicians in British Columbia used EMRs (National Physician Survey, 2010). In 2009, the data placed physician use in the early majority phase of Rogers's theory, with members of the physician community adopting EMRs only after some time had passed. There may be a number of explanations for this,

Table 2 ***Rogers's Adopter Categories***

Adopter Category	**Description**	**% of Respondents at This Stage**
Innovators	Those who are among the first to adopt an innovation; likely to be younger, take risks, be of a higher social class, and have contact with the innovators.	2.5
Early adopters	Opinion leaders; may adopt an innovation if it helps them to maintain a central position in a communication network.	13.5
Early majority	Those who take longer to adopt an innovation; are slower to adapt; have contact with early adopters.	34
Late majority	Those who adopt an innovation only after an average member of society does so; are often highly sceptical about the innovation; have lower social status.	34
Laggards	Those who are among the last to adopt an innovation; are traditional and averse to change; may also be older.	16

Source: Adapted from Rogers (1962).

including (a) physicians are slow to adopt EMRs, and (b) the organizations where physicians practise are slow to adopt EMRs.

There may be several reasons for the difference in the percentage of NP and MD adopters of EMRs, a difference of approximately 48%. According to Smith, adoption rates among physicians vary according to practice size. In a recent report, Smith (2010) reveals that physicians in British Columbia who work in full-service practices have an EMR adoption rate of 90%, compared to 33% of those in small to medium-sized practices and 5% to 10% of those in solo practices. Our NP respondents worked in many settings, with the majority in primary care, clinic, and ambulatory outpatient settings. These settings often provide a number of services. As employees rather than private practitioners, NPs are unable to make choices about EMR use. It may be that the EMR rate for NPs is high because NPs are more likely to work in organizations that have implemented the EMR. As well, physician EMR adoption rates may have increased since 2009. Ideally, the NP data would be compared to physician EMR adoption data collected in 2012. However, the National Physician Survey was not administered in 2012. More research is needed to understand NPs' use of EMRs and whether working in full-service practice settings is a reason for high adoption rates.

Among our respondents, 60% who used EMRs were somewhat to very satisfied with the technology while 36% were somewhat to very dissatisfied. There could be a number of reasons for the high rate of dissatisfaction. Respondents noted a number of challenges with EMRs, including (a) slow and inconsistent computer or Internet access, (b) time-intensiveness of EMR use, (c) incomplete EMRs, (d) the system dictates clinical practice, and (e) the system lacks features and functions that support NP work activities such as ordering lab tests and producing requisitions. Other factors include poor interface design, inability of the technology to fully support NP practice requirements or practice-based workflows (Kushniruk, Borycki, Kuwata, & Kannry, 2006), lack of a terminology interface that represents all aspects of NP practice, and poor implementation services. This last factor includes lack of customization of the interface design/workflows emerging from the technology, as well as inadequate training (Walker, Bieber, & Richards, 2005). Further research is needed to refine and customize existing EMR terminology, interface designs, workflows imposed by the technology, and implementation services. Researchers may wish to explore the similarities and differences in NP and physician workflows to inform future EMR design and implementation.

Our findings are congruent with those of previous research: several researchers have identified poor electronic record design as a concern. Health professionals are increasingly cognizant of the impact of poor system usability on workflow (Kushniruk et al., 2006) and on practice. In some cases this has resulted in lack of improvement in patient outcomes or to technology-induced errors (Borycki & Kushniruk, 2008; Kushniruk et al., 2006; Kushniruk, Triola, Borycki, Stein, & Kannry, 2005). Furthermore, electronic records that do not support NP workflow can lead to inefficiencies and can impact the quality of care provided (Kushniruk et al., 2006), because many EMRs have been developed for use by physicians rather than by NPs. Less attention has been given to identifying the user requirements, workflow processes, and terminologies employed by NPs. Inadequate attention to NP-specific aspects of work during the requirements-gathering, design, and development phases of EMR design, in conjunction with a greater focus on physician aspects of work to be supported by the technology, may have led some NPs to become dissatisfied with EMRs. We need research to determine whether EMR vendors have incorporated NP-specific terminology, workflow, and practice needs into commercially available EMRs, as the practice patterns of NPs differ from those of physicians and many EMR designs have been modelled on physicians' work. Such information should be posted on public Web sites so that NPs are well informed when procuring, recommending, or selecting EMRs for their practice. This is currently the case for physicians in some Canadian jurisdictions — for example, Ontario. Some provinces, including Ontario, make user ratings of EMR attributes available to the public and encourage physicians to post information about their experiences in implementing and using the technology.

In our study, NPs used differing EMR functions in their day-to-day work. For example, 73% used EMRs most or some of the time to store patient demographic information, 67% used EMRs to record clinical notes, 72% to view laboratory results, 62% to maintain patient medication lists, and 81% to view patient problem lists. In most cases NPs employed the technology to support day-to-day practice activities. Here, participants primarily used the technology to view test results, record information, and enter clinical notes. These basic or minimal EMR functions involve using the EMR as a source of information and as a documentation tool (Jha et al., 2009). Only a limited number of respondents used the EMR as an information reminder, to generate screening lists, and/or to manage large groups of patients at the practice level. Given the high rates of EMR adoption, it is important that policy-makers develop supports for NPs that enable full use of the technology to support their practice. NPs are adept at using the EMR as a source of information and as a documentation tool. The next important step is to provide them with educational opportunities to identify population-based issues in their practice. NPs need to be able to use EMRs to help them identify individuals who have an uncontrolled chronic illness, such as diabetes, or who are at risk for illness, such as those who are not immunized against pertussis. They would then be able to identify at-risk individuals and begin the process of helping them to address their health issues in a proactive manner.

Limitations

Although this work took place in one of the largest health-care jurisdictions in Canada, the study was limited to one region of the country. Research in other Canadian jurisdictions and in other countries is needed, in order to compare policy initiatives and impacts on NP EMR adoption and usage rates. In addition, the effects of setting (e.g., clinic, hospital) and location (e.g., urban vs. rural) on EMR adoption rates and use of EMR features and functions need to be examined. This study included NPs working in multiple roles in inpatient and outpatient settings. Future research could examine differences in inpatient and outpatient settings in terms of EMR use.

The study was limited from a sample-size perspective (*n* = 31), even though all NPs in the jurisdiction were invited to participate (Jackson & Verberg, 2007). Nonetheless, the number of respondents is consistent with that of other surveys attempting to gauge health professionals' use of electronic records, such as the National Physician Survey (2012a). It must be noted that there are a number of possible reasons for the small number of respondents, the main one being the newness of the NP role in British Columbia as compared to other provinces, notably Ontario. Also, the number of NPs practising in British Columbia has been influenced by factors such as the time taken to educate NPs and the time taken for organizations to integrate the new role.

Conclusions

The findings from this research can be applied to other jurisdictions in Canada and to other countries where NPs are currently practising or where governments are about to introduce the NP role. NPs, unlike their physician counterparts, are in the late stages of EMR adoption (Rogers, 2003). There may be a number of reasons for this, including the nature of the settings where NPs work and NPs' co-location with other health professionals in full-service practice settings. It may be that in the large-practice settings where NPs work they are more easily supported by EMR vendors and that the nature of the large-practice setting has a greater need for clear communication and documentation support, for which the EMR is well suited. It may also be a result of NPs' status as employees, whereas most physicians are independent practitioners.

Even so, a significant number of NPs continue to be dissatisfied with their EMRs. There are several possible reasons for this, including cases where the EMRs are designed, developed, and implemented to support physician practice alone, rather than the practices of other health professionals as well, such as NPs. Throughout the health-care literature there is a recognition that physician and NP practices differ. The differences should be echoed in the technology's terminology interfaces, user interfaces, design, and implementation where NPs are concerned. EMR vendors need to begin customizing existing EMR systems and designing systems that support the unique and differing aspects of physician and NP practices. EMRs support specific types of workflow and practice activity; if these workflows and activities are not fully supported, then the efficiencies, productivity levels, and patient outcomes (or clinical value) expected of EMR as a technological support for NP practice will not be achieved (Kushniruk et al., 2006). Lastly, this research represents the first attempt in Canada and internationally to learn more about NPs' use of EMRs. More research is needed to measure this use in other jurisdictions and countries. British Columbia's high rate of EMR adoption by NPs over a short period, since the introduction of the NP role in 2005, suggests that there is much to be learned from this province about the influence of context and EMR eHealth strategies on EMR adoption by NPs.

References

American Association of Nurse Practitioners. (2013). *NP fact sheet.* Austin, TX: Author. Retrieved September 30, 2013, from http://www.aanp.org/all-about-nps/np-fact-sheet.

Backstrom, C. H., & Hursh-César, G. (1981). *Survey research.* New York: John Wiley.

BC Stats. (2011). *Population estimates.* Victoria: Government of British Columbia. Retrieved August 8, 2012, from http://www.bcstats.gov.bc.ca/StatisticsBySubject/Demography/PopulationEstimates.aspx.

Borycki, E. M., & Kushniruk, A. W. (2008). Where do technology-induced errors come from? Towards a model for conceptualizing and diagnosing errors caused by technology. In A. W. Kushniruk & E. M. Borycki (Eds.), *Human, social, and organizational aspects of health information systems* (pp. 148–166). Hershey, PA: IGI Global.

Borycki, E. M., Lemieux-Charles, L., Nagle, L., & Eysenbach, G. (2009). Evaluating the impact of hybrid electronic-paper environments upon novice nurse information seeking. *Methods of Information in Medicine, 48*(2), 137–143.

British Columbia Ministry of Health. (n.d.). *Public health in BC: How is the public health system organized in BC?* Victoria: Author. Retrieved October 7, 2013, from http://www.health.gov.bc.ca/pho/public-health-org-details.html #1010.

Canada Health Infoway. (2011). *Infoway invests $380 million to help physicians and nurse practitioners implement electronic medical record (EMR) systems.* News release. Ottawa: Author.

Canadian Institute for Health Information. (2013). *Regulated nurses: Canadian trends, 2007–2011.* Ottawa: Author. Retrieved September 30, 2013, from https://secure.cihi.ca/free_products/RegulatedNurses2012Summary_EN.pdf.

Canadian Nurse Practitioner Initiative. (2006). *Nurse practitioners: The time is now. A solution for improving access and reducing wait time in Canada. Technical report.* Ottawa: Author. Retrieved August 10, 2013, from http://www.npnow.ca/docs/tech-report/section1/01_Integrated_Report.pdf.

DesRoches, C. M., Campbell, E. G., Rao, S., Donelan, K., Ferris, T. G., Jha, A., . . . Blumenthal, D. (2008). Electronic health records in ambulatory care: A national survey of physicians. *New England Journal of Medicine, 359,* 50–60.

DesRoches, C., Donelan, K., Buerhaus, B., & Zhonghe, L. (2008). Registered nurses' use of electronic health records: Findings from a national survey. *Medscape Journal, 10*(7), 164.

Eysenbach, G. (2005). Using the Internet for surveys and research. In J. G. Anderson & C. E. Aydin (Eds.), *Evaluating the organizational impact of healthcare information systems* (pp. 129–143). New York: Springer.

Furukawa, M. F., Raghu, T. S., & Shao, B. B. (2011). Electronic medical records, nurse staffing, and nurse-sensitive patient outcomes: Evidence from the National Database of Nursing Quality Indicators. *Medical Care Research and Review, 68*(3), 311–331.

Haines, J. (1993). *The nurse practitioner: A discussion paper*. Ottawa: Canadian Nurses Association.

Hodge, T. (2011). EMR, EHR and PHR – Why all the confusion? *Infoway Connects,* April 7. Retrieved August 8, 2011, from http://infowayconnects.infoway-inforoute.ca/blog/electronic-health-records/374-emr-ehr-and-phr-%E2%80%93-why-all-the-confusion/.

Jackson, N. B. (2003). Opinions to spare? Click here. *New York Times,* July 3, p. G1.

Jackson, W., & Verberg, N. (2007). *Methods: Doing social research* (4th. ed.). Toronto: Pearson, Prentice Hall.

Jha, A. K., DesRoches, C. M., Campbell, E. G., Donelan, K., Rao, S.R., Ferris, . . . Blumenthal, D. (2009). Use of electronic health records in US hospitals. *New England Journal of Medicine, 360,* 1628–1638.

Kushniruk, A., Borycki, E., Kuwata, S., & Kannry, J. (2006). Predicting changes in workflow resulting from healthcare information systems. *Healthcare Quarterly, 9,* 114–118.

Kushniruk, A. W., Triola, M., Borycki, E., Stein, B., & Kannry, J. (2005). Technology induced error and usability. *International Journal of Medical Informatics, 74,* 519–526.

Martin-Misener, R., Crawford, T., DiCenso, A., Akhtar-Danesh, N., Donald, F., Bryant-Lukosius, D., & Kaasalainen, S. (2010). *A survey of nurse practitioner practice patterns in primary health care in Nova Scotia.* Halifax: College of Registered Nurses of Nova Scotia and Dalhousie University School of Nursing. Retrieved March 6, 2014, from http://www.crnns.ca/documents/PracticePatternsStudyJan31-2010.pdf.

Maxson, E., Jain, S., Kendall, M., Mostashari, F., & Blumenthal, D. (2010). The Regional Extension Center program: Helping physicians meaningfully use health information technology. *Archives of Internal Medicine, 153*(10), 666–670.

McCarthy, D., How, S. K. H., Fryer, A.-K., Radley, D. C., & Schoen, C. (2011). *Why not the best?* New York: Commonwealth High Commission.

Nagle, L. M., & Clarke, H. F. (2004). Assessing informatics in Canadian schools of nursing. *Studies in Health Technology and Informatics, 107,* 912–915.

National Physician Survey. (2010). *2010 results.* Mississauga, ON: Author. Retrieved August 10, 2012, from http://www.nationalphysiciansurvey.ca/nps/2010_Survey/2010results-e.asp.

National Physician Survey. (2012a). *A national collaboration: Comprehensive and influential.* Mississauga, ON: Author. Retrieved August 10, 2012, from http://www.nationalphysiciansurvey.ca/nps/aboutus/about_us-e.asp.

National Physician Survey. (2012b). *About us.* Mississauga, ON: Author. Retrieved August 8, 2012, from http://www.nationalphysiciansurvey.ca/nps/aboutus/about_us-e.asp.

Nohr, C., & Boye, N. (2008). Towards computer supported clinical activity: A roadmap based on empirical knowledge and some theoretical considerations. In A. W. Kushniruk & E. M. Borycki (Eds.), *Human, social, and organizational aspects of health information systems* (pp. 67–83). Hershey, PA: IGI Global.

Office of the National Coordinator for Health Information Technology. (2011). *Electronic records and meaningful use.* Retrieved August 8, 2012, from http://healthit.hhs.gov/portal/server.pt?open=512&objID=2996&mode=2.

Physician Information Technology Office. (2012). *Update on EMR post-implementation support initiatives.* Retrieved August 11, 2012, from http://www.pito.bc.ca/cms/news/12/08/update-emr-post-implementation-support-initiatives.

Protti, D. (2008). US regional health organizations and the nationwide Health Information Network: Any lessons for Canadians? *Healthcare Quarterly, 11*(2), 96–101.

Protti, D. (2009). Integrated care needs integrated information management and technology. *Healthcare Quarterly, 13,* 24–29.

Rogers, E. (1962). *Diffusion of innovations*. Glencoe, NY: Free Press.

Rogers, E. (2003). *Diffusion of innovations* (5th ed.). New York: Free Press.

Smith, J. (2011). EMR + physician + patient = benefits to both sides. *BC Medical Journal, 53*(90), 460–482.

Smith, K. (2010). GP adoption of electronic medical records. *BC Medical Journal, 52*(6), 288–289.

Urowitz, S., Wiljer, D., Apatu, E., Eysenbach, G., Delenardo, C., Harth, T., . . . Leonard, K. J. (2008). Is Canada ready for patient accessible electronic health records? A national scan. *BMC Medical Informatics and Decision Making, 7,* 8–33.

Walker, J. M., Bieber, E. J., & Richards, F. (2005*). Implementing an electronic health records system.* New York: Springer-Verlag.

Elizabeth Borycki, RN, PhD, is Associate Professor, School of Health Information Science, University of Victoria, British Columbia, Canada. Esther Sangster-Gormley, RN, PhD, is Associate Professor, School of Nursing, University of Victoria. Rita Schreiber, RN, DNS, is Professor, School of Nursing, University of Victoria. Mindy Swamy, RN, MN, is Research Assistant, School of Nursing, University of Victoria. April Feddema, BA, is Research Coordinator, School of Nursing, University of Victoria. Janessa Griffith, MSc, is Research Assistant, School of Health Information Science, University of Victoria.

CJNR 2014, Vol. 46 Nº 1, 66–86

Designing Tailored Messages About Smoking and Breast Cancer: A Focus Group Study With Youth

Joan L. Bottorff, Rebecca Haines-Saah,
John L. Oliffe, Laura L. Struik, Laura J. L. Bissell,
Chris P. Richardson, Carolyn Gotay,
Kenneth C. Johnson, Peter Hutchinson

The purpose of this study was to design an approach to supporting the development of gender- and Aboriginal-specific messages regarding the link between tobacco exposure and breast cancer, drawing on youth perspectives. Focus groups were held with 18 girls (8 First Nations and Métis) and 25 boys (12 First Nations and Métis) to solicit advice in the design of messages. Transcribed data were analyzed for themes. Girls preferred messages that included the use of novel images, a personal story of breast cancer, and ways to avoid second-hand smoke. Boys endorsed messages that were "catchy" but not "cheesy" and had masculine themes. First Nations and Métis participants confirmed the use of Aboriginal symbols in messages as signalling their relevance to youth in their communities. The results can be used as a guide in developing tailored health promotion messages. Challenges in developing gender-appropriate messages for youth are described.

Keywords: gender, youth health, health promotion, tobacco use, second-hand smoke, breast cancer

CJNR 2014, Vol. 46 Nº 1, 66–86

Résumé

La création de messages adaptés sur le tabagisme et le cancer du sein : une étude fondée sur des groupes de discussion auprès des jeunes

**Joan L. Bottorff, Rebecca Haines-Saah,
John L. Oliffe, Laura L. Struik, Laura J. L. Bissell,
Chris P. Richardson, Carolyn Gotay,
Kenneth C. Johnson, Peter Hutchinson**

Notre étude visait à mettre au point une approche propice à la création de messages axés sur le lien entre l'exposition au tabac et le cancer du sein, qui s'adresseraient aux jeunes Autochtones de chaque sexe et s'inspireraient de leurs perspectives. Nous avons tenu des groupes de discussion formés de 18 filles (issues de huit Premières nations et du peuple métis) et de 25 garçons (issus de 12 Premières nations et du peuple métis), dans le but d'obtenir leur avis sur cette question. Les données transcrites ont été analysées pour en dégager les thèmes principaux. Chez les filles, on préfère des messages qui proposent des images originales, une histoire personnelle sur le cancer du sein et des conseils sur les façons d'éviter de s'exposer à la fumée secondaire. Les garçons préfèrent quant à eux des messages « accrocheurs », qui ne sont pas « de mauvais goût » et comportent des thèmes masculins. Tous et toutes ont jugé que le recours à des symboles autochtones dans les messages était pertinent pour les jeunes de leurs communautés. Ces résultats pourront servir de guide en vue de créer des messages ciblés axés sur la promotion de la santé. On explique les difficultés que présente la formulation de messages adaptés en fonction du sexe des jeunes.

Mots clés : sexe, santé des jeunes, promotion de la santé, tabagisme, fumée secondaire, cancer du sein

Background

Tobacco smoke exposure has been reported recently as a modifiable risk factor for premenopausal breast cancer (BC), based on evidence from epidemiological and toxicological studies demonstrating a link between active smoking and long-term regular second-hand smoke (SHS) exposure and premenopausal BC (Collishaw et al., 2009; Dossus et al., 2014; Gantz & Johnson, 2014; Johnson, 2012; Johnson et al., 2011). Given evidence that breast tissue in its growth stage (from the beginning of puberty to the end of the first pregnancy) is especially sensitive to exposure to carcinogens in tobacco smoke (Innes & Byers, 2001; Lash & Aschengrau, 1999; Okasha, McCarron, Gunnell, & Smith, 2003), we need to raise awareness about smoking as a modifiable risk factor for BC among adolescents (Bottorff et al., 2010; Haines et al., 2010). Young women should be aware of the evidence indicating that tobacco smoke is consistent with causality for premenopausal BC. Because young men may expose young women to tobacco smoke, it is important that they also be aware of girls' increased risk for premenopausal BC when exposed to tobacco smoke.

Despite decreases in smoking prevalence in many countries, adolescent girls' and boys' uptake of smoking continues to be a concern. For example, rates of smoking among US youth (grades 9–12) are reported to range from 8.5% to 26.1% across state surveys (Eaton et al., 2010), while in Canada recent data indicate that 13% of boys and 14% of girls aged 15 to 19 smoke tobacco (Health Canada, 2012). Many young women are also exposed to SHS in their homes (Health Canada, 2012). Furthermore, there is evidence that girls who smoke are more likely to be surrounded by more smokers in their social environment than boys who smoke and their romantic partners are also more likely to be smokers (Branstetter, Blosnich, Dino, Nolan, & Horn, 2012).

In Canada, Aboriginal youth have a higher prevalence of smoking and start smoking earlier than the general population (Hutchinson, Richardson, & Bottorff, 2009; Johnson et al., 2004; National Aboriginal Health Organization, 2002/03). High rates of cigarette smoking in Aboriginal communities are also associated with increased levels of exposure to SHS among Aboriginal girls (Elton-Marshall, Leatherdale, & Burkhalter, 2011).

Puberty is marked by physical changes and development of gender identity related to social norms and expectations for women and men (Johnson & Repta, 2012). Periods of heightened awareness and shifting identities have been identified as presenting teachable moments for cancer prevention initiatives (McBride, Emmons, & Lipkus, 2003). Youth may, therefore, be especially receptive to gender-specific messages about the link between tobacco exposure and BC. Although gender differences with respect to smoking initiation and patterns of exposure to tobacco are beginning to be described, few gender-specific approaches for tobacco reduction have been developed (Haines et al., 2010). The value of gender-specific messages for tobacco reduction and prevention is evident in the consistent use of gendered marketing strategies by the tobacco industry (Campaign for Tobacco-Free Kids, 2009; White, Oliffe, & Bottorff, 2013). Reviews of anti-smoking advertising directed towards youth indicate a positive influence, although the findings are not consistent (Wakefield, Flay, Nichter, & Giovino, 2003). Researchers have argued that to improve the effectiveness of tobacco control messages it is critical that audience research be conducted in order to develop messages that are "in tune" with youth (Farrelly, Niederdeppe, & Yarsevich, 2003). Although there is limited evidence related to the use of anti-tobacco messages for Aboriginal groups, we need tobacco control messages that are perceived as socially and culturally relevant for Aboriginal communities (Aboriginal Cancer Care Unit, 2008; Gould, McEwen, Watters, Clough, & van der Zwan, 2013). Involving Aboriginal youth in developing and delivering anti-smoking messages has been recommended (Valentine, Dewar, & Wardman, 2003). The purpose of this study was to draw on the perspectives of youth in developing gender- and Aboriginal-specific messages about the link between tobacco exposure and BC.

Methods

The study employed a qualitative descriptive design as described by Sandelowski (2000) and drew upon the tenets of naturalistic inquiry (Lincoln & Guba, 1985) through the use of focus groups. First Nations and Métis (FNM) and non-Aboriginal boys and girls between the ages of 12 and 17 were recruited through referrals, advertisements, and contact with leaders of community youth groups in a mid-sized city in British Columbia, Canada. Both smokers and non-smokers were eligible for the study. Youth were invited to participate in a focus group discussion on the topic of smoking. Approval was granted by a university ethics board.

Participants

The sample comprised 43 youth (mean = 15.0 years; males = 58%; FNM = 46%). Most participants (98%) were born in Canada. Two non-FNM participants self-identified as Asian and one as Black; the remainder identified as Caucasian. Over one third (34%) of the participants smoked at least once in the previous month. A larger proportion of girls (43%) than boys (32%) reported smoking in the previous month. In comparison to the other groups, FNM girls were twice as likely to state that they had ever smoked a whole cigarette. Over half (60%) of the participants had smokers living in their home. The majority (88%) of FNM girls and half (50%) of non-FNM girls were living with someone who smoked. Having a family member with BC was reported by 10% of non-FMN girls, 63% of FNM girls, 18% of non-FMN boys, and 17% of FNM boys.

Data Collection

Eight semi-structured focus groups were held outside school hours in community locations over a period of 4 months. Two focus groups were held with each of the following groups: FNM girls, non-Aboriginal girls, FNM boys, and non-Aboriginal boys. Two focus groups were held with each subgroup to capture diversity of opinion within each subgroup and to meet target participant numbers.

The objective of the focus groups was to engage youth in discussing the merits and limitations of a variety of sample messages related to smoking and BC and in generating ideas to guide youth-friendly message development and delivery media. The research team developed gender-neutral and gender-specific sample messages as discussion prompts and to explore youth responses to both types of message. Gender-neutral messages included images that could be used with either girls or boys (e.g., iPhone with text messages). Whereas feminine images and colours (e.g., pastel bras) as well as words (e.g., BFF) were used in sample messages for girls, masculine images and colours (e.g., sports images) and words (e.g., MVP) were used for boys. The messages drew on team members' extensive experience with youth, gendered norms (e.g., socially prescribed roles that influence who smokes and how, where, and when), our previous research (Bottorff et al., 2010; Haines et al., 2010), and current evidence regarding tobacco exposure and BC. Building on the findings of previous tobacco research (Lee, Capella, Lerman, & Strasser, 2011), the messages omitted smoking images to avoid inadvertently promoting smoking. Also excluded were fear appeal messages, due to a lack of evidence demonstrating the effectiveness of this approach for youth (Prevention First, 2008). The team was aware that the topic of BC is often depicted using sexualized stereotypes and we debated the use of provocative images to capture boys' attention on this topic and the potential for reinforcing heteronormativity and heterosexism. In the end, the sample images shared with boys included one plain-coloured message with silhouettes (recognizable as female by their long hair and skirts) along with the following text: "Guys love boobs. It's that simple. Cigarette smoke – even second-hand – puts girls at twice the risk of getting early breast cancer. Respect the girls in your life by not exposing them to the harmful effects of SHS. If you smoke, think about reducing and quitting. Do it yourself and for all the girls you know!" While this message reflected gender stereotypes and an assumption of heterosexuality, we reasoned that its inclusion with sample messages containing sporting images might engage boys on the topic of sexualized messages without the use of overtly sexualized images and might prompt suggestions for improving messages directed at boys. We also included a girls' message about a young woman who died of BC (Team Shan Breast Cancer Awareness for Young Women; www.teamshan.ca). Although it was not possible to directly link tobacco exposure to her BC diagnosis, we developed this message in order to extend the range of the discussion. We added recognizable symbols (i.e., medicine wheel, feathers) to the sample messages to gauge their effectiveness in engaging FNM youth. These symbols have been recognized as enhancing health message saliency in Aboriginal communities (Stout & Kipling, 2002). The sample messages developed as focus group prompts are shown in Figure 1.

The focus group discussions were facilitated by members of the research team. Following dual consent (parental and youth), participants completed a brief questionnaire on demographics, smoking history, and family history of BC. At the beginning of each focus group, participants were introduced to evidence linking tobacco exposure with BC through an interactive question-and-answer activity. The sample messages specific to the gender of the group along with gender-neutral messages were displayed as large posters. Participants were asked to write comments about what they liked, disliked, and would change about the messages under these headings on a sheet of paper placed beside each poster. Open-ended questions were then posed to encourage youth to expand on these comments and to reflect on ways of conveying and disseminating information on smoking and BC to other youth. Finally, participants were asked to develop a youth-friendly message using the information they had acquired during the session.

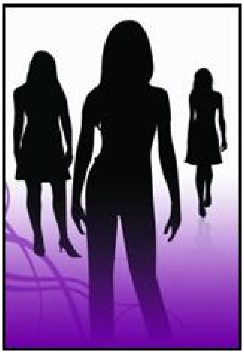
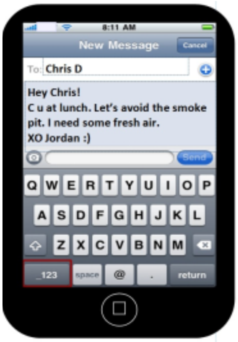
Participants were provided a $40 honorarium to cover travel costs and as an expression of appreciation for their time. All focus groups were audiorecorded and transcribed verbatim. Written comments about posters related to each message were also transcribed for analysis.

Data Analysis

As is common in qualitative research, we took a data-driven, inductive approach to analysis (Morse & Richards, 2013; Sandelowski, 2000). Team members read transcripts independently, highlighting important comments and identifying topic codes by making notations in the margins. Team discussion of initial coding and observations in the data were used to reach consensus on categories and subcategories for a coding framework. Data were then entered and coded using the framework in NVivo to facilitate data retrieval and further analysis. Subgroup node reports

Figure 1 ***Overview of Sample Messages to Prompt Focus Group Discussions***

Targeted Gender	**Image and Message Title**	**Message Content**
Girls	***It Might Be Pretty*** 	It might be pretty . . . but it will not stop the dangerous effects of cigarette smoke. Tell your friends. Smoking — even second-hand — puts girls at twice the risk of getting early breast cancer. If someone is smoking near you or your friends, try saying, "I'd like to ask you a favour. Would you please not smoke around me/us?" If you smoke, think about reducing and quitting. Do it yourself and for all the girls you know. It's your right to protect yourself. Declare your body a smoke-free zone.
	Hanging With Your BFF 	Hanging with your BFF [breast friends forever]? Clear the air and be breast friends for life. Cigarette smoke — even second-hand — puts girls at twice the risk of getting early breast cancer. It's your right to protect yourself. Declare your body a smoke-free zone. Avoid places where you and your friends will be exposed to second-hand smoke.
	A BC Story 	Young women get breast cancer too! Shanna Larsen 1981–2005. A beloved daughter, sister, and friend, Shanna baffled her doctors when she was diagnosed with breast cancer following months of symptoms. She was only 24 when she lost her battle with breast cancer. Know your risks. Girls who smoke or are exposed to second-hand smoke have double the risk of developing breast cancer at a young age. Shanna did not smoke cigarettes but was exposed to second-hand smoke while working in the service industry. Remember Shanna's story and reduce your risks. If you smoke, think about quitting.

Targeted Gender	**Image and Message Title**	**Message Content**
Boys	***Step Up and Step Out*** 	Second-hand cigarette smoke puts girls at twice the risk of getting early breast cancer. Step up and step out. Protect girls from the harmful effects of tobacco by not exposing them to second-hand smoke.
	Most Valuable Protector 	It doesn't matter what you play. You can be a most valuable protector. Second-hand cigarette smoke puts girls at twice the risk of getting early breast cancer. If you smoke, think about reducing and quitting. Do it for yourself and for all the girls you know.
	It's That Simple 	Guys love boobs. It's that simple. Cigarette smoke — even second-hand — puts girls at twice the risk of getter early breast cancer. Respect the girls in your life by not exposing them to the harmful effects of second-hand smoke. If you smoke, think about reducing and quitting. Do it for yourself and for all the girls you know!
Gender-neutral	***Getting the Message Out***  To: Chris D Hey Chris! C u at lunch. Let's avoid the smoke pit. I need some fresh air. XO Jordan :)	Smoking around girls doubles their risk of getting early breast cancer. Protect the girls you know from the harmful effects of cigarette smoke. Tell your friends that you care about your health and ask them to "Clear the air. Please don't smoke around me."

were reviewed and important ideas that might advance the development of gender-specific messages were highlighted and placed in table format to facilitate comparison. Sample messages that received the most favourable and least favourable responses by each group were reviewed in conjunction with youth comments. Particular attention was paid to each group's suggestions for improving messages and its ideas for other types of message. Comparisons were made to identify similarities and differences in perspectives within and among groups based on gender and Aboriginal/non-Aboriginal status.

Results

The results are summarized in relation to three categories: assessments of the tailored messages, suggestions for messaging other youth, and strategies for disseminating information about tobacco exposure and BC. Table 1 provides an overview of key themes among the participant groups.

Youth Assessments of the Tailored Messages

General assessments by youth. Overall, participants indicated that, while they understood the health risks associated with tobacco use, they were not aware of the connection between smoking and BC. Although youth were doubtful that the draft messages were enough to convince current smokers to quit, they thought that the messages held potential for encouraging youth to think about how smoking impacts not only their own health but also the health of those around them. In general, messages tailored to gender were more strongly endorsed for messaging youth about active smoking and SHS and BC than the generic message. Also, the inclusion of Aboriginal symbols was perceived as an effective way to attract the attention of FNM youth as well as enhance the relevancy of the messages for them specifically: "It's just something we can relate to."

Girls' messages. Images that were atypical and creative were the most successful with both FNM and non-Aboriginal girls (e.g., bras in unexpected places). These images caught their attention and encouraged them to read the full message. The girls also indicated that they were more inclined to be receptive to the health information displayed in "Hanging With Your BFF" because it was portrayed in a way they could relate to: "The bras on that one, they're more youthful, so it showed that it impacts younger people too, not just older women."

Messages that drew attention to the effect of SHS on other girls (especially girlfriends) resonated with the girls. Although one non-Aboriginal smoker talked about why and how she attempted to protect others from SHS, her comments reflect important misconceptions about SHS exposure:

Table 1 ***Messaging Themes***

Girls' messaging preferences	
Non-Aboriginal	**FNM**
• Images of activities/contexts popular among girls their age • Promote self-efficacy by offering choice • Real-life stories • Creative/novel images • Include significant others in messages • Promote protecting girlfriends/family members • Minimal written detail	• Images of activities/contexts popular among girls their age • Promote self-efficacy by offering choice • Real-life stories • Creative/novel images • Strategies and advice for avoiding exposure to tobacco • Aboriginal images
Boys' messaging preferences	
Non-Aboriginal	**FNM**
• Images of activities/contexts popular among boys • Humour • Genuine vs. unrealistic/cheesy • Include significant others in messages • Represent masculinity (respect/protect girls)	• Images of activities/contexts popular among boys • Humour • Genuine vs. unrealistic/cheesy • Emphasis on images • Minimal written detail • Use of graphics, such as graffiti • Represent masculinity (respect/protect girls) • Omit stereotypical "sexy" images of girls • Aboriginal images

> *It's just out of respect. Like, any little kid or a non-smoker, I blow it [smoke] away in a different direction. . . . I smoke in my house — everyone does — but when my friend comes over who doesn't smoke, I keep it away from her. I don't want to be caught up in it, so I don't want her to be caught up in it either.*

Some girls thought that the multiple bras and the "breast friends forever" message in "Hanging With Your BFF" created a sense of solidarity in protecting each other from tobacco exposure: "It gives a sense of being more united, I guess, or having more people to send your message across to." This sense of unity was thought to be important because girls did not want to feel alone in their efforts to either protect their non-smoking friends or stay smoke-free themselves. These quotes reflect the importance of intimate friendships and peer support among adolescent girls. Messages offering girls strategies for avoiding SHS were also endorsed. For example, the "Hanging With Your BFF" message was described as "helpful" because it provided advice: "It gave you the information that you needed to know. Because it might be hard to tell your friend to quit smoking [or], like, go somewhere else. It might be a little awkward to bring it up. And having a suggestion would make it a little easier." Evident here is the difficulty girls might have, within relationship-oriented friendships, in addressing friends' smoking. This could partly explain their receptivity to suggestions.

The girls expressed a high level of interest in the message that included a real-life example of a young woman with BC. They suggested that the message generated an emotional response and encouraged them to think more deeply about the risk of BC from smoking. One girl who had recently reduced her smoking was prompted to rethink her exposure to tobacco smoke:

> *I thought it was a little bit plain, but when I started reading it, it caught my eye, because I don't really smoke that much any more and just reading about how she [might have] got it from just second-hand smoke really made me think about where I'm hanging around when people are smoking.*

Peers and peer relationships were often brought up as an influence in girls' receptivity to health messages, reflecting the influence of friends on behaviours, including smoking, within female networks. For example, one girl discussed how peer pressure can override the importance of avoiding health-risk behaviours, such as smoking: "When I started smoking I knew all the risks, but I started smoking anyway. It depends how you're starting smoking, if you're being peer-pressured." Therefore, messages that appeared to challenge the notion that smoking is "cool" were perceived as encouraging them to consider the risks that tobacco posed to their health. Another girl, who was in the process of quitting, summarized her understanding of "It Might Be Pretty": "I like the saying at the top, because some people might think that it's cool, or [that] you look better if you smoke, but it's not really cool. And [I like the fact that] it tells you about the effects of second-hand smoke."

These views suggest that girls are likely to be responsive to messages that challenge attitudes towards smoking as a cool or mature behaviour.

Boys' messages. All of the boys in the focus groups endorsed messages that used humour or catchy images, such as "graffiti," to attract the attention of young men around the topic of SHS and BC. The boys indicated that they identified with humour and that any attempts to make the message go viral would require an inspirational and humorous message.

Some of the messages developed for boys were criticized as being "cheesy." When asked to explain, participants indicated that the messages lacked authenticity. For example, one boy offered the following comment on "Step Up and Step Out": "My friends would see that and laugh, and be, like, 'that's a joke' and wouldn't even bother reading it." Participants thought that the use of more masculine images would enhance the effectiveness of the messages. One boy suggested using masculine endorsements, such as Nike, to gain the receptivity of young men around messages linking smoking to BC: "If you're saying, 'step up and step out,' you should get a Nike shoe to do that, because it's advertising, obviously . . . and it makes it better because it's Nike."

Another participant suggested using more masculine terminology, such as "man up and show respect." One non-Aboriginal boy explained that the topic of BC was not something he and his friends would usually associate with, and therefore required a more masculine focus.

These data show adolescent boys' awareness of masculine norms and could reflect a need to prove their masculinity. By being brand-conscious, the boys were able to reinforce their masculine identity. A strategy that is commonly used is to display an image or status in order to gain the social acceptance of peers.

"It's That Simple" was the only message perceived to be gender-specific to young men. The idea of respecting girls depicted in this message resonated with the boys in the focus groups. They described how respecting girls was something that they "live by" and said that messages promoting the masculine role of protecting and respecting girls held potential for messaging boys about SHS in relation to BC. However, while they wanted to protect girls from smoke, boys who smoked did not want to reduce their own smoking. Discussions about tobacco reduction appeared to be a contentious topic among the boys who smoked, because quitting smoking was associated with being less of a man. One non-Aboriginal boy talked about how he would hear people saying that "quitting is for quitters" and this was a major reason for his own continued smoking and that of other males. A dominant theme underlying these responses to the sample messages was the emerging importance of masculinity in the way that boys project identities that align with strength, risk-taking, and protecting.

The use of sexualized images and messages proved to be distracting for some boys and inhibited their ability to engage in a close reading of the message. For example, several admitted that they did not pay much attention to the content of the message in "It's That Simple" and that they "stopped caring about the tobacco [message]" because they were focused on the silhouette of the girl. One boy in an FNM focus group stated, "It catches your attention, but it's distracting. You stop thinking about cigarettes and start thinking about boobs." Conversely, some boys stated that the message had encouraged them to keep reading: "I read the whole thing, not just because it had a sexy image, but I wanted to know what it had to do with it."

Suggested Practices for Messaging Youth

The boys and girls in the focus groups made suggestions for reaching youth with messages about BC and tobacco exposure. The use of images over text was especially endorsed: "Of the posters I've seen, the best [are] the ones that are strong and simple. If you put too [many] words, I just don't think that works as much for kids and teenagers." Participants further stressed the importance of choosing the right images for youth and suggested that these be gender-, culture-, and age-specific.

Diverse messaging strategies were recommended. While youth agreed that a standard print campaign (e.g., posters in school hallways) would be appropriate, they proposed a number of additional interactive and creative methods. For example, most participants indicated that they frequently used social networking (e.g., Facebook) and believed that using this medium would be one of the best strategies for reaching out to youth. Various multimedia outlets to broadcast the message were also proposed, including online videos (e.g., YouTube), radio and television ads, and ads in movie theatres. Bringing the issue directly to schools by organizing "special days," holding assemblies such as Breast Cancer Awareness Week, and holding group discussions similar to the focus groups was also suggested. One non-Aboriginal boy thought that school assemblies were particularly effective: "School assemblies are the best way to get points across, if you think about it, because I've heard the stupidest things at school assemblies, but I still remember them, and I still know them, and everyone still talks about them." In combination with these strategies, there was strong support for the development and sale of items (e.g., T shirts, water bottles) communicating information about the risks of BC and smoking, provided they be youthful and have "cool designs . . . like graffiti."

Discussion

The methods described in this article for developing health messages targeting youth contribute to a growing body of literature on the need for health promotion strategies tailored to sub-populations. The methodology provides a useful guide for including youth perspectives, illuminating important misconceptions (e.g., regarding SHS exposure, BC), and taking account of social influences (e.g., gender and culture) in tailoring messages to the needs and characteristics of particular groups. Although the perspectives were gathered from a small sample of youth, the approach was effective in generating messages that depart from the neutral approaches used in many BC messages to reflect the perspectives of "ordinary" youth. Nevertheless, we acknowledge that some youth (e.g., gay, lesbian) were not well represented in this study.

Based on the themes identified in the analysis of these data, the team developed a set of tailored messages. While mindful of youth input, we also drew on the team's expertise, the technical expertise of graphic designers, and our desire to infuse the messages with a gender-specific approach (while avoiding gender stereotypes), which is often lacking in youth health promotion messages. The gendered message for girls included catchy images of girls holding brightly coloured bras to attract their attention, brief information about the risk of tobacco exposure in relation to BC, a strategy for reducing SHS risk, and encouragement to quit smoking for their own sake and the sake of their girlfriends. In the photo shoot, we purposely included non-Aboriginal and FNM girls. Developing a gender-specific message for boys about a women's health issue was particularly challenging. The gendered message we developed for boys drew on their interest in demonstrating respect. The colours and image were selected to achieve a masculine look without heteronormative overtones. We focused on the effects of SHS and included a message to boys who smoke to think about quitting for themselves and for the girls they know. In the messages for FNM girls and boys, a feather was added to the background as a symbol of Aboriginal culture. Two of the resulting images are shown in Figures 2 and 3.

The methods used to develop tailored messages about smoking and BC raise important issues in designing gendered messages. As we have indicated throughout this article, when tackling the issue of gender-specific messaging for adolescents, tension arises between developing messages that mobilize gender roles in a way that appeals to a younger audience and reinforcing heteronormative gender ideals or identities. For example, the message that "guys love boobs" used in the focus groups sparked intense debate among members of the research team. In addition to believing that this message could be interpreted as sexually objectifying young women's bodies, team members thought it had the potential to marginalize non-heterosexual youth and gender minorities (i.e., not "all guys" love boobs). A similar issue arose in relation to the "Most Valuable Protector" message, encouraging boys to safeguard girls from exposure to SHS. While the intention was to mobilize young men around a "positive" gendered role — men as caring for and being protective of women — such messaging can position young women as vulnerable and *in need of* protection and promote passive gender roles for

Figure 2 ***Message for Aboriginal Girls***

Figure 3 ***Message for Non-Aboriginal Boys***

women. Concerns about heternomativity are not often addressed in messaging to youth. This article offers direction for further exploration of these issues in health messaging for youth when it is important to account for gender-related factors; it also acknowledges the need to address stereotypes in gendered messaging (Haines-Saah, 2011).

Nevertheless, our findings support gender-specific strategies for messaging about tobacco exposure and BC. For young women, messages oriented to relationships and friendships were most strongly endorsed. Other authors have also recommended health promotion initiatives that support and promote social ties (Umberson & Montez, 2010), especially for young women, because they attach great importance to their relationships with significant others (Hurdle, 2011). The girls' preference for hearing young women's BC stories is perhaps not surprising given the power of personal narratives of cancer. Messaging young women about the link between tobacco smoke and BC through women's narratives of BC is challenging, however, because the causal mechanisms are not yet known (Collishaw et al., 2009). While it is important to incorporate girls' gender-specific preferences in messaging, we must be careful not to do so in misleading ways.

Messaging young men about a young women's health issue creates a different set of challenges in that it disrupts idealized heterosexual gender relations in the context of health and illness. Women are expected to, and most often do, look after the health of the men in their lives (Lee & Owens, 2002). In addition, males typically have been depicted as estranged from health-related concerns, especially female ones. However, the findings of this study suggest that appealing to the protector instinct as a "masculine" virtue focused on equality and respect holds potential for summoning young men to action. Thus, the patriarchal power so often criticized in men can be implicitly repositioned as an opportunity for young men to embody the power differential for the benefit of others.

The use of humour to message men draws on longstanding masculine ideals for how best to entice men to "do health" (Oliffe, Ogrodniczuk, Bottorff, Hislop, & Halpin, 2009). However, the final message we developed for boys (Figure 3) breaks with those ideals by speaking plainly to men. It is possible that the humorous overtones in the message titled "It's That Simple," and the young men's responses to it, gave purchase to some participants to signal their straight masculine identity in ways that lightened the connections between smoking and BC. While researchers have demonstrated empirically in other health and illness contexts that masculine ideals are neither all good nor all bad for men's health (Oliffe, Bottorff, & Sarbit, 2012; Sloan, Gough, & Conner, 2010), gender researchers are forced to make difficult decisions about how gender identities can be effectively taken up to advance health and well-being. By defaulting to the end-user's interpretations, some of these researcher dilemmas are eased in this regard.

Our findings also confirm the importance of including the views of Aboriginal youth when developing health messages. Although the perspectives of FNM youth were similar to those of their non-Aboriginal peers, a noteworthy departure was the perceived need for symbols as an entry point for Aboriginal youth to interact with the messages. This is in line with recommendations by others that symbols be used to recognize Aboriginal people's interest in their culture and their values (Stout & Kipling, 2002). The addition of meaningful symbols in health messages can be a discreet yet creative way to increase the relevance of health messages for Aboriginal youth.

Finally, participants' recommendations for reaching a wide range of youth are informative. The use of social media (e.g., Facebook) for message dissemination is supported in recent research investigating ways to message young women about the link between tobacco smoke and BC (Haines et al., 2010) and recent evidence that one third of teens who go online search the Internet for health information (Lenhart, Purcell, Smith, & Zickuhr, 2010). Furthermore, the consumer-generated nature of online health information offers opportunities to tailor messages to specific youth populations (Sarasohn-Kahn, 2007).

Conclusion

Our findings suggest that, while challenges exist, youth perspectives are a promising starting point when designing health messages for this group. The methodology used in our study provides an avenue for developing gender- and culture-specific approaches to messaging youth about health-related issues.

References

Aboriginal Cancer Care Unit, Cancer Care Ontario. (2008). *A case study approach: Lessons learned in Ontario – Aboriginal tobacco cessation.* Toronto: Author. Retrieved December 9, 2013, from https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=13636.

Bottorff, J. L., McKeown, S., Carey, J., Haines, R., Okoli, C., Johnson K. C., . . . Ptolemy, E. (2010). Young women's responses to smoking and breast cancer information. *Health Education Research, 25,* 668–677.

Branstetter, S. A., Blosnich, J., Dino, G., Nolan, J., & Horn, K. (2012). Gender differences in cigarette smoking, social correlates and cessation among adolescents. *Addictive Behaviors, 37,* 739–742.

Campaign for Tobacco-Free Kids. (2009). *Deadly in pink: Big tobacco steps up its targeting of women and girls.* Retrieved December 9, 2013, from http://www.lung.org/assets/documents/publications/other-reports/deadly-in-pink.pdf.

Collishaw, N. E., Boyd, N. F., Cantor, K. P., Hammond, S. K., Johnson, K. C., Millar, J., . . . Turcotte, F. (2009). *Canadian Expert Panel on Tobacco Smoke and Breast Cancer Risk – Full report.* Toronto: Ontario Tobacco Research Unit. Retrieved December 9, 2013, from http://www.otru.org/pdf/special/expert_panel_tobacco_breast_cancer.pdf.

Dossus, L., Boutran-Ruault, M.-C., Kaaks, R., Gram, I. T., Vilier, A., Fervers, B., . . . Clavel-Chapelon, F. (2014). Active and passive cigarette smoking and breast cancer risk: Results from the EPIC cohort. *International Journal of Cancer, 134*(8), 1871–1888.

Eaton, D. K., Kann, L., Kinchen, S. A., Shanklin, S., Ross, J. G., Hawkins, J., . . . Wechsler, H. (2010). Youth risk behavior surveillance – United States, 2009. *Morbidity and Mortality Weekly Report 2010, 59*(SS05), 1–142.

Elton-Marshall, T., Leatherdale, S. T., & Burkhalter, R. (2011). Tobacco, alcohol, and illicit drug use among Aboriginal youth living off-reserve: Results from the Youth Smoking Survey. *Canadian Medical Association Journal, 183*(8), e480–e486.

Farrelly, M., Niederdeppe, J., & Yarsevich, J. (2003). Youth tobacco prevention mass media campaigns: Past, present, and future directions. *Tobacco Control, 12*(Suppl 1), i35–i47.

Gantz, S. A., & Johnson, K. C. (2014). The Surgeon General Report on Smoking and Health 50 years later: Breast cancer and the cost of increasing caution. *Cancer Epidemiology, Biomarkers and Prevention, 23*(1), 37–46.

Gould, G. S., McEwen, A., Watters, T., Clough, A. R., & van der Zwan, R. (2013). Should anti-tobacco media messages be culturally targeted for Indigenous populations? A systematic review and narrative synthesis. *Tobacco Control, 22,* e7.

Haines, R. J., Bottorff, J. L., Barclay-McKeown, S., Ptolemy, E., Carey, J., & Sullivan, K. M. (2010). Breast cancer messaging for younger women: Gender, femininity, and risk. *Qualitative Health Research, 20*(6), 731–742.

Haines-Saah, R. J. (2011). Pretty girls don't smoke – gender and appearance imperatives in tobacco prevention messaging. In K. Bell, A. Salmon, & D. McNaughton (Eds.), *Alcohol, tobacco, obesity: Morality and the new public health* (pp. 191–211). New York: Routledge.

Health Canada. (2012). *Tobacco use statistics: 2011.* Ottawa: Author. Retrieved December 9, 2013, from http://www.hc-sc.gc.ca/hc-ps/tobac-tabac/research-recherche/stat/index-eng.php.

Hurdle, D. E. (2011). Social support: A critical factor in women's health and health promotion. *Health and Social Work, 26*(2), 72–79.

Hutchinson, P. J., Richardson, C. G., & Bottorff, J. L. (2009). Emergent cigarette smoking, correlations with depression and interest in cessation amongst Aboriginal adolescents in British Columbia. Canadian *Journal of Public Health, 99*(5), 418–422.

Innes, K. E., & Byers, T. E. (2001). Smoking during pregnancy and breast cancer risk in very young women. *Cancer Cause Control, 12*(2), 179–185.

Johnson, J. L., & Repta, R. (2012). Sex and gender: Beyond the binaries. In J. Oliffe & L. Greaves (Eds.), *Designing and conducting gender and sex health research* (pp. 17–37). Thousand Oaks, CA: Sage.

Johnson, J. L., Tucker, R. S., Ratner, P. A., Bottorff, J. L., Prkachin, K. M., Shoveller, J. A., & Zumbo, B. (2004). Socio-demographic correlates of cigarette smoking among high school students: Results from the British Columbia Youth Survey on Smoking and Health. *Canadian Journal of Public Health, 95*(4), 268–271.

Johnson, K. C. (2012). Tobacco smoke and breast cancer risk: Rapid evolution of evidence and understanding in the early 21st century. In G. G. Chen (Ed.), *Cigarette consumption and health effects* (pp. 1–19). Ottawa: Nova Science.

Johnson, K. C., Miller, A. B., Collishaw, N. E., Palmer, J. R., Hammond, K. S., Salmon, A. G., . . . Turcotte, F. (2011). Active smoking and secondhand smoke increase breast cancer risk: The report of the Canadian Expert Panel on Tobacco Smoke and Breast Cancer Risk (2009). *Tobacco Control, 20*(e2).

Lash, T. L., & Aschengrau, A. (1999). Active and passive cigarette smoking and the occurrence of breast cancer. *American Journal of Epidemiology, 149*(1), 5–12.

Lee, C., & Owens, R. G. (2002). *The psychology of men's health.* Buckingham, UK: Open University Press.

Lee, S., Cappella, J. N., Lerman, C., & Strasser, A. A. (2011). Smoking cues, argument strength, and perceived effectiveness of antismoking PSAs. *Nicotine and Tobacco Research, 13*(4), 282–290.

Lenhart, A., Purcell, K., Smith, A., & Zickuhr, K. S. (2010). *Social media and mobile Internet use among teens and young adults.* Washington: Pew Research Center. Retrieved December 9, 2013, from http://www.pewinternet.org/Reports/2010/Social-Media-and-Young-Adults.aspx.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

McBride, C., Emmons, K., & Lipkus, I. (2003). Understanding the potential of teachable moments: The case of smoking cessation. *Health Education Research, 18*(2), 156–170.

Morse, J. M., & Richards, L. (2013). *README FIRST for a user's guide to qualitative methods* (3rd ed.). Thousand Oaks, CA: Sage.

National Aboriginal Health Organization. (2002/03). *NAHO fact sheet: Breast cancer and Aboriginal women.* Retrieved December 9, 2013, from http://www./naho.ca/documents/naho/publications/breastCancer.pdf.

Okasha, M., McCarron, P., Gunnell, D., & Smith, G. D. (2003). Exposure in childhood, adolescence and early adulthood and breast cancer risk: A systematic review of the literature. *Breast Cancer Research and Treatment, 78,* 223–276.

Oliffe, J. L., Bottorff, J. L., & Sarbit, G. (2012). Mobilizing masculinity to support fathers who want to be smoke free. In S. Coen & E. Banister (Eds.), *What a difference sex and gender make: A gender, sex and health research casebook* (pp. 94–101). Vancouver: CIHR Institute of Gender and Health.

Oliffe, J. L., Ogrodniczuk, J. S., Bottorff, J. L., Hislop, T. G., & Halpin, M. (2009). Connecting humor, health, and masculinities at prostate cancer support groups. *Psycho-Oncology, 18*(9), 916–927.

Prevention First. (2008). *Ineffectiveness of fear appeals in youth alcohol, tobacco, and other drug (ATOD) prevention.* Springfield, IL: Author. Retrieved December 9, 2013, from https://www.prevention.org/resources/SAPP/documents/IneffectivenessofFearAppealsinYouthATODPrevention-FINAL.pdf.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health, 23,* 334–340.

Sarasohn-Kahn, J. (2007). Health 2.0: It's not a noun, it's a verb, a movement. *iHealth Beat,* October 3. Retrieved December 9, 2013, from: http://www.ihealthbeat.org/perspectives/2007/health-20-its-not-a-noun-its-a-verb-a-movement.

Sloan, C., Gough, B., & Conner, M. (2010). Healthy masculinities? How ostensibly healthy men talk about lifestyle, health and gender. *Psychology and Health, 25*(7), 783–803.

Stout, M., & Kipling, G. (2002). *The Health Transition Fund synthesis series: Aboriginal health.* Ottawa: Health Canada.

Umberson, D., & Montez, J. K. (2010). Social relationships and health: A flashpoint for public policy. *Journal of Health and Social Behavior, 51*(Suppl), S54–S56.

Valentine, J., Dewar, M., & Wardman, D. (2003). An exploration of smoking cessation and prevention interventions for Aboriginal youth. *Pimatziwin: A Journal of Aboriginal and Indigenous Community Health, 1*(2), 135–152.

Wakefield, M., Flay, B., Nichter, M., & Giovino, G. (2003). Effects of anti-smoking advertising on youth smoking: A review. *Journal of Health Communication, 8,* 229–247.

White, C., Oliffe, J. L., & Bottorff, J. L. (2013). Marketing manhood: Catalyzing African American and White American masculinities in cigarette advertising. *American Journal of Public Health, 103*(4), e44–e55.

Acknowledgements

This research was supported by funding from the Canadian Breast Cancer Research Alliance and the Canadian Breast Cancer Foundation (grant #020659) and also through a Michael Smith Foundation for Health Research scholar award to Dr. Oliffe and a Canadian Institutes of Health Research scholar award to Dr. Richardson.

Competing interests: The authors have no competing interests to declare.

Joan L. Bottorff, RN, PhD, is Professor, School of Nursing, and Director, Institute for Healthy Living and Chronic Disease Prevention, University of British Columbia, Okanagan campus, Kelowna, Canada. Rebecca Haines-Saah, PhD, is Research Associate, School of Nursing, University of British Columbia, Okanagan. John L. Oliffe, RN, PhD, is Professor, School of Nursing, University of British Columbia, Vancouver campus. Laura L. Struik, RN, MSN, is a PhD *student, Institute for Healthy Living and Chronic Disease Prevention, University of British Columbia, Okanagan. Laura J. L. Bissell, MA, is Research Coordinator, Institute for Healthy Living and Chronic Disease Prevention, University of British Columbia, Okanagan. Chris P. Richardson, PhD, is Associate Professor, School of Population and Public Health, University of British Columbia, Vancouver. Carolyn Gotay, PhD, is Professor, School of Population and Public Health, University of British Columbia, Vancouver. Kenneth C. Johnson, PhD, is Adjunct Professor, Department of Epidemiology and Community Health, University of Ottawa, Ontario, Canada. Peter Hutchinson, PhD, is Manager, Chronic Disease Surveillance Program, Métis Nation of British Columbia, Abbotsford.*

CJNR 2014, Vol. 46 Nº 1, 87–101

Reflections of a Novice Institutional Ethnographer

Kathleen Benjamin, Janet Rankin

Institutional ethnography (IE) was developed by Dorothy E. Smith, a Canadian sociologist, in the 1980s. This method of inquiry helps to uncover how the everyday experiences of people in local settings are organized by and linked to the work of others. The purpose of this article is to provide newcomers to IE with insights gained from the first author's learning as a novice institutional ethnographer. These insights stem from her doctoral thesis, which examined how the promotion of physical activity is socially organized in long-term-care homes. The benefits of using IE are considered and the challenges encountered in trying to understand and use this method of inquiry are examined. Strategies used to overcome the challenges are discussed.

Keywords: physical activity, institutional ethnography, long-term care, nursing homes

CJNR 2014, Vol. 46 Nº 1, 87–101

Résumé

Réflexions d'une novice en ethnographie institutionnelle

Kathleen Benjamin, Janet Rankin

L'ethnographie institutionnelle est une méthode de recherche élaborée par la sociologue canadienne Dorothy E. Smith. Elle permet de découvrir comment l'expérience quotidienne des gens dans un milieu donné s'organise et se coordonne en fonction du travail des autres. Le présent article vise à faire profiter les novices en la matière de réflexions sur l'apprentissage de la première auteure en tant qu'ethnographe débutante. Son projet de doctorat consistait à étudier comment s'organise, dans les centres d'hébergement et de soins de longue durée, la promotion de l'activité physique d'un point de vue social. Les auteurs analysent les avantages de l'ethnographie institutionnelle et les difficultés que présentent la compréhension de la méthode et sa mise en œuvre. Elles discutent de stratégies susceptibles de surmonter celles-ci.

Mots clés : activité physique, ethnographie institutionnelle, soins de longue durée, maisons de soins infirmiers

Reflections of a Novice Institutional Ethnographer

Kathleen Benjamin, Janet Rankin

This article describes the first author's experiences in learning institutional ethnography (IE) for her doctoral research into the social organization of personal support work (PSW)[1] and its influence on the promotion of physical activity in long-term-care (LTC) homes (Benjamin, 2011). Primarily using examples from this research, we discuss IE concepts, the benefits and challenges of using IE, and strategies for addressing these challenges. Use of the first person refers to the first author. The second author was a consultant on the methodology and contributed substantively to the article.

Overview of the Doctoral Study

Data were collected at two LTC study sites in the Canadian province of Ontario through participant observation and interviewing of PSWs and other individuals such as nurse managers and representatives from the Ontario Ministry of Health and Long-Term Care (MOHLTC). Institutional texts such as forms, policy statements, and memos were also collected. The data and the process of data analysis resulted in the researcher focusing on two significant work processes — the PSWs' work in the dining room and their handling of transfers (e.g., lifting a person from bed to chair). The PSWs' work involved in lifts and transfers has an obvious relation to physical activity, while work processes related to the dining room seem unrelated to how PSWs promote physical activity for residents. We show how examining the social organization of the PSWs' work processes leads to a new understanding of the social organization of physical activity in LTC. It produces an analysis that departs from many of the currently circulating explanations concerning physical activity (Benjamin, Edwards, & Caswell, 2009; Benjamin et al., 2011; Chen, 2010). Rather than examining education, attitudes, awareness, and time limitations, we link these work practices to MOHLTC standards for LTC homes.

The purpose of standards of care is to produce something *good* for residents. However, some of the standards result in practices that actually constrain the efforts of PSWs to support residents' daily physical activity. Moreover, the standards organize not only particular work processes but also a mindset among staff in LTC homes. This mindset relies on assumptions about how physical activity can be achieved — for example, activities of daily living are not viewed as physical activity or exercise. This understanding contradicts our knowledge of how elderly people living

---

[1] Personal support workers (PSWs) are also known as health-care aides or personal care attendants (PCAs). They are unregulated health-care workers and provide most of the direct hands-on care in LTC homes, where typically they are supervised by registered nurses or registered practical nurses (RPNs).

independently maintain their physical strength by performing activities of daily living. The LTC setting organizes physical activity as separate from its routine dailiness and regards it as a program add-on that takes place a few times per week. Consequently, the promotion of movement and physical resilience is professionalized, mainly under the purview of physiotherapists or activity aides. Known as a ruling relation in IE, this formulation of physical activity limits the ability of PSWs to integrate it as a feature of residents' daily routine. More information about the concept of ruling relations is presented below in the subsection titled ***Texts and ruling relations.***

Institutional Ethnography

IE is a method of inquiry developed by Dorothy E. Smith, a Canadian sociologist, in the early 1980s. It selectively uses Marxist and feminist philosophy (Smith, 1999). Smith's feminist consciousness rooted in the women's movement of the 1970s and her work as a professor in a male-dominated sociology faculty informed her thinking about IE (Campbell & Gregor, 2004; Smith, 2005). She recognized that her knowledge and her experiences as a single mother were largely invisible in the sociology that she taught and realized that the everyday work of women (e.g., housekeeping, child care) was essentially concealed in the male-dominated academic world in which she participated (Campbell & Gregor, 2004; Smith, 1987, 1990a, 1990b, 2005). Smith began to question the official positioning of single mothers as deviants from the norm. She determined that single mothers' deviance was socially organized within a school system that relied on the work of mothers — for example, helping with homework. In exploring the everyday work of single mothers, Smith discovered many competing demands on their time. Within dominant systems of schooling, troubles were generated for both the children and their mothers when mothers were unable to produce *their* homework in its expected form. Influenced also by her reading of Marx, Smith embarked on a sociology that could account for women's knowledge-based work that had heretofore been subordinated. Her project was an activist enterprise invested in social justice. She established a sociology directed towards learning about how the social world is organized. Incorporating what she learned from Marx, her method guides a material discovery to uncover how certain forms of knowledge are overlooked in the authorized formulations of what counts as knowledge.

The materiality embedded in Smith's method of inquiry directs the careful examination of texts and people's activities related to texts (Smith, 1987, 1990b, 2001, 2005). Smith recognized that textual practices contribute to the social organization of knowledge and are powerful coordinators that produce dominant and subordinate knowledge practices. Commonly, texts such as policy statements and memos mediate this organization across geography and time and coordinate practices among multiple people (Smith, 2005). Nursing is heavily regulated by textual practices — in their daily work, nurses in Ontario activate the standards of practice developed by the College of Nurses of Ontario.[2] Embedded in the annual registration processes, and taken up by health-care authorities in policy documents or hiring practices, the textual coordination that arises within nurses' regulatory framework organizes the practices of nurses, clerical staff, and managers across Ontario.

A tenet of IE is that all knowledge is socially organized (Campbell & Gregor, 2004). Considering that knowledge about the world is a social entity, we can discover how it is structured within practices of dominance and authorization and how contradictory practices become taken for granted (Campbell & Gregor, 2004). For example, a PSW's knowledge about the individual needs of a resident is overlooked because it does not fit within the routines and knowledge that officially organize that work. In the next section we present the first author's personal reflections at various stages of the research.

Reflections at the Various Stages

Introduction to Institutional Ethnography

Prior to my doctoral research, in 2006 I conducted a study to examine factors that influence the promotion of physical activity in nine LTC homes in Ontario (Benjamin et al., 2009, 2011). Although the study captured influencing factors at the individual, environmental, and organizational levels, it did not adequately capture those originating outside of the LTC setting (e.g., legislation). Based on my experiences as an LTC nurse and researcher, I knew that LTC homes were highly regulated environments and that the promotion of physical activity did not happen haphazardly. Unlike conventional ethnographic approaches, IE allows a researcher to look beyond the local setting and what can be known from there, to discover other factors that shape and organize people's everyday actions. Thus, the utility of IE made it an appealing and promising method of inquiry that could extend my previous research work.

Understanding the Key Concepts of Institutional Ethnography

Problematic. The utility of a research problematic is a key concept discussed by institutional ethnographers. In order to focus the doctoral

---

[2] Governing body for RNs, RPNs, and nurse practitioners (NPs) in Ontario.

research, I spent a considerable amount of time trying to formulate a research problematic at the outset of the research. The problematic is neither the research question nor the problems that people are experiencing (Campbell & Gregor, 2004). It is those instances when a researcher notices a disjuncture (contradiction) between the official explanation of how things happen, or even the explanations provided by people who are experiencing the issue, and the observations of what actually goes on (Bisaillon, 2012; Campbell & Gregor, 2004; Smith, 1990a). For instance, the PSWs spent a great deal of time providing a particular form of dining service (e.g., unhurried, one course served at a time). The official explanation for using this approach was to provide *pleasant dining experiences* for residents. Official reports and accreditation practices also contained this explanation. However, this explanation did not represent what was actually happening. Despite devoting a considerable amount of time to the dining experience, the PSWs sometimes rushed residents through their meals. The dining room work also placed pressure on other types of work, related to toileting, bathing, and dressing. The problematic arose at the moment when the official version of what was happening in the dining room (pleasant dining experiences) was at odds with what was actually happening (residents being rushed).

Standpoint. Conceptually, standpoint is an entry point for the researcher to position himself/herself in the everyday expert knowledge of people's daily activities (Rankin, Malinsky, Tate, & Elena, 2010). It is a particular location within the institutional order. Typically, an institutional ethnographer "takes the standpoint of those that are being ruled" (Campbell & Gregor, 2004, p. 16) and works on behalf of the people who are experiencing the problems (Rankin et al., 2010).

I took the standpoint of PSWs, for two reasons. First, PSWs are unregulated providers who deliver the largest proportion of direct resident care — they are the backbone of the labour force in LTC. Although they are in a prime position to assist residents with their physical activity, my experience indicated that typically this does not happen. Understanding the social organization of PSWs within the roles and responsibilities of nurses who are regulated and within the other relations that organize their employment appeared to be the optimal way to learn how the physical strength of some elderly people declines when they enter residential care. Second, based on my research and clinical practice, I speculated that the problem was not a lack of awareness of the benefits of activity. Despite PSWs' positive beliefs about physical activity, their heavy workloads made it difficult for them to assist residents with their physical activities. PSWs' explanation that there was *not enough time* to promote physical activity did not explain the complexity of the issue nor provide the direction to address it. As the doctoral research progressed, I interviewed participants other than PSWs (e.g., nurse managers) at the LTC study sites. Their official explanations of how the PSWs' work was organized were often convincing and compelling. Keeping sight of what the PSWs told me in the interviews was challenging, because my training and work experience as a registered nurse is positioned in a ruling relationship to PSWs. The use of standpoint helped to refocus my attention on what the PSWs were saying. Observing the PSWs in their work also helped me to stay firmly grounded in the research standpoint. For example, some of the nurse managers explained that residents were encouraged to eat in the dining room because it provided opportunities for them to socialize (official explanation). This explanation seemed perfectly logical because I was trained in this ideology as an LTC nurse. I learned how to pay attention to the occasions when the official explanations were activated, trailing with them all the professional ideology.

Social relations. In IE, social relations are distinct from interpersonal relations, as they are often understood outside sociology. A social relation is "something happening that links individuals together" (Rankin et al., 2010, p. 335). Conceptually, social relationships are the intersections of people's actions and their practices (Bisaillon, 2012). The texts that people produce and use mediate many of these intersections — they are material forms of social relations (Smith, 2005). For example, I gathered and analyzed texts used or produced by the PSWs in their daily work, in search of the material links that connected their work to the work of others outside the local setting (extra-local). After observing and interviewing PSWs, I spoke with other people to see how their work intersected with that of the PSWs. Thinking of social relations as something other than personal relations and as something *happening* that included the talk and actions linking people's actions across settings were two conceptual challenges for me.

Texts and ruling relations. An institutional ethnographer views a ruling relation as a practice occurring in a local setting that infuses institutional interests into the setting (Rankin et al., 2010). For example, the administrative requirement to meet meal-service standards did not seem to make sense in the daily lives of the PSWs and residents. The PSWs sometimes wheeled residents to the dining room rather than helping them to walk, because wheeling is faster. Although wheeling residents is necessary in order for PSWs to get their work done, the practice arises as contradictory and may not be in the best interest of residents. It not only reduces opportunities for physical activity but may override residents' personal preferences and PSWs' informed judgement. With regard to ruling relations, institutional ethnographers view people as active participants in the ruling relations and not as passive bystanders (Campbell & Gregor, 2004). People in the local setting are often completely captured by the ruling relation and its apparent rationality. For example, an MOHLTC standard mandates that residents be offered two baths per week. PSWs participate in this ruling relation by taking up and activating the standard as they implement the practice into their daily work. They understand it as a best practice that is necessary. However, when looking at this practice with a critical eye, it does not always make sense when contrasted with how bathing practices unfold in real-life conditions and with people's individualized and personal bathing needs.

Institutional ethnographers pay attention to texts in order to explicate ruling relations. It is important to emphasize this point. In contemporary societies, people's activities are often mediated by their work with texts. The materiality of Marx guides IE researchers' attention to texts that are the material threads of ruling relations that can be discovered (Marx & Engels, 1976; Smith, 2005). People's activation of texts can be observed and analyzed for their institutional traces. Texts include all media that can be replicated across time and geography. An example of a text that organizes PSWs' daily work is the bath list — a taken-for-granted document that PSWs often do not even look at. It complies with the textual directions of the MOHLTC standard related to two baths per week and works behind the scenes, introducing the ruling relations into the LTC setting, as it unfolds in PSWs' daily work.

Looking at the LTC Literature Differently

My research training taught me to review the literature to identify gaps and to use this knowledge as a basis for developing a research project. However, institutional ethnographers do not review and use the literature as fact. They position themselves as questioners within the popular discourses of authorized knowledge and empirical evidence. Even studies judged to be rigorous, interesting, and useful are analyzed for their epistemological and ontological premises. Institutional ethnographers read the literature with a critical eye to discover how the dominant discourses, which conceptually operate in a confining circular pattern, reproduce over and over again, explanations that appear rational and logical. They read published studies to discover how people's activities carry traces of the literature and where the ideas in the literature appear in the texts that organize people's daily experiences. Pragmatically, I read the literature to identify the paradigm in which it was generated and the practices it reproduced. The first paradigmatic view contained the official theorized explanations about how things happen and the second included the rare paper that framed the issue as socially organized and held traces of the material world. These were the papers where people's *doings* could actually be seen before they were abstracted into categories, concepts, and theories.

Looking for the Right Type of Data

I had to learn what type of data to look for and what questions needed to be asked. Institutional ethnographers do not study subjects' individual perspectives (McCoy, 2005). Instead, they focus on work processes. I began by observing the PSWs as they went about their typical day and interviewed them about their work. I looked for the contradictions, the things that seemed to make sense until one really looked at what was happening, as well as the linkages that connected the PSWs' work to the work of others. Most people lack a useful analysis of how their daily experiences are socially organized in contradictory ways. They may recognize that some things are at odds, but often, over time, people's daily experiences become routine taken-for-granted practices. For instance, the PSWs' explanation for why meals were served in such a manner was *this is the way things are done around here*.

In IE, data collection moves back and forth between what is learned from observing and interviewing the standpoint informants and work going on outside the purview of the local setting. What I learned from the PSWs informed me about who to talk to next and what types of questions to ask. When I directed my attention beyond the local arrangements of the PSWs and their knowledge, I began to talk with other individuals (e.g., nurse managers).

I was initially overwhelmed by the huge amount of text-based materials in the study settings and did not know what texts to collect. However, as my research progressed I gained clarity about the work processes that became my focus and directed my attention towards the texts that intersected with that work. I identified pertinent texts by listening for clues in the participants' interviews and by observing texts used or produced by the participants in their daily work. For example, I watched and talked to the PSWs as they completed the basic care flow sheet at the end of each shift, paying particular attention to what was included and what was left out. When I directed my data collection to texts outside the setting — with the puzzle related to the dining room work and how it appeared on the basic care flow sheet — I asked a manager about how all this worked. I was told that there were standards related to how the meals were to be served in the dining room. I then went searching for a copy of those standards.

Understanding Data Analyses

Understanding how to proceed with data analysis was the most challenging aspect of doing an IE study. My prior experiences with content or thematic analyses differed from those of the data analysis used in IE. An IE researcher does not assign labels or nodes to segments of the data to identify emergent themes, because those processes abstract the data from its material work processes (social relations), which are central to an IE study (Campbell & Gregor, 2004). IE researchers avoid categorizing data in any way that might serve to conceal their materiality (Campbell & Gregor, 2004). One must steadfastly ensure that people and their *doings* remain visible in any data-analysis approach, in order to avoid the very disjunctures that IE researchers problematize. Several strategies were used to facilitate data analyses and analytical writing.

When reading the transcripts and field notes, I asked questions of my data such as *what are the PSWs doing and how is their work connected to the work of others?* I searched for traces of the institution in the talk and work of the PSWs so that I could understand these intersections. To remain focused on the social relations during my analytical writing, I frequently asked myself the question *how does this (work) happen?* (Campbell & Gregor, 2004). After collecting preliminary data from the standpoint of participants, I mapped out how the activities of PSWs connected to the activities of other people. I excerpted data from the transcripts and pasted the excerpts onto large sheets of poster paper (Smith, 2006). This process helped me to visualize the organization of a PSW's typical workday and how the work of PSWs connected to the work of others. For instance, one excerpt described a PSW's work related to meal service. This attracted my attention because in order to organize their work in the dining room, the PSWs had to rush to complete their other work (e.g., bathing). This observation linked to a manager's reference to the written standards related to meal service. I located these standards in the LTC program manual and pasted the excerpts onto sheets to visualize the connections.

I used the analytical writing process as another strategy to assist with the data analyses. I began the analytical writing process immediately after the first observation. I read the transcripts or field notes, reflected on the data, and then wrote an account of what I saw in the data and anything missing that remained curious and unexplained. Each repetition of this process resulted in greater clarity about the PSWs' work. For instance, I found several instances in the transcripts of PSWs describing the meal service work as challenging, hectic, and demanding and explaining why this was so. Excerpts from my field notes and transcripts described the PSWs offering meal choices, clearing tables, and scraping plates between courses, all the while noting who was eating and who needed help. All these excerpts were included in my analytic chunks of writing.

Primary in an IE analysis is how people engage and use specific texts. Smith (2005) guides researchers to think about how texts are used and how they shape and organize people's work, a process she refers to as text-action-text sequences. To help me think of these sequences, I asked questions such as *what is this text used for and what does it accomplish?* I retained a copy of the daily basic care flow sheet that PSWs completed at the end of each shift. This form documents the care provided to residents in the areas of personal care, skin integrity, repositioning, use of assistive devices, and urinary/bowel elimination. A PSW explained that she had to do this work because the MOHLTC could come and check the sheet to see what care was done. Notable in the analysis of this accountability work and what it produced was that there was no section on the form related to the promotion of physical activity. It was at this point that I began to realize that physical activity was being textually organized as something other than an activity of daily living. I do not imply that we should work to capture physical activity in the theorized accountability practices of the other aspects of daily living. Rather, I mean that it was during this process of textual analysis that I began to see the ruling relation that organized physical activity as something other than an activity of daily living.

Engaging in conversations with other researchers who shared the IE ontological position was the most successful data-analysis strategy. Fortunately I had an experienced institutional ethnographer on my thesis committee. She used two key strategies that were especially helpful in flushing out the data and pushing the analyses forward. First, she helped me to refocus my attention on the knowledge provided by my standpoint participants (PSWs) when I activated my tendency to move to the abstract or theorized explanations of how things worked. For example, according to some LTC managers, the meal service was designed to provide pleasant dining experiences and opportunities for residents to socialize. This official explanation was compelling. However, I did not observe many residents talking to each other in the dining room. In fact, what I observed could be framed as bizarre. When I was redirected to my field notes describing the linen tablecloths, restaurant-like meal service, and frail elderly people routinely enjoying an idealistic *five-star* dining experience, I was able to refocus on what the PSWs were showing me and telling me. Refocusing on the actual observations helped me to drive my data analyses and writing forward.

The second strategy that my IE advisor taught me was how to render the instances of work as fundamentally mysterious (Rankin et al., 2010). She consistently reminded me not to take any of the practices that I was seeing or hearing about for granted. For example, PSWs mentioned that their assignments were especially heavy on the day shift because they had to care for eight to 10 residents. Since I had worked as an LTC nurse, I initially took this statement at face value and did not pay particular attention to it. My advisor guided me to investigate it further by asking questions such as *who makes the decisions about resident assignment?* This process helped me to flush out the data and to explicate the ruling relations.

A final strategy involved a back-and-forth reflexive process. I read the transcripts, reflected on what I had read, wrote notes and questions, and then repeated the process. This helped me to see the institution in the data and how the ruling relations shaped and controlled the contradictory work of PSWs as it was organized to unfold in the dailiness of residents' lack of physical activity. In the next section I provide an example of my initial thought processes and reflections, which supported my analytical writing.

My Reflections Regarding the Work in the Dining Room

I noted that the PSWs on the day and evening shifts spent a considerable proportion of their time working in the dining room. At first I did not pay particular attention to this because at the outset of the study I saw dining in its ideological form, as it is organized in the LTC industry. However, as I wondered why the PSWs were rushed and why some residents who could walk with assistance were wheeled to the dining room, I realized that these dining activities were intricately connected to everything else going on in the LTC setting and paid close attention to this work organization. In my chunks of analytic writing, I noted that a PSW working a 7.5-hour day shift spent about 2 hours in the dining room. As previously noted, the dining rooms were rather formal and the way the PSWs served the meals reminded me of a restaurant. The PSWs spent a lot of time transporting residents to and from the dining room, which meant that meal times were especially busy for the PSWs. My transcripts contained data about the PSWs' dining room work. I wrote this into the analytic chunks I was preparing, including their explanations that this work was difficult to complete, especially if they were short-staffed. I made a note to follow up on this institutional feature of being *short-staffed*. In my writing, I included the PSWs' interview comments describing the many rules and regulations they had to follow (e.g., one course at a time). *The one course at a time rule* meant that the PSWs had to wait until the residents finished each course and then clear the dishes before serving the next course. This lengthened the time that the PSWs had to devote to dining room activities. I then turned to the managers' and nursing supervisors' data to locate their comments about dining room work. I wrote about their understanding of the PSW dining room work and how they saw it as providing a pleasant dining experience and a home-like environment for the residents. I began to articulate and write about the obvious contradiction in the way the PSWs described their work (and what I had observed) and the way the supervisors and managers talked about it. Slowly, in my chunks of analytic writing, I began to locate the contradictory practices that I could formulate as a research problematic that directed further exploration.

To advance my analytic writing, I described the standards that shaped the PSWs' work in the dining room and identified instances where I could trace the activation of the textual directions that the standards organized, such as the standard that meals be served one course at a time. Beyond the *one course at a time,* I could see and write about the detailed and complicated work this apparently simple standard produced, under conditions where meals were transported on hot trolleys to satellite kitchens and PSWs worked with residents, some of whom had cognitive impairments, to mediate the *one course at a time* rule. I was able to see and write about how these standards, intended to produce pleasant dining experiences, produced something contradictory and hampered the PSWs' efforts to promote physical activity. For instance, some of the PSWs used a mechanical lift to transfer residents from bed to chair instead of using a more independent type of transfer such as stand and pivot. They believed that the mechanical lift was faster, and getting residents to the dining room on time was a priority. However, this practice limited opportunities for the residents to bear weight and to use their bodies to assist with the transfer. Based on this reflective process, I identified the second work process that became the focus of my analysis — the organization of work that supported PSWs using a mechanical lift to transfer residents. The PSWs commented that there were several policies related to the use of mechanical lifts. Foremost was the policy that two staff members had to be present when operating a mechanical lift. I turned to my field notes and learned about the complicated arrangements related to finding and waiting for another PSW when a lift was needed, the concurrent work of preparing for the helper, and the contradictions that were embedded there. Similarly, I followed the clues in these data to the MOHLTC standards and occupational health and safety discourse that organize the work related to resident transfers.

Conclusion

The above reflections are based on my doctoral research. My journey as a novice institutional ethnographer produced occasions when I was caught between my previous training, the advice of my supervisors, and the significant differences that the alternative IE approach demands. It is my hope that this article, a stepwise reflection of the process of data collection and data analysis, will be helpful to others who take up the IE method of inquiry. I decided to use this method because I believed that it would help me to better understand how physical activity happens in LTC homes. Lacking a background in sociology, I grappled with some of the complex writings of Dorothy Smith. Data analysis was initially a daunting process, partly owing to the fact that there are limited written resources on how to do data analyses when using an IE approach. The most useful strategy that helped me to flush out my data and drive the analyses forward was having conversations with other researchers who shared the IE ontological position, knew how to keep me grounded in the materiality of my data, and helped me to resist the propensity to make the shift into abstract theorizing. Despite the challenges, IE provided a framework that enabled new insights about the promotion of physical activity by PSWs.

References

Benjamin, K. M. B. (2011). *The social organization of personal support work in long-term care and the promotion of physical activity for residents: An institutional ethnography.* Doctoral dissertation, University of Ottawa. Retrieved May 1, 2012, from http://www.ruor.uottawa.ca/en/handle/10393/20397.

Benjamin, K., Edwards, N., & Caswell, W. (2009). Factors influencing the physical activity of older adults in long-term care: Administrators' perspectives. *Journal of Aging and Physical Activity, 17*(2), 181–195.

Benjamin, K., Edwards, N., Guitard, P., Murray, M. A., Caswell, W., & Perrier, M. J. (2011). Factors that influence physical activity in long-term care: Perspectives of residents, staff, and significant others. *Canadian Journal on Aging, 30*(2), 1–12.

Bisaillon, L. (2012). An analytic glossary to social inquiry: Using institutional and political activist ethnography. *International Journal of Qualitative Methods, 11*(5). Retrieved March 2, 2013, from http://ejournals.library.ualberta.ca/index.php/IJQM/article/view/17779/14579.

Campbell, M., & Gregor, F. (2004). *Mapping social relations: A primer in institutional ethnography*. Aurora, ON: Garamond.

Chen, Y. M. (2010). Perceived barriers to physical activity among older adults residing in long-term care institutions. *Journal of Clinical Nursing, 19*(3/4), 432–439.

Marx, K., & Engels, F. (1976). *The German ideology*. Moscow: Progress.

McCoy, L. (2005). HIV-positive patients and the doctor-patient relationship: Perspectives from the margins. *Qualitative Health Research, 15*(6), 791–806.

Rankin, J. M., Malinsky, L., Tate, B., & Elena, L. (2010). Contesting our taken-for-granted understanding of student evaluation: Insights from a team of institutional ethnographers. *Journal of Nursing Education, 49*(6), 333–339.

Smith, D. E. (1987). *The everyday world as problematic: A feminist sociology*. Boston: Northeastern University Press.

Smith, D. E. (1990a). *The conceptual practices of power: A feminist sociology of knowledge*. Boston: Northeastern University Press.

Smith, D. E. (1990b). *Texts, facts, and femininity: Exploring the relations of ruling.* London: Routledge.

Smith, D. E. (1999). *Writing the social: Critique, theory, and investigations.* Toronto: University of Toronto Press.

Smith, D. E. (2001). Texts and the ontology of organizations and institutions. *Studies in Cultures, Organizations and Societies,* 7(2), 159–198.

Smith, D. E. (2005). *Institutional ethnography: A sociology for people.* Walnut Creek, CA: AltaMira.

Smith, D. E. (2006). *Institutional ethnography as practice.* Lanham, MD: Rowman & Littlefield.

Acknowledgements

The first author wishes to acknowledge the financial assistance of the following organizations during her doctoral program: Alumnae of the Royal Victoria Training School for Nurses, Montreal; Ontario Training Centre in Health Service and Policy Research; Élisabeth-Bruyère Research Institute, Ottawa; Community Health Research Unit, University of Ottawa; and Dr. Nancy Edwards' Nursing Chair Award, which is funded by the Canadian Health Services Research Foundation, the Canadian Institutes of Health Research, and the Government of Ontario.

The opinions expressed herein are those of the authors. Publication does not imply endorsement of these views by any of the organizations listed above.

Kathleen Benjamin, RN, PhD, is Postdoctoral Fellow, University of Calgary–Qatar, Doha. Janet Rankin, RN, PhD, is Assistant Professor, Faculty of Nursing, University of Calgary–Qatar.

CJNR 2014, Vol. 46 Nº 1, 102–116

Promoting Health Equity Research: Insights From a Canadian Initiative

Miriam J. Stewart, Kaysi Eastlick Kushner

In 2002 the Canadian Institutes of Health Research launched a national initiative to promote health equity research reflecting the World Health Organization imperative of investment in health equity research. Funded researchers and teams have investigated health disparities faced by vulnerable populations, analyzed interactions of health determinants, and tested innovative interventions. Strategies for building research capacity have supported students, postdoctoral fellows, new investigators, and interdisciplinary research teams. Partnerships have been created with 10 national and 7 international organizations. Strategies used to secure and sustain this research initiative could be adapted to other contexts. Nurse scholars led the launch and have sustained the legacy of this national research initiative. Moreover, nurse researchers and research trainees, supported by the initiative, have contributed to the expansion and translation of the health equity knowledge base.

Keywords: determinants of health, health disparities, population health, vulnerable populations

Résumé

La promotion de la recherche sur l'équité en matière de santé : observations issues d'une initiative canadienne

Miriam J. Stewart, Kaysi Eastlick Kushner

En 2002, les Instituts de recherche en santé du Canada ont lancé une initiative pancanadienne visant à promouvoir la recherche sur l'équité en matière de santé, conformément à une recommandation émise par l'Organisation mondiale de la Santé soulignant l'importance d'investir dans ce domaine. Les chercheurs et les équipes bénéficiant d'un financement se sont penchés sur les disparités touchant les populations vulnérables en matière de santé. Ils ont également analysé les interactions entre les déterminants de la santé et ont mis à l'épreuve des interventions novatrices. Des stratégies destinées à accroître la capacité de recherche ont appuyé les efforts des étudiants, des boursiers de recherches post-doctorales, des nouveaux chercheurs et des équipes de recherche interdisciplinaire. Des partenariats ont été créés avec dix organisations nationales et sept organisations internationales. Les stratégies utilisées pour consolider et soutenir cette initiative de recherche pourraient être adaptées à d'autres contextes. Les chercheurs en sciences infirmières ont assuré le lancement et maintenu l'héritage qu'a laissé cette initiative de recherche pancanadienne. De plus, les chercheurs et les stagiaires de recherche en sciences infirmières qui ont bénéficié de l'initiative ont contribué à l'expansion et à l'application de la base de connaissances sur l'équité en matière de santé.

Mots clés : déterminants de la santé, disparités en matière de santé, populations vulnérables, équité en matière de santé

Achieving health equity is prominent in the pursuit of the Millennium Development goals, as recorded in a 2010 editorial in the *Lancet*. The World Health Organization Commission on Social Determinants of Health (World Health Organization [WHO], 2008), chaired by Dr. Michael Marmot, recommended increased investment in health equity research. While concern about health inequities is growing internationally, "the evidence base on health inequity, the social determinants of health, and what works to improve them needs further strengthening" (Marmot et al., 2008, p. 1668). Although research has documented health disparities within and across countries, there is an urgent need to analyze disparities among vulnerable populations nationally, understand interplay among social and biological determinants of health, describe mechanisms through which factors such as poverty compromise health, illuminate barriers that impede action even when there is knowledge, and evaluate programs that reduce health disparities. In 2009 a Canadian Senate committee recommended that "population health intervention research on housing and mitigating the effects of poverty among . . . vulnerable populations be considered priorities" (Senate Subcommittee on Population Health, 2009, p. 31). Comprehensive interdisciplinary research is needed to investigate the ways in which biologic determinants of health link with social, economic, and cultural factors to create and sustain health disparities. Critical analyses by nurses, in collaboration with members of other disciplines, guide identification and intervention regarding the fundamental causes of health inequities (Reutter & Kushner, 2010).

To address the need to understand pathways to health equity and reduce health disparities, in 2002 the Canadian Institutes of Health Research (CIHR) launched a ground-breaking initiative, Promoting Health Equity, which incorporated innovations in research, created partnerships for change, and promoted knowledge translation. Strategies used to launch this national initiative, overcome obstacles, and ensure success and sustainability over the past decade may be a model for advancing the World Health Organization (WHO) recommendations. Nurse researchers have played a key role in creating and continuing this research initiative.

Fostering Research on Health Equity

Assessment of research funding practices reveals a poor fit between funding mechanisms and the intervention research that addresses health inequities (Edwards & Di Ruggiero, 2011). The funding opportunities provided by CIHR and its partners were designed to stimulate the research community to focus on vulnerable populations, factors that influence vulnerability and disparities, health disparities at the population level, ethical and legal issues associated with health inequalities, and relevant interventions. The dramatic increase in health equity research expenditures and number of grants following the launch of the Promoting Health Equity initiative is documented in a recent CIHR report (CIHR Institute of Population and Public Health [IPPH], 2011). Strategic funding opportunities emphasize analysis of disparities across populations and the design of interventions that reduce inequalities and promote the health of vulnerable populations. Researchers are encouraged to consider the diverse factors that influence health disparities, including biological determinants (e.g., sex differences, developmental abnormalities) as well as socio-environmental, cultural, and structural determinants (e.g., unemployment, low socio-economic status, inadequate housing, discrimination, social support deficits, gender inequalities). Research that designs and tests innovative multi-level, multi-sectoral, and multiple-strategy population interventions (Raphael, 2008), pilot testing of interventions, and evaluation of differential impacts of interventions on vulnerable population subgroups is encouraged. Research gaps remain in our understanding of mechanisms underlying health inequalities and the evaluation of interventions that reduce inequalities (Bleich, Jarlenski, Bell, & LaVeist, 2012). Community-based participatory research to address the social determinants of health (Hawe & Potvin, 2009; Stewart, Letourneau, & Kushner, 2010) is invited. One funded researcher makes the following observation:

> *The focus on reducing disparities and creating equity forces research with these populations to move out of areas that are primarily descriptive and to identify concrete mechanisms for change.*

Funded interdisciplinary teams have focused on (1) understanding biological, socio-environmental, cultural, and structural factors that contribute to health inequities at individual and population levels; (2) addressing health disparities through intervention research and evaluation of the effects of practice, programs, and policies on health inequities; and (3) comparative research within and between countries. Some studies have emphasized health disparities experienced by specific vulnerable populations; others have examined interactions among social determinants of health. Four themes emerge in the funded research and research teams: health equity across the lifespan, vulnerable populations, social determinants of health, and access to services. Exemplar studies and anonymous quotations from funded researchers, derived from CIHR reports, illustrate these themes (CIHR, 2007; CIHR Institute of Gender and Health [IGH], 2011).

Health Equity Across the Lifespan

Mackenbach's (2011) analysis of a British initiative intended to diminish disparities in life expectancy and infant mortality reveals continuing challenges. Mackenbach advocates research using rigorous implementation and evaluation of targeted interventions. Supported studies have focused on such issues as children's health and development pathways, vulnerability trajectories for homeless youth, stigma and resilience among vulnerable youth, promoting equity for nursing home residents, and health equity for pregnant and parenting women facing substance use. A funded researcher comments as follows:

> *The analysis supported our hypotheses that older persons of ethnic minority status were less likely to utilize health services compared to those of the ethnic majority group and that health services utilization differs across socio-economic groups.*

Vulnerable Populations

Social, cultural, and economic circumstances influence quality of life and health disparities and have the potential to reduce inequities experienced by vulnerable populations (e.g., Dowd, Zajacova, & Aiello, 2009; Mier et al., 2008). Immigrants, refugees, the disabled, the poor, the homeless, the illiterate, Indigenous people, and women in precarious circumstances are vulnerable populations, more likely than others to become ill and less likely to receive appropriate health services (Beiser & Stewart, 2005). Funded research has examined diverse themes, including homelessness, housing, and health, vulnerability among sexual minorities, Indigenous/Aboriginal people's access to water, health barriers for immigrants, and migrant perinatal health.

Determinants of Health

We need evidence on determinants, including health practices, education, and socio-economic resources that can reduce health inequalities (Blakely & Carter, 2011; Goldman & Smith, 2011; Mackenbach, 2011). Exemplar funded programs have investigated pertinent topics such as communities in extreme poverty, social and economic inclusion of single mothers, and nutrition needs of homeless youth.

> *Ethnicity was not a good predictor of general health. In fact, poor socio-economic status, restrictions in activities, lower sense of cohesiveness, and poor social support were more predictive of poor general health.*

Access to Services

Improving the health of poor, vulnerable populations and reducing health disparities are linked to access to preventive and restorative services for underserved populations (Allin, Grignon, & Le Grand, 2010; Lebrun, 2012; Mier et al., 2008). Supported studies have emphasized varied issues, including equitable access to health services for Aboriginal people, community medicine for people without health insurance, uptake of antiretroviral therapy among survival sex workers, and primary health care for marginalized populations.

> *Our research shows that people (children and adults as well as seniors) who live with disabilities are the highest users of health services. . . . Disability is a stronger predictor of utilization of health services than age, gender, education, income, ethnicity, or any of the other social predictors.*

Building Research Capacity in Health Equity

Building a health-equity knowledge base requires the development of research capacity (Edwards & Di Ruggiero, 2011). The Canadian research initiative has offered diverse tools for building research capacity, ranging from 1-year catalyst or pilot project grants and research program development grants to 5-year research program grants and interdisciplinary team grants. Application pressure for all strategic funding opportunities has been high. Since this major initiative was launched, over 60 large teams of researchers, practitioners, program planners, and policy-makers have been funded. More than 400 researchers and research users from nursing and other disciplines have been supported, reflecting widespread commitment in Canada to understanding and diminishing disparities. The funded research teams are notable for their interdisciplinary approaches, multi-site representation spanning cities and provinces, and numerous institutions. These teams, covering the full spectrum of health research (biomedical, clinical, health services, population health), focus on health across the lifespan, access to health services, social determinants of health, and illness burden in vulnerable populations. This strategic initiative has significantly enhanced Canadian capacity in health equity research by investing in training and mentorship. To illustrate, research capacity built through research teams has encompassed over 450 graduate students, fellows, and new investigators (CIHR IPPH, 2011). One team investigating rural maternity care supported 27 students from across disciplines for 5 years. Another team examining stigma, resilience, and youth supported its trainees through writing groups, workshops, and a conference. The initiative influenced the careers of established and new researchers by providing opportunities to conduct innovative research; intensifying programs of research; fostering the involvement of knowledge users and researchers; and creating a community of scholarship through online contacts, workshops, and conferences (CIHR IPPH, 2011).

Influencing Health Equity Policies, Programs, and Practice Through Research

Future research should guide policy and program decisions regarding factors that influence health (Dankwa-Mullan et al., 2010). The Canadian initiative has promoted the exchange of transferable knowledge. National symposia, workshops, and the publication, in 2005, of a special issue of the *Canadian Journal of Public Health* devoted to health equity research are some of the vehicles used to promote exchange. The initiative has compiled an electronic mailing list to maximize contact among researchers and alert researchers and has developed a Web site where researchers and knowledge users share information.

The importance of linking research to policy and practice is increasingly recognized. However, policy development to reduce health disparities "is still largely intuitive and would benefit from incorporation of rigorous evidence-based approaches" (Mackenbach & Bakker, 2003, p. 1409). The initiative has emphasized knowledge translation and transfer by encouraging funded programs and teams to engage policy-makers, the public, program planners, and the voluntary sector and to conduct intervention research that might inform policies, programs, and practice.

In 2004 a National Policy Forum on Health Disparities was hosted in partnership with five national organizations. More than 50 participants, including funded researchers and policy-makers at the federal, provincial, and territorial levels, examined the policy implications of health disparities research and discussed synthesis papers commissioned by this initiative, ultimately leading to policy influence. In 2005 funded research teams investigating homelessness and health participated in a workshop with program planners, practitioners, and policy-makers to develop strategies for fostering participatory research and for mobilizing programs, practices, and policies based on research evidence. At the Canadian Public Health Association conference in 2005, a workshop was held to discuss the research-policy interface. Speakers included Dr. Margaret Whitehead of the Department of Public Health at the University of Liverpool, Canadian researchers and policy-makers, and representatives of six national partner organizations.

The Canadian research initiative also supported the Health Equity Group of the Cochrane Collaboration of Canada in establishing priorities for systematic reviews on health equity for policy-makers. In 2007 it hosted a public research communication event, in partnership with Human Resources and Social Development Canada, on homelessness and health. A 2011 workshop on H1N1 in vulnerable populations and a 2012 health equity workshop co-led with the National Centre on Social Determinants of Health engaged researchers and policy influencers (Edwards & Di Ruggiero, 2011).

The funded teams are shaping practice, informing the design of interventions and service-delivery models, and supporting evidence-informed decision-making. One researcher describes the impact of research funded by this Canadian initiative on programs and policies:

> *This grant has translated directly into policy initiatives. I have led the provincial team recommending HPV co-testing as part of cervical cancer screening. . . . have significant involvement in the HPV vaccine recommendation and evaluation process led by the [provincial] Centre for Disease Control.*

Innovative modes of knowledge translation have increased the accessibility and use of research evidence. One interdisciplinary team developed the Rural Birth Index, an evidence-based tool for assessing maternal health-care needs in rural areas. A funded researcher reports: "Since its development in 2007 and publication [Grybowski, Kornelsen, & Schuurman, 2009], the Rural Birth Index has been used to strengthen advocacy for vulnerable populations by quantifying a community's need." Policy briefs produced by this team continue to inform rural maternal health-care policy (CIHR IGH, 2011). Another team presented research results to government committees and informed a provincial plan to reduce poverty (CIHR IPPH, 2011).

The teams have expanded the knowledge base on the underlying causes of disparities and on tailoring relevant interventions. Supported researchers describe the impacts of their funded research:

> *The team . . . designed a CIHR-funded pilot study to develop a new Quality of Life Instrument for Homeless and Hard to Reach Individuals. From a program planning and policy perspective, this study implies that homelessness prevention strategies would be more efficient if they were specifically aimed at [population] clusters.*

Another research team was interested in access to health services for immigrants and refugees:

> *Our preliminary research points to remedies that should be considered . . . including elimination of 3-month waiting periods in the provinces that require it; facilitation of health coverage for those who are eligible; improvements to the refugee claims process; implementation of emergency health insurance coverage for those in need while their claims are in process . . . and at community health clinics; increases in capacity and relaxation of enrolment.* (Caulford & Vali, 2006, p. 1254)

One team conducted the largest study to date of high-risk exploited youth in North America. Another team developed a gender-sensitive scale for accessing barriers to cardiac rehabilitation available to health practitioners online (CIHR IGH, 2011).

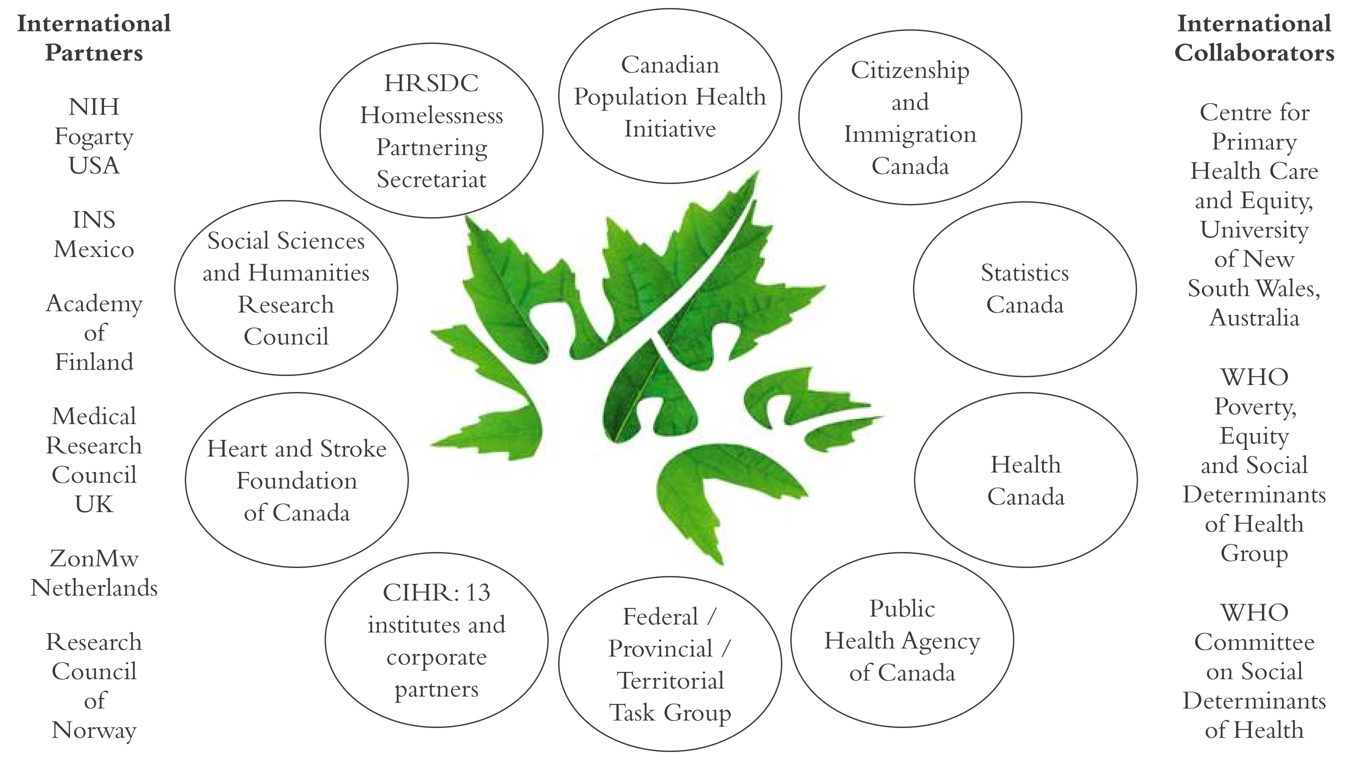
The initial 20 funded research teams communicated their findings through 430 journal articles, over 200 newspaper/magazine articles, and over 1,000 presentations at national and international conferences. Collectively, the teams successfully leveraged more than $40 million in additional funding (CIHR IPPH, 2011), representing a significant return on investment.

Creating Partnerships to Promote Health Equity Research

Research partnerships are essential in pursuing an evidence base focused on eliminating health disparities (Dankwa-Mullan et al., 2010). In Canada, responsibility for health is shared among federal and provincial/territorial governments. Consequently, the initiative forged important linkages with the Federal-Provincial-Territorial Task Force on Population Health, a body charged with advising government and government organizations at all levels. Ten national organizations, including major funders of health and social sciences research and organizations focused on influencing health-related policies (e.g., Canadian Population Health Initiative, Citizenship and Immigration Canada, Statistics Canada, Health Canada, Public Health Agency of Canada, Social Sciences and Humanities Research Council, National Homelessness Secretariat), joined the initiative as partners. These national partners helped guide strategic funding opportunities, support specific studies, and translate knowledge into effective practice, programs, and policies. Partnerships also were created with counterpart organizations internationally. International collaborators included the Fogarty International Center of the US National Institutes of Health, INS Mexico, the Academy of Finland, the Medical Research Council in the United Kingdom, ZonMW Netherlands, the Research Council of Norway, and the WHO Poverty, Equity and Social Determinants of Health Group (see Figure 1).

Reduction or elimination of health inequalities has become an international aim (Bleich et al., 2012). In preparation for an international think tank in 2003, the initiative commissioned leading Canadian scholars to prepare six papers synthesizing relevant research, published subsequently (Beiser & Stewart, 2005). The think tank attracted 103 researchers from across Canada, the United States, Mexico, Australia, and New Zealand. An international symposium held in 2006, dedicated to promoting interdisciplinary research and knowledge translation in Canada and other countries, engaged more than 130 researchers, research trainees, policy-makers, and representatives of non-governmental organizations. Dr. Michael Marmot, Chair of the WHO Commission on Social

Figure 1 *National and International Partners and Collaborators*



Determinants of Health, presented innovative research models and affirmed the importance of evidence-based policy: "This [Canadian] initiative aims not just to understand health disparities but to contribute to reducing and ultimately eliminating them" (Marmot, 2006).

The Canadian research initiative generated partnerships with the directors of the NIH National Center for Minority Health and Disease in 2004 and the Fogarty International Center in 2005. During Global Health Forum 8 and Ministerial Summit on Health Research in Mexico in 2004, meetings were held with delegates from Canada and Mexico to promote research collaboration and a Mexican–Canadian Dialogue on Vulnerable Populations was launched. In 2007 funding opportunities were generated with research organizations in five countries, leveraging millions of dollars through international partnerships. To illustrate, Public Health Challenges and Health Inequalities was created with the Academy of Finland, the Research Council of Norway, the Medical Research Council in the United Kingdom, ZonMW Netherlands, and five CIHR institutes.

Insights from the Canadian initiative were also shared with international audiences at the International Conference on Inner City Health (2002), the Mexico–Canada Collaboration Workshop (2002), the Canadian–Australian Dialogue on Health Disparities (2004), the Canadian Reference Group for the WHO Commission (2006), and the International Union for Health Promotion and Education (2007).

Other international impacts have emerged from the funded research. One team has worked with the ministry of health in Peru on a cord-clamping intervention to reduce infant anemia, while an investigation of marginalized youth has been cited as a promising intervention by the US Office of Juvenile Delinquency (CIHR IPPH, 2011).

Another supported researcher explains:

> *There has been considerable interest in our work by the international community of researchers in the field of intellectual disabilities, as several countries (Britain, Scotland, the United States, Australia) have all identified health disparities for this population as a major policy issue.*

Concluding Comments

This Canadian research initiative, mentioned in a recent review (Bleich et al., 2012), dedicated to promoting health equity and reducing health disparities began by focusing on creating new knowledge and building partnerships with organizations in health and health-related sectors that could use the information to effect change. It initially faced extremely limited research capacity and lack of funding partners. Moreover, challenges emerged in the early years regarding consensus on research priorities and the launch of specific strategic research initiatives. Barriers were posed by scepticism regarding the significance of a full spectrum of biomedical, clinical, health services, and population health research in understanding health disparities and health equity, of multiple methodologies, and of partnerships with health-related sectors — including those influencing income, education, justice, and culture at the provincial, national, and international levels, not just the health sector alone. Peer-review committees comprising established health-equity researchers had to be formed to bridge the gap in existing committees and to foster relevant and rigorous evaluation of proposals. Securing and sustaining funding to ensure excellent research is a continuing challenge. Successful strategies used to overcome these obstacles are emphasized in this article, including investing in consultation on research priorities; creating innovative and comprehensive strategic research funding opportunities; building research capacity through training and interdisciplinary multi-site teams and programs; promoting intervention research; fostering knowledge translation and transfer to policy, program, and practice domains; and mobilizing partnerships at the provincial, national, and international levels.

Research on how and why health inequities arise is facilitated when partners are committed to reducing them. Understanding disparities within and between countries and between groups in countries (WHO, 2008) and developing strategies to eliminate them depends not only on national partnerships but also on international collaborations. Consequently, the Canadian initiative has led an international think tank; facilitated international research partnerships with counterpart organizations in Mexico, Norway, the United Kingdom, the Netherlands, and the United States; and leveraged research funding through its international partnerships.

Canada's national community of scholars, practitioners, policymakers, and program planners set in motion by this CIHR initiative continues to pursue its conjoined goals: promoting health equity in Canada and striving to meet the international challenge articulated in the 2008 WHO report. Researchers and research institutions, in collaboration with knowledge users in practice and policy domains, can advance the priority need identified in this report for "Knowledge — of what the health situation is, globally, regionally, nationally, and locally; of what can be done about that situation; and of what works effectively to alter health inequity" (p. 33). This initiative reflects the call for translational, transformational, and transdisciplinary research on health disparities (Dankwa-Mullan et al., 2010) and the call for nursing research that promotes health equity (Reutter & Kushner, 2010). Nurse scholars led the launch and have sustained the legacy of this national research initiative. Moreover, nurse researchers and research trainees, supported by the initiative, have contributed to the expansion and translation of the health equity knowledge base.

References

Allin, S., Grignon, M., & Le Grand, J. (2010). Subjective unmet need and utilization of health care services in Canada: What are the equity implications? *Social Science and Medicine, 70*(3), 465–472.

Beiser, M., & Stewart, M. J. (2005). Reducing health disparities: A priority for Canada. *Canadian Journal of Public Health, 96*(Suppl 2), S4–S7.

Blakely, T., & Carter, K. (2011). Reflections from the antipodes on the English strategy to reduce health inequalities and Mackenbach's analysis. *Journal of Epidemiology and Community Health, 65*(7), 594–595.

Bleich, S., Jarlenski, M., Bell, C., & LaVeist, T. (2012). Health inequalities: Trends, progress, and policy. *Annual Review of Public Health, 33,* 7–40.

Canadian Institutes of Health Research. (2007). *Promoting Health Equity initiative 2001–2007.* Ottawa: Author.

Canadian Institutes of Health Research Institute of Gender and Health. (2011). *CIHR Institute of Gender and Health – Report for the 2011 International Review Panel.* Ottawa: Canadian Institutes of Health Research.

Canadian Institutes of Health Research Institute of Population and Public Health. (2011). *Internal assessment for 2011 international review. Canadian Population Health Initiative. (2008). Reducing gaps in health. A focus on socio-economic status in urban Canada.* Ottawa: Canadian Institute for Health Information.

Caulford, P., & Vali, Y. (2006). Providing health care to medically uninsured immigrants and refugees. *Canadian Medical Association Journal, 174*(9), 1253–1254.

Dankwa-Mullan, I., Rhee, K., Stoff, D., Pohihaus, J., Sy, F., Stinson, N., & Ruffin, J. (2010). Moving toward paradigm-shifting research in health disparities through translational, transformational, and transdisciplinary approaches. *American Journal of Public Health, 100*(Suppl 1), S19–S24.

Dowd, J., Zajacova, A., & Aiello, A. (2009). Early origins of health disparities: Burden of infection, health, and socioeconomic status in US children. *Social Science and Medicine, 68*(4), 699–707.

Edwards, N., & Di Ruggiero, E. (2011). Exploring which context matters in the study of health inequities and their migration. *Scandinavian Journal of Public Health, 39*(Suppl 6), 43–49.

Goldman, D., & Smith, J. (2011). The increasing value of education to health. *Social Science and Medicine, 72*(10), 1728–1737.

Grybowski, S., Kornelsen, J., & Schuurman, N. (2009). Planning the optimal level of local maternity service for small rural communities: A systems study of British Columbia. *Health Policy, 92*(2/3), 149–157.

Hawe, P., & Potvin, L. (2009). What is population health intervention research? *Canadian Journal of Public Health, 100*(1), 18–19.

Lebrun, L. (2012). Effects of length of stay and language proficiency on health care experiences among immigrants in Canada and the United States. *Social Science and Medicine, 74*(7), 1062–1072.

Mackenbach, J. (2011). Can we reduce health inequalities? An analysis of the English strategy (1997–2010). *Journal of Epidemiology and Community Health, 65*(7), 568–575.

Mackenbach, J., & Bakker, M. (2003). Tackling socioeconomic inequalities in health: Analysis of European experiences. *Lancet, 362*(9393), 1409–1414.

Marmot, M. (2006). *Keynote.* Reducing Health Disparities Interdisciplinary Research and Policy Symposium, March 9–10, Toronto.

Marmot, M., Friel, S., Bell, R., Houweling, T., Tanja, A. J., & Taylor, S. (2008). Closing the gap in a generation: Health equity through action on the social determinants of health. *Lancet, 372*(9650), 1661–1669.

Mier, N., Ory, M., Zhan, D., Conkling, M., Sharkey, J., & Burdine, J. (2008). Health-related quality of life among Mexican Americans living in colonies at the Texas–Mexico border. *Social Science and Medicine, 66*(8), 1760–1771.

Raphael D. (2008). Getting serious about the social determinants of health: New directions for public health workers. *IUHPE Promotion and Education, 15*(3), 15–20.

Reutter, L., & Kushner, K. E. (2010). "Health equity through action on the social determinants of health": Taking up the challenge in nursing. *Nursing Inquiry, 17*(3), 269–280.

Senate Subcommittee on Population Health. (2009). *A healthy, productive Canada: A determinant of health approach. Standing Senate Committee on Social Affairs, Science and Technology final report.* Ottawa: Author.

Stewart, M. J., Letourneau, N. L., & Kushner, K. E. (2010). Participatory pilot interventions for vulnerable populations. *Social Science and Medicine, 71*(11), 1913–1915.

World Health Organization. (2008). *Closing the gap in a generation: Health equity through action on the social determinants of health. Commission on Social Determinants of Health final report. Executive summary.* Geneva: Author.

Acknowledgements

The authors are grateful for the important contributions to this initiative made by Dr. John Frank, former Scientific Director of the CIHR Institute of Population and Public Health (IPPH), who was co-lead with the CIHR Champion of the initiative, Dr. Miriam Stewart, former Scientific Director of the CIHR Institute of Gender and Health (IGH); Dr. Morton Beiser, National Scientific Coordinator of the initiative; Erica Di Ruggiero, current Associate Director of IPPH; and Ximena Ramos Salas, former Assistant Director of IGH. Significant support for the initiative from other CIHR institutes and centres, national and international partners or collaborators, and funded researchers and research trainees is also greatly appreciated. The authors are grateful to Dr. Nancy Edwards for reviewing an earlier draft of the article as current Scientific Director

of IPPH. The authors are delighted that Pathways to Health Equity is being led by Dr. Malcolm King, Scientific Director of the CIHR Institute of Aboriginal Peoples' Health, and supported by IGH and IPPH.

Miriam J. Stewart, PhD, FRSC, FCAHS, is Professor, Faculty of Nursing, University of Alberta, Edmonton, Canada. Kaysi Eastlick Kushner, RN, PhD, is Associate Professor, Faculty of Nursing, University of Alberta.