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Erratum

In *CJNR* Vol. 38, N° 4 (Dec. 2006), the name of Maher M. El-Masri is misspelled. Dr. El-Masri is co-author of “Methodological Issues Associated with Using Different Cut-off Points to Categorize Outcome Variables” (p. 162). The Journal regrets and apologizes for this error.

Une erreur s'est glissée dans l'orthographe du nom de Maher M. El-Masri dans le Vol. 38, n° 4 (déc. 2006) de la revue CJNR. Le Dr El-Masri est un des auteurs de l'article intitulé « Problèmes méthodologiques liés à l'utilisation de différentes limites d'inclusion pour catégoriser les variables de résultats » (p. 162). Nous regrettons cette erreur et désirons nous en excuser.

EDITORIAL

Canadian Nursing Scholarship: A Time to Celebrate, a Time to Stand Guard

As we embark on this, the 39th volume of *CJNR*, I am amazed at how far nursing scholarship has come in a relatively short period. There is much to celebrate this year. Here are but a few examples of recent achievements by nurse researchers in Canada:

- At the fifth annual Canadian Institute of Health Research (CIHR) awards, held in November, two of the seven awards went to nurses. Nicole Letourneau received the Peter Lougheed New Investigator Award as Canada's premier young researcher for her work in promoting healthy child development in high-risk, vulnerable families, and Anne Snowden received the CIHR partnership award for her work with Daimler/Chrysler in promoting child health and safety (2006 Canadian Health Research Awards, 2006).
- Sean Clarke, an early graduate of one of Canada's first doctoral programs in nursing (at McGill University) and *CJNR*'s Associate Editor, was recently inducted as a Fellow of the American Academy of Nursing for his research on quality and safety issues in health care.
- Joan Bottorff and her colleagues report, in this issue of the Journal, on an intervention study of women's responses to information about mammographic breast density. This comes on the heels of the publication of the finding — widely reported in the media — by a landmark medical study that breast cancer is more common in women with dense breast tissue (www.cbc.ca/health/story/2007/01/17/breast-density.html). The concurrent publication of these two sets of results is an excellent illustration of nursing science's contribution to women's health and its complementary role to that of medicine.

There are many other indications that nursing is making an impact on health care:

- Nurses are key players in several of the (US) Institutes of Health and sit on many CIHR committees (Edwards, DiCenso, Degner, O'Brien-Pallas, & Lander, 2002).
- Five nurses hold 10-year investigator chairs awarded by the Canadian Health Service Research Foundation and the CIHR.

- Nursing research is funded by all the major national and provincial funding agencies.
- CIHR nursing grants have more than quadrupled, increasing from \$2.3 million in 2000 to over \$11.6 million in 2005. More significantly, financial commitments have gone from 30 in 2000 to 105 in 2005 (statistics provided by the CIHR).
- Between 1990 and 2004, 167 nurses completed PhDs in nursing at Canadian universities (Canadian Nurses Association and Canadian Association of Schools of Nursing [CNA and CASN], 2005).
- In the 4-year period 1998 to 2001, nursing research funding in Canada more than tripled, increasing from \$8.5 to \$27.5 million (Canadian Association of University Schools of Nursing, as cited in Pringle, 2006).

It has taken a mere 17 years to develop this critical mass of nurse scholars who have already made an unmistakable impact on the nursing profession and on health care. Although the Canadian nursing community built these successes, not all will remember the battles that were fought to arrive at this point. Those of us who were around in the early days never imagined how quickly the seeds of change, once planted, would take root and produce this amazing growth.

I consider myself a member of the second generation of nurse scholars, and I was both a witness to and a participant in the changes. As a young scholar, I attended the research meetings of the Canadian Association of University Schools of Nursing (CAUSN) in 1978 and 1980 where the first generation of nurse scholars developed strategies for establishing PhD programs in Canada. Among those who led the charge were Moyra Allen (McGill University), Marie-France Thibodeau (Université de Montréal), Shirley Stinson (University of Alberta), Helen Glass (University of Manitoba), and Marilyn Willman (University of British Columbia). They decided that the first PhD program would be a joint program of McGill University and the Université de Montréal. In the early 1980s a joint submission was made to the two universities, only to be rejected by the Faculty of Medicine at McGill because the powers that be did not understand nursing scholarship and did not believe there was enough science to support it. It took almost another decade for the University of Alberta to secure approval for a PhD program in nursing; 2 years after that, the university received funding to admit its first student.

In the meantime, as McGill and the Université de Montréal regrouped and prepared to resubmit their request, McGill mounted a PhD program in nursing through an “ad hoc” route, under the Faculty of Graduate Studies and Research (reserved for departments without formal PhD programs in their own discipline). The first student was

admitted in 1984. The first graduate was Francine Ducharme — in fact she was the first recipient of a doctorate in nursing from a Canadian university. Once Alberta's program received its funding, the McGill/Université de Montréal joint program was approved by both universities and the Quebec government. These programs were followed in quick succession by programs at the University of Toronto, the University of British Columbia, and McMaster University. The tipping point had clearly been reached.

The securing of funding for nursing research and the support of young investigators was yet another hard-fought battle. Through persuasive arguing, lobbying, and networking, the Canadian Nurses Association and CAUSN, under the able leadership of Dorothy Pringle (University of Toronto) and Mary-Ellen Jeans (McGill), earned respect and, more importantly, funding for a joint initiative of the Medical Research Council and the National Health Research and Development Program to support nurse scholars. The year was 1988. This infusion of financial support launched the research programs of many of today's senior scholars, including Celeste Johnston (McGill), Annette O'Connor (University of Ottawa), and Janice Morse (University of Alberta). There were three cycles of competition before the program was phased out. This initiative not only gave a tremendous boost to the research careers of these scholars, but also demonstrated to the granting agencies that nurses had the talent and skill to make a significant contribution to health-care research and to successfully compete for funds.

These developments, however, tell only part of the story. Equally noteworthy are the courage, commitment, and chutzpah that nurse scholars have shown — daring to be different in the face of repeated rejection. Some of these pioneers tried to fit their ideas and projects into existing academic environments, but without success. Others chose to move beyond traditional medical-epidemiological approaches to health research, favouring holistic, patient-centred, patient-empowered approaches to care. These nurse scholars were at the vanguard of a new movement. They developed theories and methodologies consistent with clinical realities. They embraced participatory-action research designs and feminist theory; used qualitative methodology; focused on the health needs and concerns of marginalized groups; created translation models to narrow the gaps between scholars, clinicians, and patients; and found ways to make a difference by developing and testing approaches together with patients/clients. Many nurse scholars continue to favour these theories and methods today, but with a difference — where once they had been outsiders, they are now virtually in the mainstream. There is growing recognition of these approaches within other disciplines and increasingly more discourse around such issues within granting agencies.

Other nurse scholars have used the more traditional positivist model to their advantage to address their research questions, and have gained recognition for this work; many have published widely in nursing, medical, and interdisciplinary journals.

In short, nurses have emerged from their insular and isolated world wrapped in feelings of inferiority and have gained the self-confidence needed to dare to be different. Many have become exemplary leaders, earning the acceptance, recognition, and respect of their peers in nursing and in other disciplines, and have played key roles in advancing interdisciplinary, collaborative work in their fields of research.

The first generation of leaders dreamt about what could be and knew that investment in education was the key to opening up the frontiers of nursing and health-care knowledge. They worked together for a common vision. They were relentless in their pursuit of this vision and refused to take no for an answer. In short, they were warriors. The battles they waged seemed unwinnable at times. In the beginning, there were few victories. What kept them going was mutual support, cooperation (with some competition), and conviction. Like all visionaries and pioneers, they were ahead of their time. Nonetheless, their work prepared the ground. When the timing was right, their ideas won them allies and supporters and eventually took hold.

Those of us who belong to the first and second generations of nurse scholars are proud of the accomplishments of the third generation and have confidence in the abilities of the fourth. The achievements of the new generation have been remarkable. These nurse scholars have the courage and negotiating skills necessary to thrive in an ever more competitive and difficult research environment (only 15% of submissions to the CIHR are successful). The new generation of scholars have succeeded because of hard work, solid training, high standards, willingness to make sacrifices, knowledge of the rules, and determination to stand their ground.

In short, they “get it,” just as their mentors “got it.” Many are now in mid-career and have developed exciting research programs. They have impressive publishing track records, have built sound research programs, and have produced, along with their students, an enviable body of work. They are respected scholars and mentors. Many have contributed to *CJNR* as reviewers or as authors of well-designed studies. They are now serving as guest editors, lending their considerable talents and expertise to advancing the knowledge of nursing science and providing knowledge for the practice of nursing and to the improvement of health services.

And yet as I write these words I see some disturbing trends. In recent years there has been a significant increase in the number of PhD

programs in nursing in Canadian universities. There are now 15 Canadian universities offering doctoral training in nursing, with 350 nursing students currently enrolled (CNA and CASN, 2005). We need to pause and think about where we are going and what is driving us as a profession and as a discipline. We need to consider whether we have the resources to support this number of high-quality doctoral programs. We need to ask ourselves: Do all of these programs have a critical mass of professors with the advanced nursing knowledge and research expertise necessary to train good scientists? Can all of these programs provide environments that are not merely adequate but rich and stimulating? How many doctoral students can a program support? What are the repercussions — for the number and quality of clinicians and advanced practitioners — of diverting resources from undergraduate and master's programs to doctoral programs? Some of these issues were raised by our colleagues in the United States when doctoral programs there were growing at a prodigious rate regardless of whether they possessed the resources and know-how to ensure high-quality training (Holzemer, 1990; Lenz & Hardin, 2001).

There is mounting evidence that we may be producing doctoral nurses who are inadequately prepared and will have difficulty making meaningful scientific contributions and competing successfully for grants. At *CJNR* we regularly receive manuscripts from doctorally prepared authors reporting on studies with fatal conceptual and methodological flaws, as well as “half-baked” manuscripts being rushed to submission for publication. We also receive submissions based on research studies that employ designs inappropriate for the questions being addressed, as well as papers that offer stunningly superficial interpretations of findings simply because the authors lack foundational knowledge in the underlying field. The list goes on.

The success of the last 17 years has been built on a strong foundation of nursing science and well-considered doctoral curricula implemented by well-trained, experienced, established, respected nurse scholars able to truly mentor newcomers by guiding them through a variety of research experiences. It is hardly surprising that graduates of these programs have been able to compete with the best and brightest scientists from other fields.

We are at a critical juncture. If we compromise quality and lower our standards, we run the risk of endangering the reputation of nursing as a serious science and, more importantly, providing poor science for the practice of nursing. We must stand on guard in order to protect what has already been built and determine the conditions that have to be in place to train first-rate nurse scientists. In the coming decade, we will have to go from strength to strength, not weakness to weakness. It is time for us

to pause, take stock of our successes, and reflect on current trends so that nursing as a discipline can continue to celebrate excellence.

Laurie N. Gottlieb
Editor-in-Chief

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GUEST EDITORIAL

Health Information Technology and Nursing Care

Carmen G. Loiselle and Sylvie Cossette

Nursing in the information age presents ample opportunities to transcend disciplinary, socio-economic, and geographical boundaries to enhance health-related outcomes.

With this first *CJNR* issue on Health Information Technology and Nursing Care, Drs. Gottlieb and Clarke had the vision of setting up a context for nurse researchers and others engaged in this booming field to share expertise on timely topics such as the latest knowledge developments, methodological challenges, and informative study findings as well as future directions.

Described as society's most knowledge-intensive environments (Snyder-Halpern, Corcoran-Perry, & Narayan, 2001; Sorrells-Jones & Weaver, 1999), health-care settings (which include health-care sites, health-care systems, and individual users) have been transformed by the information age and associated communication technologies. Ready access to timely information means that clinicians, administrators, policy-makers, researchers, and the public can more proactively engage in the processes of accessing health care, engaging in preventive actions, managing illness and trauma, considering treatment options, and ensuring follow-up care — regardless of where people live. However, with dramatic increases in health information and technology, nursing has begun to address critical issues pertaining to quality, usability, and equity of informational support while keeping in mind the context of users' background in terms of age, literacy, health and socio-economic status, and culture.

Although the concepts of health information technology, health informatics, nursing informatics, and e-health have yet to be clearly delineated, the articles presented herein share the goal of generating new knowledge and innovative care interventions that address the above issues to ensure that the resulting care approaches are safe, timely, effective, and efficient while responding to the needs of individuals (see also Bakken, 2006). In their study undertaken in Leuven, Belgium, on the effectiveness of a videophone nursing intervention on functioning of the home-

bound elderly, Drs. Arneart and Delesie show how such interventions enhance functioning for subgroups such as the elderly with restricted resources, whether family, social, or professional. Because home-based services are key to future health-care delivery, this article contributes to our knowledge about the types of interventions that are most suitable to particular groups of individuals. The findings of Drs. Arnaert and Delesie underscore the need to address issues of *what, when, to whom, and how* in terms of nursing interventions in the context of increasingly limited health-care resources.

In their cutting-edge study, Dr. Bottorff and her colleagues tested the impact of providing individualized information about personal risk for breast cancer on women's intention to undergo yearly breast cancer screening and on their perceptions of breast cancer risk status. This article informs nursing practice that relevant information provided to women enhances their self-confidence in engaging in preventive behaviours. This study also suggests that providing patients with health-related information does not necessarily increase their anxiety. Although general information about health and illness is widely available through e-health, personally relevant diagnostic information such as presented in this article, although often difficult to access, can be of great benefit to people.

The article by Drs. Kennedy and Hannah on the impact of an international classification system for nursing practice on health-care outcomes informs readers about the reliability of using standardized language to document nursing practice in various health-care settings. As Dr. Mathieu points out in the Discourse, there is an emerging trend towards the use of uniform nursing language to demonstrate the impact of specific nursing interventions on health-related outcomes across settings. Drs. Kennedy and Hannah provide evidence that the development of such a system can be well informed by research pertaining to nursing phenomena, nursing actions, and nursing outcomes.

Dr. Kerr and her colleagues test the contribution of two different preventive messages (tailored and targeted, provided through interactive game-type multimedia) on use of hearing protection among construction workers. Although noise-induced hearing loss is a major public health problem, conventional educational messages certainly did not attain their goal of modifying behaviour in this population, some three quarters of whom are affected by significant hearing loss. This article informs nursing practice by suggesting that social and interpersonal influences and perceptions of both barriers and benefits play important roles in explaining use of hearing protection.

Through a broad lens that includes the fields of consumer psychology and marketing, Ma and his colleagues propose an interesting research paradigm that involves both psychological and biological indicators of

stress related to mammography screening, using a computer-based imagery technique instead of relying solely on self-report of stress. These more sensitive measures show promise for detecting biomarkers of stress. By knowing *if* and *how* various preventive screening procedures induce stress, nurses will be able to design more targeted interventions to help alleviate such stress.

Last, Dr. Nguyen and her colleagues discuss methodological challenges in study design in e-health intervention studies. The discussion centres on issues encountered in previous studies but is also informed by the authors' own ongoing intervention work. Because the scientific underpinnings pertaining to e-health interventions remain in early developmental stages, there is ample opportunity for such theoretical and methodological discussions.

Recent research advances in the field are indeed well represented by the series of papers selected for this issue of *CJNR*. These works attest to nursing's readiness to engage actively in advancing the enriched care environment afforded by health information technology. A remaining challenge is to more directly address topics that have yet to receive enhanced empirical attention, such as e-health literacy, impact of e-technology on nursing practice and outcomes, acceptance and use of health information technology, patients' privacy and confidentiality issues, and the impact of nursing informatics on the nurse-patient relationship. Health information technology in nursing care is at a most promising juncture, with immense potential for advances in research, education, administration, and practice. The dynamic and responsive research agenda in nursing informatics being formed worldwide is likely to benefit both those receiving nursing care and the providers of such care.

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Carmen G. Loiselle, N, PhD, is Assistant Professor, School of Nursing, and Director, Oncology Nursing Program, McGill University; Senior Researcher, SMBD Jewish General Hospital; and Scientific Director, Psychosocial Oncology Research Training (PORT) program, Montreal, Quebec, Canada. Sylvie Cossette,

N, PhD, is Associate Professor, Faculté des sciences infirmières, Université de Montréal, Researcher, Centre de recherche de l'Institut de cardiologie de Montréal, and Co-director, Groupe de recherche interuniversitaire en sciences infirmières de Montréal.

Discourse

Nursing Informatics: Developing Knowledge for Nursing Practice

Luc Mathieu

This issue of *CJNR* on Information Technology and Nursing Care offers an excellent opportunity to examine this relatively new area of nursing practice and to review research in the field.

The term nursing informatics is often used to describe the integration of information technologies and communications into nursing practice. The American Nurses Association defines it as

A specialty that integrates nursing science, computer science, and information science to manage and communicate data, information, and knowledge in nursing practice. Nursing informatics facilitates the integration of data, information and knowledge to support patients, nurses, and other providers in their decision-making in all roles and settings. This support is accomplished through the use of information structures, information processes, and information technology. (American Nurses Association Workgroup, 2001, p. 4)

To what extent does this definition apply to actual nursing environments? Nursing is recognized as a profession in which the documentation of patients' characteristics and associated tasks take up a considerable amount of the practitioner's time. According to Bowles (1997), nurses in clinical settings spend up to 50% of their time documenting patient-related information. Snyder-Halpern, Corcoran-Perry, and Narayan (2001) describe nurses as knowledge workers and suggest that nurses base their practice on a large body of clinical information and on specialized knowledge, which enable them to engage in decision-making and to evaluate the decision-making process, its results, and their actions. The authors also identify four tasks performed by the nursing knowledge worker: collection of data, organization of information, interpretation of information, and development of knowledge. They state that these reflect the general tasks associated with human information processing. To fulfil their roles, nurses must be supported by clinical practice environments

designed with a clear understanding of knowledge workers' roles and the kinds of decisional support they require. It is my deep conviction that nursing information systems and information technologies have the potential to play a major role in supporting nurses. However, efforts must be made to ensure that nursing, as a discipline and as a profession, is satisfied with the proposed information and communication technologies.

Information systems that are acquired or developed within health-care establishments and used by nurses are essentially transactional and are seldom fully integrated. In addition, the interface among systems is often less than optimal. For instance, these systems handle transactions for which the data are often standardized (e.g., laboratory results, medications). They function more as clinical-administrative systems than as purely clinical ones (Ordre des infirmières et infirmiers du Québec, 2002) and serve nurses primarily in their role as data collectors. If this trend persists, nurses may have difficulty integrating information technology into their daily practice. Indeed, if nursing information systems continue to restrict nurses' tasks, there is a risk that nurses will resist using them, as they offer so little support to the more complex functions of knowledge utilization and knowledge development. Since nurses who devote a considerable amount of time to documenting their practice feel increasingly burdened with information management, it seems more appropriate to develop information systems that support nurses in their decision-making and other functions, where timely access to knowledge is crucial.

These propositions are consistent with the goals articulated in *E-Nursing Strategy for Canada*, a report published recently by the Canadian Nurses Association (CNA) (2006). One goal of this strategy is the full integration of information and communication technology (ICT) into nurses' practice, in order to optimize client outcomes and permit nurses to avail themselves of the knowledge they need to support their practice. Achievement of the goals proposed in this report requires greater involvement by nurses in the development and testing of the ICT systems on which they are expected to rely. These include systems to assist with clinical decision-making, electronic health charts, virtual communities for learning and practice, and tele-nursing. Too often it is the other way around — nurses are required to adapt to ICT, making their workload heavier rather than lighter. For instance, nurses could proactively engage in project development within Canada Health Infoway, whose mission is “to foster and accelerate the development and adoption of electronic health information systems with compatible standards and communications technologies on a pan-Canadian basis, with tangible benefits to Canadians” (<http://www.infoway-inforoute.ca/>

[en/Home/home.aspx](#)). Unfortunately, there is no critical mass of nurses involved in Infoway's ongoing projects.

It is becoming increasingly clear that nurses must adopt a common language pertaining to patients' health-related issues, nursing "diagnostics," nursing interventions, and health outcomes. I am referring to the Nursing Minimum Data Set (NMDS) and its Canadian equivalent, Health Information: Nursing Components (HI:NC). Work has been ongoing for several years, under the guidance of the CNA and the Canadian Institute for Health Information, to establish consensus on the use of the International Classification of Nursing Practice (ICNP). A broadening of the collaboration to include provinces, such as Quebec, would serve to benefit the profession. This presents various challenges, however: we must first agree on the key elements to include in the HI:NC and then ensure that information-system developers include them in their applications; in addition, the knowledge generated must be taught in colleges and universities so that nurses are equipped with the language and tools they need.

In spite of these challenges, considerable progress has been made in Canada in recent years towards making nursing informatics a reality. The Canadian Nursing Informatics Association (CNIA) and the Association québécoise des infirmières et infirmiers en systèmes et technologies de l'information (AQIISTI) are two complementary bodies that share the goals of creating networks of nurses interested in ICT, promoting the development of nursing expertise in ICT, and providing a forum for dialogue on issues in the field. The CNIA has conducted a national study (*Assessing the Informatics Education Needs of Canadian Nurses—Educational Component. Educating tomorrow's nurses: Where's nursing informatics?*), publishing its findings in 2003 (Canadian Nursing Informatics Association, 2003). More recently, it has launched the *Canadian Journal of Nursing Informatics*. The AQIISTI recently published a position paper on the need for nurses at every health-care site in Quebec to be knowledgeable about nursing informatics (*Avis concernant une ressource infirmière en systèmes et technologies de l'information (STI): Un enjeu pour les établissements de santé pour le Québec*), distributed to all health-care institutions in the province. The AQIISTI is currently preparing a position paper on the need for systematic training of nurses in nursing informatics.

I am well aware that this overview does not address all issues related to information technology in nursing. Additional issues worthy of discussion include remote training, rates of Internet use among nurses, and the future of tele-nursing.

I see several promising avenues for research, although prioritizing them is no small task:

- Which development methodologies are most efficient in ensuring that nursing information systems truly support nurses in their practice?
- How can ICT be used to support the knowledge-management work of nurses in order to promote the efficient integration of research results into nursing practice?
- How can ICT provide nurses with ready access to data, information, and knowledge when they need it and in the desired format?
- How best can nursing practice be documented in nursing information systems using nursing classifications?
- What factors serve to facilitate and to limit the use of ICT by nurses?
- What are the most efficient strategies for deploying ICT for nursing?

From an evaluation perspective, we need to address the following questions:

- What impact does the use of ICT have on nurses? On patients?
- What is the organizational impact of nurses' use of ICT?
- What are the most suitable person-system interfaces for nurses to use with the ICT they are offered?

I cannot conclude this commentary without affirming the urgency of the need to educate nurses in nursing informatics. At the very least, all nurses should receive basic training so they become judicious users of information technology. The CNIA study proposes several related avenues to pursue. We can also draw inspiration from the work of Staggers, Gassert, and Curran (2001) in developing training programs in nursing informatics. These authors identify four levels of competence within nursing informatics: beginning nurse, experienced nurse, informatics nurse specialist, and informatics innovator. I believe that, with the development of training programs up to the level of innovator, nursing informatics will eventually become widely recognized as a nursing specialty in Canada, as it has been among our American colleagues since 1992.

Finally, I would like to thank Drs. Carmen Loiselle and Sylvie Cossette for entrusting me with the task of writing this position paper.

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Luc Mathieu, DBA, is Associate Professor and Director, École des sciences infirmières, Faculté de médecine et des sciences de la santé, Université de Sherbrooke, Quebec, Canada.

L'efficacité du vidéotéléphone dans les soins infirmiers donnés aux personnes âgées confinées à domicile

Antonia Arnaert et Lucas Delesie

Le but de la présente étude était double : d'abord, concevoir un instrument de mesure du fonctionnement des personnes âgées confinées à domicile; ensuite, définir les caractéristiques des groupes chez qui les soins infirmiers par vidéo-téléphone apportent des résultats notables. Le projet s'inscrit dans le cadre de l'évaluation d'un programme de télésoins établi en Belgique. On a analysé les données recueillies auprès des 71 patients inscrits au programme pour tenter de décrire la nature du rapport entre les soins et l'aide reçus et les résultats cliniques obtenus. Onze critères de mesure du changement ont été mis au point à l'aide d'algorithmes d'analyse multidimensionnelle et appliqués au schéma décisionnel. Ils ont permis d'identifier des groupes de patients ayant démontré une amélioration notable après avoir reçu des télésoins dans des sphères de fonctionnement bien définies. Les résultats de l'étude suggèrent que les télésoins constituent un modèle alternatif pouvant être intégré aux services de soins à domicile dans l'optique d'offrir aux personnes âgées des soins holistiques.

Mots clés : télésoins, vidéotéléphone, personnes âgées confinées à domicile, résultats cliniques

Effectiveness of Video-Telephone Nursing Care for the Homebound Elderly

Antonia Arnaert and Lucas Delesie

This study had a dual purpose: to develop measures of change in functioning among the elderly, and to identify the characteristics of groups of homebound elderly whose functioning is significantly improved with video-telephone nursing care. As part of the evaluation of a home telecare program in Belgium, data from all 71 elders who received home care were examined in order to describe the nature of the relationship between the care/support received and health outcomes. The elders' functioning was measured using 8 assessment scales. Eleven measures of change in functioning were developed using multi-dimensional scaling algorithms. Use of these measures in the decision tree model made possible the identification of groups of homebound elderly who showed significant improvement following tele-nursing care in well-defined domains of functioning. The findings suggest that telecare is an alternative care model that could be integrated into existing home-care services to provide older people with integrated health services.

Keywords: tele-nursing care, video-telephone, homebound elderly, health outcomes

Introduction

As people age, accumulated and continuing changes and losses occur in their health, emotional, mental, social, and functional status (Schein, Gagnon, Chan, Morin, & Grondiness, 2005). Without appropriate care and support, the interactions of these multiple issues place older people at risk for adverse health outcomes, including mortality, falls, institutionalization, and hospitalization (Fried et al., 2001). Caring for the elderly with complex needs continues to be a challenge for health-care systems. In recent years community-based care has been promoted in health policies, as it offers the prospect of considerable cost savings as well as improved outcomes (Johri, Béland, & Bergman, 2003). The home is arguably the best site for the provision of community services, as most older people hope to continue living at home for as long as possible (Hellström & Hallberg, 2001). Health and social programs should be client-centred and respond holistically to the needs and preferences of care recipients (Chapman, Keating, & Eales, 2003; Fisher, 2005).

However, health services are still fragmented (Béland et al., 2006) and involve various health professionals, with little apparent coordination (Young et al., 2004). Some health-care reform initiatives in geriatrics, such as a single-entry-point system with case management, have been implemented successfully (Duke, 2005; Johri et al.). However, the challenge remains to develop complementary evidence-based models of integrated care that provide tailored care and result in improved health outcomes for the homebound elderly (Brown, 2003; Nies & Berman, 2004; Shaul, 2000).

Increasingly, multiple technologies are being used to deliver health care to patients in their homes (Marziali, Serafini, & McCleary, 2005). The availability of health care when it is needed is one of the key benefits of home telecare. This type of care has been defined as the use of information, communication, measurement, and monitoring technologies to evaluate health status and deliver care from a distance to patients in their homes (Celler, Lovell, & Chan, 1999). Home telecare trials for the elderly have shown that the delivery of interventions focused on monitoring, teaching, communication, support, and care results in improved health, autonomy, and quality of life (Bowles & Dansky, 2002; Chumbler, Mann, Wu, Schmid, & Kobb, 2004; Johnson et al., 2001; Savenstedt, Zingmark, & Sandman, 2003). The telecare delivery model makes it feasible, through the deployment of telecommunications networks, to target packages of care in response to assessed needs (Challis & Hughes, 2002). It promotes the delivery of targeted health and social services and enhances cost control, which is of interest to governments everywhere. According to Young (2003), the efficacy of community services is difficult to demonstrate due to a lack of targeting, which dilutes the effect of the interventions over a broad and diverse elderly population. Identifying groups of elderly at particular risk for certain outcomes is an important step in addressing their needs, expectations, and preferences (Diwan, Ivy, Merino, & Brower, 2001). Developing a better profile of the characteristics of the homebound elderly will be useful in formulating strategies that personalize treatment at the point of care and result in improved health outcomes. Although knowledge about the effects of home telecare on health outcomes for the elderly is increasing, and although the need for identification of the types of patients who could benefit from home telecare has been recognized (Shaul, 2000), the effects of tele-nursing on health outcomes for specific groups of homebound elderly have not yet been studied.

The present study had a dual purpose: to develop measures of change in functioning among the elderly, and to identify the characteristics of groups of homebound elderly whose functioning is significantly improved with video-telephone (VT) nursing care.

Methods

Design

As part of the evaluation of Telesenior, an established home telecare program in Belgium, data from all elders ($N = 71$) who received the home telecare intervention were examined in order to describe the nature of the relationship between the care and support received and health outcomes. The protocol was approved by the Telesenior Internal Review Board and the informed consent of the participants was obtained.

Home Telecare Program

Because of the existence of different terms, such as picture-phone, the concept of VT has been used to refer to an audiovisual technological tool for interactive, real-time interpersonal communication. Telesenior began to provide VT nursing services to the homebound elderly in 1992. The clients were 60 years of age or older, had a variety of chronic illnesses, had some degree of functional impairment, required assistance with activities of daily living (ADL), and lived in a geographical area with a well-developed two-way cable television network. The teleservice centre was equipped with a VT, a camera, a Public Switched Telephone Network (PSTN) alarm centre, and a line adapter unit connected to a maximum of three telephone lines. The unit allowed the nurse to switch voice connection among three simultaneous calls based on urgency. Audio and video signals were transmitted bi-directionally using a PSTN channel and an analogue broadcast television channel. Clients were supplied with an integrated home terminal, consisting of an alarm station, telephone, television, camera, and necklace transmitter in case of emergency. Telesenior cost some €1.5 million over the period 1992 to 1996. During the project, the equipment and VT communication were free for all clients, while some clients received additional benefits, such as an updated television set and free telephone or television cable connection. Each client paid only 50% of all telephone and cable services beyond the limits of the VT project.

The tele-nurses delivered psychosocial support and educational interventions based on three principles: contact and communication, safety and protection, and care mediation (Arnaert & Delesie, 2005). The total number of VT calls during the project was 11,209, but, as one VT call could cover a number of VT interventions, the tele-nurses recorded 21,013 VT interventions, categorized as follows: contact, recreation, physical health, psychological health, social health, housing, finances, care services, social administration, leisure activities, and other care. The main

reasons for making a VT call were contact, physical health, and social support.

Characteristics of the Sample

The mean age of the 71 participants was 72 years ($SD = 9.3$). The sample was 39.4% male (28 participants) and 60.5% female (43 participants). The majority (70.4%) were widowed and lived alone. Of the participants, 51 (71.8%) had attended high school until the age of 14. In 24 cases (33.8%), informal care was provided by a “child not living at home,” and 54 participants (76.0%) received formal care.

Procedure and Measures

On the first data-collection date, a trained nurse interviewed the participants in their homes about their use of support services provided by lay and professional caregivers. Sociodemographic data were also collected (age, gender, level of education, marital status, and family situation). Participant functioning was measured on three dates, at intervals of 6 months, using seven reliable assessment scales selected from the literature: Loneliness scale (12 items) (de Jong-Gierveld & Kamphuis, 1985), Geriatric Depression Scale SF-15 (GDS; 15 items) (Burke, Roccaforta, & Wengel, 1991), Lubben Social Network Scale (LSNS; 10 items) (Lubben, 1998), Activities of Daily Living (ADL; 6 items) (Katz & Apkom, 1976), Instrumental Activities of Daily Living (IADL; 8 items) (Lawton & Brody, 1969), Medical Outcome Study SF-36 (MOS SF-36; 36 items) (Ware, Snow, Kosinski, & Gandek, 1993), and Philadelphia Geriatric Center Morale Scale (PGCMS; 22 items) (Lawton, 1975). Mental status was measured using the Mini-Mental State Examination (MMSE; 11 items) (Folstein, Folstein, & McHugh, 1975) on the second date only. Data on the frequency of VT calls were gathered by the tele-nurses. Only calls actually involving VT care were retained; those concerning technical support or equipment training were excluded, as were accidental calls.

Analysis

The first step was to develop measures of change in functioning. As there was considerable overlap among the scales — for example, the concept of loneliness was measured twice in the PGCMS and in the Loneliness scale; and the MOS SF-36, the GDS, and the PGCMS all included items associated with the concept of depression — the original 120 items across all scales were aggregated into 24 measures of functioning using two multidimensional scaling (MDS) algorithms (Kruskal & Myron, 1978): SPSS®-PRINCALS and SAS®-PRINQUAL (Delesie, 2000). MDS encompasses a set of data analysis techniques that allow investiga-

tion of possible non-linear relationships between the items, between the elderly, and between the items and the elderly through geometrical representation of the relationships. Differences in ridit (Sermeus & Delesie, 1996) scores were used to measure *change in functioning* for the 24 measures. The concept of change in functioning differs from that of functioning, in the same way that acceleration differs from velocity and mood swing differs from mood; it requires more pinpointed, accurate, and sensitive measurement than concept measurement. Because no data were available to measure the change in mental state and only one common change measure for men and women could be retained from the original separate measures of physical IADL, 22 measures of change in functioning resulted. These 22 measures were aggregated using the MDS algorithms into *11 new measures of change in functioning* in the following domains: (1) general health functioning, (2) positive self-perception, (3) feelings of melancholy, (4) memory impairment, (5) levels of social activity, (6) emotional loneliness, (7) social loneliness, (8) ADL, (9) IADL, (10) family network, and (11) friends network. These 11 new measures were used in the analysis of benefits of VT care for specific groups of homebound elderly using the non-linear model of the decision tree algorithm (Takane, Oshima-Takane, & Shultz, 1994), which creates a hierarchical structure of classification rules (if...then...) resembling a tree. The input variables in the decision tree models pertained to support services, sociodemographic variables, and the 24 measures of functioning at the date of entry into the Telesenior program. The target variables in the decision tree models were the 11 new measures of change in functioning. The Goodman-Kruskal gamma coefficient of association (Goodman & Kruskal, 1979) for ordinal data was used to test the association between the 11 new measures and the frequency of VT calls for each group of clients identified in the decision trees.

Results

Measures of Change in Functioning

Table 1 shows, for each of the 11 measures of change in functioning, the key groups of homebound elderly for which VT care had a positive or negative impact. For each group, the significance of the association between the change and the frequency of VT calls is shown.

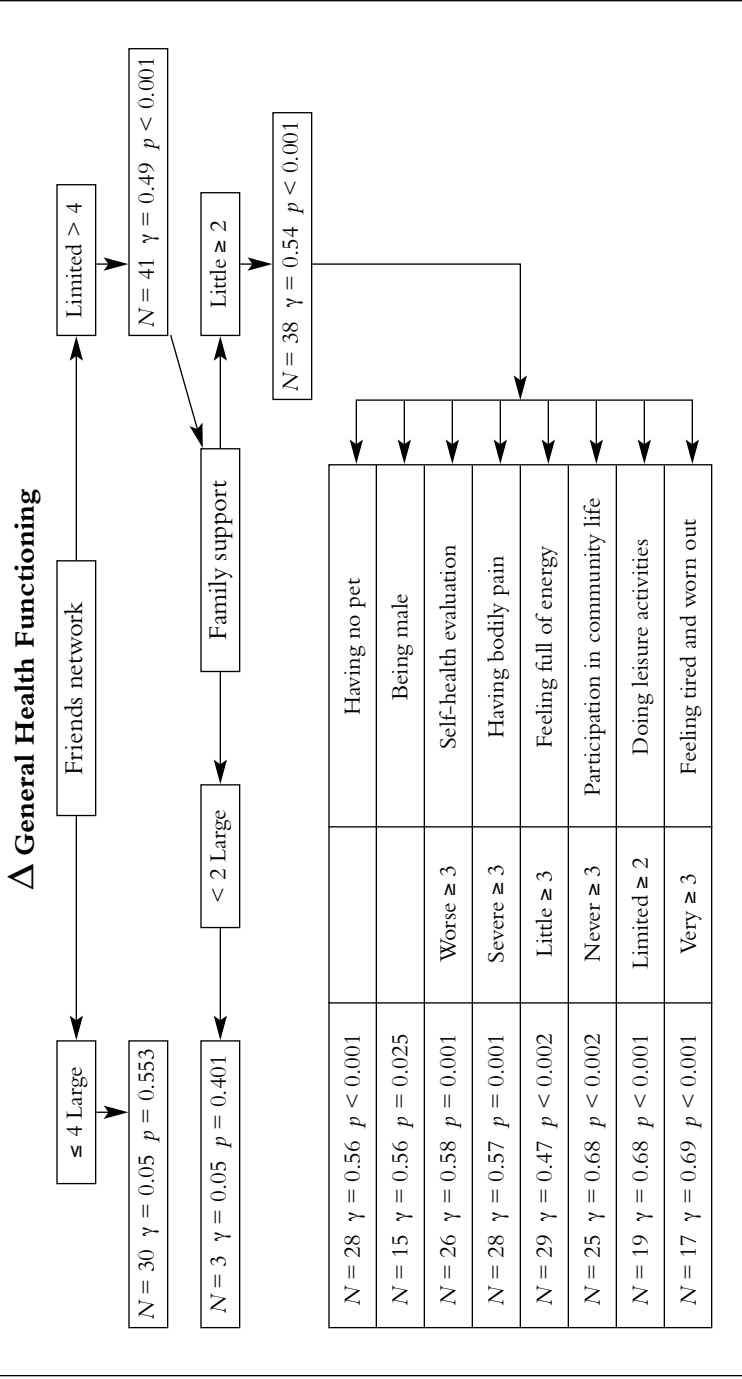
An example of the decision tree model for the measure *change in general health functioning* is outlined in Figure 1. For all relevant input variables, high scores correspond to poor functioning. For example, physical pain ≥ 3 means severe to very severe pain, and friends network ≥ 3 means limited network. The measure *friends network* generated the first binary split from the root node. One group included 30 participants

Table 1 *Groups of Elderly for Whom VT Care Had an Impact on Each of the 11 Measures of Change in Functioning*

Change Concepts	γ	p
<p>1. <i>Change in general health functioning</i> Group of elderly with limited friends network</p>	0.49 (n = 41)	0.001*
<p>2. <i>Change in positive self-perception</i> Group of elderly age > 75 who called their family physician frequently, had a limited friends network, watched TV roughly 5 hours a day, and listened to the radio throughout the day</p>	0.67 (n = 16)	0.001*
<p>3. <i>Change in feelings of melancholy</i> Group of elderly age \leq 70 who had a limited friends network, strong feelings of emotional loneliness, and little life energy</p>	0.60 (n = 11)	0.03*
<p>4. <i>Change in memory impairment</i> Group of elderly age \geq 70 who called their family physician frequently, had severe physical limitations, had moderate housing comfort, and were dissatisfied with their lives</p>	1.00 (n = 8)	0.04*
<p>5. <i>Change in levels of social activity</i> Group of elderly age \geq 70 who had severe physical limitations, had a limited friends network, did not participate in community life, and watched TV roughly 5 hours a day</p>	0.59 (n = 11)	0.04*
<p>6. <i>Change in emotional loneliness</i> Group of male elderly age \leq 70 who had low levels of activity</p>	0.56 (n = 8)	0.005*

Group of male elderly age ≤ 70 who had moderate physical limitations	0.79 ($n = 11$)	0.01*
Group of male elderly age ≤ 70 who had severe physical pain	0.58 ($n = 16$)	0.03*
<i>7. Change in social loneliness</i>		
Group of elderly age > 66 who frequently needed nursing care and home help and had strong feelings of emotional loneliness	0.60 ($n = 11$)	0.01*
Group of elderly age > 66 who frequently needed nursing care and home help and had limited social functioning	0.69 ($n = 10$)	0.01*
<i>8. Change in friends network</i>		
Group of elderly with extreme feelings of social and emotional loneliness and limited friends and family network	1.00 ($n = 8$)	0.04*
<i>9. Change in activities of daily living (ADL)</i>		
Group of elderly with severe physical limitations, little family support, and severe physical pain	-0.64 ($n = 17$)	0.04
<i>10. Change in instrumental activities of daily living (IADL)</i>		
Group of elderly with little housing comfort and little contact with children	-0.79 ($n = 10$)	< 0.00
<i>11. Change in family network</i>		
Group of elderly with extreme feelings of social loneliness, a limited friends network, and frequent need of nursing care and home help	-0.92 ($n = 10$)	< 0.00
* p value less than 0.001.		

Figure 1 Decision Tree Analysis of One Measure, Showing Significant Associations between Change and Frequency of VT for All Groups and Subgroups



who had a moderate to large network of friends. For these participants, the association between frequency of VT calls and *change in general health functioning* was small and not significant ($N = 30, \gamma = 0.05, p = 0.553$). Conversely, there was a positive significant association between frequency of VT calls and *change in general health functioning* for the group of 41 participants with a small network of friends ($N = 41, \gamma = 0.49, p < 0.001$). The second node, *family support*, split the group of 41 into two subgroups, one with considerable family support and one with little or no family support. A positive but non-significant association was found between frequency of VT calls and *change in general health functioning* for the group with considerable family support ($N = 3, \gamma = 0.05, p = 0.401$). A positive highly significant association was found between frequency of VT calls and *change in general health functioning* for the group with poor family support ($N = 38, \gamma = 0.54, p < 0.001$). On the third step, the decision tree split the 38 participants with poor family support into eight overlapping leaf nodes, with no hierarchical order: having no pet, being male, self-health evaluation, having bodily pain, feeling full of energy, participating in community life, participating in leisure activities, and feeling tired and worn out.

A group of 16 participants improved significantly on the measure *change in self-perception*. This group included those who were over 75 years of age, called their family physician weekly or more often, had a limited friends network, watched television roughly 5 hours a day, and listened to the radio throughout the day ($N = 16, \gamma = 0.67, p = 0.001$).

No significant association was found between frequency of VT calls and *change in feelings of melancholy* for the group of 32 participants who had low levels of life satisfaction and a limited friends network ($N = 32, \gamma = 0.09, p = 0.654$). However, one subgroup of 12 who were under 70 years of age with strong feelings of emotional loneliness ($N = 12, \gamma = 0.58, p = 0.047$) and a second subgroup of 11 with little life energy ($N = 11, \gamma = 0.60, p = 0.03$) showed significant improvement on the measure *change in feelings of melancholy*.

A group of eight participants aged 70 or over who called their family physician weekly or more often, had severe physical limitations, had moderate housing comfort, and were dissatisfied with their lives showed significant improvement on the measure *change in memory impairment* ($N = 8, \gamma = 1.00, p = 0.040$).

A positive significant association was found between frequency of VT calls and *change in levels of social activity* for a group of 11 who were 70 or over, had severe physical limitations, had a limited friends network, did not participate in community life, and watched television roughly 5 hours a day ($N = 11, \gamma = 0.59, p = 0.046$).

Men under 70 years of age who had low levels of social activity ($N = 8, \gamma = 0.56, p = 0.005$), moderate physical limitations ($N = 11, \gamma = 0.79, p = 0.014$), or severe physical pain ($N = 16, \gamma = 0.58, p = 0.03$) showed significant changes on the measure *change in emotional loneliness*.

For the measure *change in social loneliness* significant improvement was found for a subgroup who frequently needed nursing care and home help and had strong feelings of emotional loneliness ($N = 11, \gamma = 0.60, p = 0.014$) and for a subgroup who had limited social functioning ($N = 10, \gamma = 0.69, p = 0.017$).

Participants with extreme feelings of social and emotional loneliness and with a limited friends and family network showed positive significant improvement on the measure *change in friends network* ($N = 8, \gamma = 1.00, p = 0.046$).

Although significant, no positive associations were found between frequency of VT calls and the three measures *change in ADL*, *change in IADL*, and *change in family network*. A group of 17 participants with severe physical limitations, little family support, and severe physical pain showed a negative significant association with the measure *change in ADL* ($N = 17, \gamma = -0.64, p = 0.046$). A negative significant association with the measure *change in IADL* was found for the group of 10 with little housing comfort and little contact with their children ($N = 10, \gamma = -0.82, p = 0.023$) and for a subgroup of men with little housing comfort ($N = 10, \gamma = -0.79, p = 0.000$). The group of 10 who had family or relatives and had extreme feelings of social loneliness, limited friends network, and frequent need of nursing care and home help showed a negative significant association with the measure *change in family network* ($N = 10, \gamma = -0.92, p = 0.000$).

Discussion

Identification of vulnerable groups of patients is a necessary first step in targeting effective strategies for those who are at risk (Diwan et al., 2001; Nies & Berman, 2004). The results of this study demonstrate an association between tailored nursing care delivered via VT and improved health outcomes for specific groups of homebound elderly. They reveal that, for certain groups of older people, an improvement in one domain of functioning is likely to have a spillover effect in another. It has been shown that the concepts of loneliness and isolation in old age, influenced to some degree by one's level of social activity, can be a major cause of "sub-clinical" levels of unhappiness (McNeil, 1995) for which individuals are unlikely to seek or receive assistance and which may lead to increased depression and deteriorated health. The finding that tailored nursing care delivered via VT can reduce feelings of loneliness for the homebound

elderly is consistent with the results of previous studies (Mickus & Luz, 2002).

Moreover, in the present study those elderly who were older, were widowed, lived alone, had financial problems, and used several health and social services showed positive changes in feelings of social loneliness. The mechanism behind this improvement may be that the VT intervention provided them with a network of relationships in which they felt accepted, had common interests and concerns, and found help, advice, and support. These elders asked to be connected, through VT, with their children who lived far away and with other participants in the telecare program. In other telecare centres (Takano, Nakamura, & Akao, 1995), the multi-point VT network specifically caters to these expectations of its elderly participants. Characteristically, the participants in the present study spent time watching television and listening to the radio from early in the morning until late in the evening. They used their television as a focal point for their daily routines. The television served as a “window to the outside world” and may have been a substitute for primary interpersonal communication and relationships, offering companionship, information, and entertainment, and thus possibly increasing their life satisfaction (Grajczyk & Zollner, 1998).

The VT care may have had an indirect effect on the self-perception of the group of older elders. The results suggest that even leisure activities provided by the VT medium, such as playing games or just having a chat or sharing a joke with the tele-nurse, can improve levels of social activity and memory. An argument can be made that these leisure activities and the use of VT may be providing memory training for some older elderly. Also, Savenstedt et al. (2003) found that VT encounters can increase the attentiveness of elderly people with cognitive impairment and can help them become more focused on communicating.

The group of younger elders who had physical and mental general health problems, low levels of life satisfaction, and reduced levels of social activity showed decreased feelings of emotional loneliness following VT care. This group also showed a positive change in feelings of melancholy. Several studies have reported on the importance of isolation from friends or family or a decline in the social support network as precipitants of depressed feelings related to low levels of life satisfaction (Demura & Sato, 2003; Minardi & Blanchard, 2004). Having a good friend with whom to talk provides a sense of security and offers opportunities for companionship and intimacy that enhance life satisfaction in old age (Holmen & Furukawa, 2002; Lindgren, Svardsudd, & Tibblin, 1994).

The present findings reveal no positive improvements in ADL or IADL despite external help with housekeeping, such as laundry and food preparation, arranged by the tele-nurse. Nakamura, Takano, and Akao

(1999) matched two groups of 16 elderly patients on the basis of age, gender, and independence in ADL, and found significantly more improvement in ADL, communication, and social integration for the telecare group compared with the conventional home-nurse group. This difference may be explained by the fact that the samples were not comparable; the present study investigated the effect of tele-nursing care on groups of homebound elderly rather than the elderly in general. It may also be that the participants in the present study accepted the inevitability of their deteriorating ADL functioning, resulting in a positive change in self-perception rather than a positive change in ADL functioning.

Limitations

This study had several limitations. Frequency of VT calls was used as a measure of intensity of VT care among the participants. Future studies might measure the nature as well as the frequency of the VT calls in order to weigh the frequencies and better represent the level of VT care used. Another limitation is that the sociodemographic characteristics and support-service parameters were recorded only at the start of the Telesenior program, and mental state was measured only at the second data collection point. Also, the intensity of support services provided by lay and professional caregivers and VT care is prone to subtle changes over time, and these changes were not taken into account. Additionally there may have been sensitization of the VT user group. All of the prospective VT recipients were motivated and were encouraged to participate in the Telesenior program. Some participants really enjoyed using the VT. They had many visitors, such as the media, health policy-makers, and health professionals. Also, participation was free of charge and included additional benefits: an updated television set and free telephone and television cable connection. The extra attention may have contributed to changes in self-perception and loneliness, especially for elders with strong social needs.

The findings of this and other studies of VT interventions, and subsequent comparison of the findings with those from control groups, will provide a larger database from which to draw conclusions and on which to base health-care decisions.

Future Directions

The need for support and friendship to combat the effects of loneliness and isolation in old age is self-evident. Combating feelings of loneliness among elderly people will likely have a spillover effect in other domains of functioning related to their quality of life. The evidence indicates that the provision of care via VT for groups of homebound elderly can be

beneficial. In addition, telecare is an alternative care model that could be integrated into existing home-care services to provide older people with integrated health and social services. Additional descriptive and experimental studies need to be carried out in other localities, cultures, and health-care systems in order to identify those patients who could benefit from tele-nursing care.

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Authors' Note

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Comments or queries may be directed to Antonia Arnaert, School of Nursing, McGill University, Wilson Hall, 3506 University Street, Montreal, Quebec H3A 2A7 Canada. Telephone: 514-398-5624. E-mail: antonia.arnaert@mcgill.ca.

Antonia Arnaert, PhD, MPA, RN, is Assistant Professor, School of Nursing, McGill University, Montreal, Quebec, Canada. Lucas Delesie, PhD, MS, Ir, is Professor, Centre for Health Services and Nursing Research, Catholic University of Leuven, Belgium.

Réactions des femmes aux données mammographiques sur la densité du tissu mammaire

**Joan L. Bottorff, Pamela A. Ratner, Joy L. Johnson,
T. Gregory Hislop, Jane A. Buxton, Cornelia Zeisser,
Weihong Chen et Birgit Reime**

Les auteurs de cette étude se sont attachés à déterminer les aspects négatifs et positifs de la divulgation des résultats de mammographie sur la densité du tissu mammaire (DTM) aux participantes d'un programme de dépistage du cancer du sein. Ils ont mené une expérience aléatoire auprès d'un échantillon de 618 femmes âgées de 50 ans et plus, montrant une DTM supérieure à 5%. L'expérience consistait à préciser, dans la lettre sur les résultats de mammographie destinée aux intéressées, la DTM obtenue et à joindre un dépliant sur le sujet. Comparativement aux groupes témoins, un plus grand nombre de sujets du groupe expérimental ont expliqué correctement la notion de densité du tissu mammaire et admis qu'il s'agissait d'un facteur de risque de cancer du sein. Lorsqu'on a consulté les participantes quatre semaines plus tard, celles du groupe expérimental ont été plus nombreuses que celles des groupes témoins à indiquer qu'elles allaient « très probablement » demander de subir un examen annuel de dépistage; toutefois, au bout de six mois, on n'a constaté aucune différence notable entre les deux groupes. Aucune différence significative n'a été relevée non plus en ce qui concerne les autres critères comportementaux ou psychologiques, malgré le fait que le risque perçu de cancer du sein était « largement inférieur » chez les groupes. Les auteurs proposent ici un moyen d'information personnalisé sur le risque de cancer du sein, qui a l'avantage d'être réalisable et non alarmiste.

Mots clés : densité du tissu mammaire, dépistage du cancer du sein, mammographie

Women's Responses to Information on Mammographic Breast Density

**Joan L. Bottorff, Pamela A. Ratner, Joy L. Johnson,
T. Gregory Hislop, Jane A. Buxton, Cornelia Zeisser,
Weihong Chen, and Birgit Reime**

The objective of this study was to determine the negative and positive outcomes of providing mammographic breast density (MBD) information to participants of a screening program. A randomized experiment was conducted with a sample of 618 women 50 years or older with MBD greater than 50% of breast volume. The intervention consisted of reporting the presence of MBD in the screening mammography results letter that was sent along with an information pamphlet. Compared to the controls, more women in the intervention group described the term breast density correctly and recognized it as a risk factor for breast cancer. Although at the 4-week follow-up the intervention group indicated that they were “very likely” to have an annual clinical breast examination more frequently than controls, no differences were detected at 6 months. There were no significant differences on other behavioural or psychological measures, although at the 4-week follow-up the control group perceived their risk for breast cancer, relative to other women their age, as “a lot lower” than did women in the intervention group. The results demonstrate a feasible and non-threatening way to provide women with important personalized information about breast cancer risk.

Keywords: Breast density, breast cancer screening, risk communication, mammography

Introduction

Mammographic breast density (MBD), determined radiologically by assessing relative amounts of fat, connective tissue, and epithelial tissue, has emerged as an important risk factor for breast cancer: women with widespread MBD have a four- to six-fold increase in risk compared with women with no MBD (Boyd et al., 2005; Harvey & Bovbjerg, 2004). Although MBD diminishes with age, the elevated risk has been shown to persist for 5 to 10 years after initial classification (Boyd et al., 1995; Byrne et al., 1995). Having a relative with breast cancer is significantly associated with smaller MBD reductions at menopause (Knight et al., 1999) and menopausal hormone therapy is associated with increases in MBD (Boyd et al., 1995; Greendale et al., 1999; Persson, Thurffjell, & Holmberg, 1997). Possible explanations for the association between high levels of MBD and increased breast cancer risk include the development of premalignant lesions, elevated growth factors, and increased estrogen

production within the breast related to aromatase (Harvey & Bovbjerg). Evidence is accumulating that MBD can be reduced among women without breast cancer through a variety of strategies, including dietary interventions (e.g., low-fat, high-carbohydrate diets), stopping menopausal therapy, and tamoxifen treatment (Boyd et al., 1997; Boyd et al., 2001; Boyd et al., 2003; Cuzick, Warwick, Pinney, Warren, & Duffy, 2004; Knight et al.). Researchers have also begun to demonstrate a trend of decreasing risk for breast cancer with diminishing levels of MBD (van Gils, Otten, Verbeek, Hendriks, & Holland, 1998). Further, a more lucent pattern may increase the possibility of early detection through mammography. Although methods for enhancing estimations of MBD have been reported (Brisson, Diorio, & Masse, 2003; Pawluczyk et al., 2003), it is particularly important that women with high levels of MBD obtain regular screening to increase the likelihood of early detection (Whitehead et al., 1985).

Despite the importance of MBD, most women do not know if they have dense breasts. Some screening programs in Canada have begun to routinely assess MBD in all mammograms, often as a means of identifying eligibility for specific clinical trials. Because of concerns about causing undue anxiety, however, only one Canadian program routinely shares this information with clients or clients' physicians (Ontario Breast Screening Program, 2003). Several factors point to the need to review the current practice. Women seeking information about their personal risk for breast cancer report that this information would motivate them to engage in activities to reduce their risk (Bottorff et al., 2000). Women recently have begun to learn about MBD on the Internet and through the media and are beginning to request information about the nature of their breast tissue. Because MBD represents a potentially modifiable risk factor for breast cancer, we need to develop effective ways of notifying women who have high levels of MBD and, in a manner that is not overly distressing, providing them with accurate information about ways that MBD may be modified and about the need for regular screening.

The impact of MBD information remains unknown, although anecdotal evidence suggests that sharing it does not lead to inordinately high levels of worry (Boyd et al., 1997). The purpose of this research was to determine the negative and positive behavioural and psychological outcomes of providing personalized information about MBD in the context of a population-based mammography program. Two central hypotheses were tested: 1. *Women who receive MBD information will demonstrate higher rates of healthful behaviours related to managing breast cancer risk (e.g., participation in screening, including breast self-examination, clinical breast examination, and intention to undergo re-screening and make dietary changes) than women in the comparison group who do not receive this information.*

2. *Women who receive MBD information will not have significantly different psychological responses (preoccupation with breast cancer, breast cancer worry, and psychological distress) from women in the comparison group who do not receive this information.*

In addition, we addressed three research questions: 1. *What is the relationship between receipt of MBD information and knowledge of MBD as a risk factor (i.e., does exposure to the informational intervention increase women's knowledge)?* 2. *What is the relationship between receipt of information about MBD and women's perceptions of their risk for breast cancer?* 3. *What is the relationship between receipt of MBD information and subsequent advice-seeking behaviour?*

Methods

Design and Setting

A randomized pre-test, post-test experiment was conducted with the Screening Mammography Program of British Columbia (SMPBC) following approval by the university research ethics board. At the time of this study, the SMPBC was encouraging women 50 to 79 years of age to have a mammogram every 2 years. Free screening is offered to women throughout the province through 21 fixed centres, 12 ancillary centres, and 4 mobile programs. The women and their physicians are informed of the mammography results by mail. Reminder letters are routinely mailed to women who are due for re-screening. In 2002 the SMPBC conducted over 230,000 examinations, 86% of which were for returning participants. Five fixed regional screening centres, including one mobile screening program serving a rural population, were selected for the study based on the following criteria: (a) the number of examinations completed at the centre in the previous year was among the highest in the SMPBC program, and (b) all of the screening radiologists working at the centre were determined to assess MBD reliably.

Participants

The target population included all women who made appointments for re-screening at one of the selected screening centres between February 2002 and August 2003 and who met the following criteria: (a) on a previous visit indicated a willingness to participate in research, (b) were 50 years of age or older, (c) were never diagnosed with breast cancer, (d) did not report the presence of breast lumps or discharge, (e) were able to comprehend English, (f) had MBD > 50% and an otherwise normal mammogram at the previous visit, (g) were not participating in other breast cancer prevention studies, and (h) were willing to participate.

Sample-size calculations were conducted for each hypothesis in light of the expected findings using Cohen's power tables (Cohen, 1988) and

Kelsey, Thompson, and Evans's (1986) formulae. The conditions set for the study were: (a) 90% statistical power, and (b) $\alpha_{(2\text{-tailed})} = .05$. The expectation for H_2 was a null effect in that we expected to find no adverse psychological effects. Consequently, we wanted to ensure that failure to note differences between the groups did not result because of insufficient power. There was a danger that too much power would result in statistically significant findings in H_2 because of trivial departures; consequently we sought to find a balance such that a minimal meaningful difference could be detected if it existed. We also took feasibility into consideration in light of attendance rates at the screening centres and an expected dropout or loss-to-follow-up rate of 10%. A priori calculations indicated that, with 535 participants, we would have an adequate number of cases to conduct multivariate analyses.

Intervention

The women in the intervention group received information about their MBD with the mailed results of their mammogram, along with a pamphlet describing MBD (including photographs showing mammograms of dense and not-dense breasts) and other risk factors for breast cancer, factors that influence MBD (i.e., age, hormone therapy, dietary fat), and risk-reduction strategies (i.e., regular breast screening, healthful low-fat diet, healthful lifestyle).¹ The results letter included a statement indicating that the woman had MBD, briefly described what is known about MBD, and provided reassurance that having MBD does not mean that a woman has or will have cancer. Because alternative screening modalities such as ultrasound are not routinely available for women with MBD in the study setting, they were not mentioned in the information pamphlet. The mammogram results letter, signed by the director of the screening program, was sent to both the woman and her family physician.

The intervention letter and pamphlet were developed in conjunction with the staff of the SMPBC and other experts, with input by women with MBD, and incorporated concepts from the Health Belief Model as well as constructs such as psychological distress and self-efficacy. The messages about MBD and breast cancer risk factors included in the intervention were designed to influence perceived susceptibility to breast cancer in addition to reassuring women that they did not have breast cancer. Since receipt of abnormal mammogram results is often associated with increased anxiety (Rimer & Bluman, 1997), information about risk-reduction strategies was framed positively, addressing the benefits of regular breast screening and the positive outcomes associated with a healthful diet and lifestyle (Finney & Iannotti, 2002). In addition, direct

¹ A copy of the intervention pamphlet and results letter can be obtained from the lead author.

linkages were made between these recommendations and women's risk for breast cancer, in order to enhance perceived control and self-efficacy.

The women in the control group and their physicians received the usual results letter sent by the screening centre (i.e., without reference to MBD). These women provided baseline and follow-up data in a manner identical to that of the intervention group.

Procedures

Women who phoned to make an appointment for re-screening and who met the initial eligibility criteria were recruited by telephone before attending the screening centre for their scheduled mammogram. Informed consent was sought from eligible women (signed consent was obtained subsequently, when the woman attended her screening appointment, or, if necessary, the consent form was mailed to the woman with a stamped, self-addressed envelope), and baseline (pre-test) data were collected via a telephone-administered questionnaire to measure anxiety, depression, breast cancer worry, subjective and objective estimates of breast cancer risk, family history of breast cancer, distance to mammography screening centre, and demographics. Women who were found, upon re-screening, to have suspicious or abnormal findings or who did not have MBD > 50% were excluded from further involvement in the study. The other women were randomly assigned to the intervention or the control group. The SMPBC computer that tracked appointments was used to determine group assignment by randomly generating a number with the generator initialized by using the computer's real time clock as the seed. The number generated was passed through a rule such that if the number fell below 500,000 the woman was assigned to the control group and if the number was 500,000 or above the woman was assigned to the intervention group.

Group-appropriate mammogram results letters were then generated and posted to the women and their physicians by the screening program staff. The usual time between screening and reporting of results was 1 week. At 4 weeks and 6 months following screening, the women in both groups were telephoned and interviewed by research assistants who were blind to group assignment.

Before commencement of the study, all family physicians in the study communities were sent a letter describing the study, along with a telephone number for the project director, a copy of the MBD pamphlet, and additional information on MBD, including a copy of a journal article (Hislop, Coldman, Warren Burhenne, Smart, & Olivotto, 1997; Tristant, Chiche, & Lvy, 2002), the purpose being to ensure that, if approached, physicians would be prepared to discuss MBD with the study participants.

To make certain that all data were of high quality, all research assistants were trained in data-collection procedures and telephone-interviewing techniques. At the SMPBC, radiologists routinely assess MBD and receive formal education in its visual assessment. As is standard practice in this screening program, assessments of MBD were limited to two categories: MBD occupying $\geq 50\%$ of breast volume, and MBD occupying $< 50\%$ of breast volume. Before the study commenced, a reliability check of MBD assessments on a sample of mammograms was made for all screening radiologists by a senior reference radiologist. Only women seen by screening radiologists with reliable scores for MBD determination were included in the study.

Measures

Perceptions of personal risk were assessed by asking the women to rate their own lifetime risk of breast cancer (1 = none at all, 6 = very high) and to compare their risk of developing breast cancer to that of other women their age (1 = a lot lower, 5 = a lot higher). The upper two response categories for each item were collapsed into one category because of infrequent endorsement.

Preoccupation with breast cancer was assessed by measuring the psychological effects of receiving the mammogram results using the intrusion-subscale of the revised Impact of Event Scale (IES) (Horowitz, Wilner, & Alvarez, 1979). This subscale has demonstrated acceptable internal consistency (Cronbach's $\alpha = .78$) and has been found to be a sensitive measure of the psychological impact of the notification of breast cancer risk (Kash, Holland, Halper, & Miller, 1992; Lerman et al., 1993; Lerman et al., 1995; Lerman, Kash, & Stefanek, 1994).

Breast cancer worry and fear were assessed using a series of Likert-type items developed by Lerman and colleagues (Lerman et al., 1993; Lerman, Trock, Rimer, Boyce, et al. 1991; Lerman, Trock, Rimer, Jepson, et al., 1991) that measure the frequency with which women worry about developing breast cancer, the impact of such worry on mood and daily functioning, and current levels of anxiety related to the results of future mammograms.

Psychological distress was assessed using the nine-item anxiety subscale of the Brief Profile of Mood States (POMS) (McNair, Lorr, & Droppleman, 1992). All 20 items of the Center of Epidemiological Studies Depression scale (CES-D) were used to measure signs of depression (Radloff, 1977).

Behavioural consequences were measured using items focused on participation in breast cancer screening and in dietary changes. First, the women were asked if they had had a clinical breast examination since their mammogram (4-week follow-up) or last interview (6-month

follow-up) and the likelihood of their having a clinical breast examination every year (at 4-week and 6-month follow-up). In a similar fashion, the women were asked about breast self-examination. These questions were taken from Canada's Health Promotion Survey (Stephens & Graham, 1993). Finally, at the 6-month follow-up the women were asked about their intention to return for mammography within the recommended time interval. At the time of the study, the SMPBC was recommending that all women over 50 years of age (regardless of MBD status) have a mammogram every 2 years. In relation to diet, at 4 weeks and 6 months the respondents were asked how healthy their diet was, if they had made changes to their diet, and what changes they had made.

Background factors measured at baseline included demographics and family history of breast cancer (using the Gail Model Risk Assessment Tool; Gail et al., 1989).

Women's knowledge of breast density was measured at the 4-week follow-up. First, the women were asked whether they had ever heard of the term breast density. If they said yes, they were asked to describe the term. Two questions were used to ask the participants to judge whether women with breast density have a greater chance of developing breast cancer than women without breast density (yes/no) and how important it is for women to know if they have breast density (1 = *not at all important*, 4 = *very important*). These two questions were also posed at the 6-month follow-up.

Advice-seeking behaviour was assessed at both follow-ups. First the women were asked if they had received information about their risk for breast cancer since their last telephone interview and whether they had discussed the information with anyone.

Psychometric Verification of Measures

The reliabilities of the IES, CES-D, and POMS anxiety subscale were found to be sufficiently high (ranging from 0.7 to 0.8), and factor analyses confirmed the established factor structures of these scales. In Lerman et al.'s (1996) work, the two breast cancer worry-impact items were found to be highly correlated ($r = 0.63$) and thus were used to create a breast cancer worry index. However, similar psychometric characteristics were not found in the present study. Therefore, the two worry-impact items were treated as individual measures.

Data Analysis

The data were screened for entry errors, missing data, and possible outliers. For all statistical analyses, critical values were set at $p < .05$ for two-tailed tests. The two study groups were compared in terms of their baseline demographic characteristics and personal background factors,

because the randomization split between the intervention and control groups was less than optimal (non-equivalent sizes).

Before testing the hypotheses, we examined whether exposure to the intervention increased women's knowledge of MBD as a risk factor for breast cancer by comparing the two randomized groups on questions related to knowledge of breast density using Chi-square analyses. We then compared the two groups on measures of participation in screening using Chi-square analysis. Multiple logistic regression analyses were conducted to explore potential covariates and predictors of intended screening participation. The dependent variables were examined for group differences using Chi-square analysis for categorical data and Student's *t* test for continuous data. Descriptive statistics were used to determine particular patterns of women's advice-seeking behaviour upon receipt of MBD information.

Results

Sample

A total of 1,328 women met the initial study criteria. Of these, we were able to contact 1,188 by telephone for further assessment of eligibility and to determine their willingness to participate. Of these women, 97 did not meet the initial inclusion criteria: 45 were unable to comprehend English; 40 did not appear for their scheduled screening appointment or had already had a mammogram; 8 had participated in other breast cancer prevention studies; and the remainder reported breast discharge ($n = 1$), a suspected lump ($n = 2$), or cancer ($n = 1$). On re-screening, 185 women did not have MBD $\geq 50\%$ or had an abnormal mammogram and were excluded. Of the 906 remaining women, 288 refused to participate in the study, the majority citing lack of interest (63.0%) or being too busy (16.2%) (participation rate = 68.2%). Non-participants were compared to participants using data available from the SMPBC. No significant differences were found for age, number of previous mammograms with abnormal findings, and number of screenings in the preceding 6 years. The mean length of time since their last mammogram at the SMPBC, however, was significantly different: 26 months for non-participants and 23 months for participants ($t_{(404.8)} = 2.03, p = .04$).

The final sample included 618 women, with 333 participants in the control group and 285 in the intervention group. The random assignment process did not result in a 50/50 split; no obvious bias was identified, however, in the greater likelihood of assignment to the control group. The two groups did not differ significantly on baseline measures (see Table 1). Of the 618 participants at baseline, 579 (93.7%) completed the 4-week survey and 586 (94.8%) the 6-month survey. Similarly, there was no differential loss to follow-up at 4 weeks ($\chi^2 (1, N = 618) = .45, p = .50$) and 6 months ($\chi^2 (1, N = 618) = .01, p = .93$).

Women's Knowledge of MBD as a Risk Factor for Breast Cancer

At the 4-week follow-up, 93.2% of the women in the intervention group and 72.1% in the control group said that they had heard the term breast density ($\chi^2 (1, N = 577) = 42.8, p < .001$). Among those who had heard the term, 24.8% in the intervention group described it correctly, 48.6% had a vague answer, and 26.6% described it incorrectly. The corresponding figures for the control group were 7.5%, 63.8%, and 28.7%. Chi-square analysis revealed that more women in the intervention group than in the control group could describe the term breast density correctly ($\chi^2 (2, N = 402) = 22.3, p < .001$). More women in the intervention group than in the control group recognized breast density as a risk factor for breast cancer (85.3% at 4 weeks and 89.2% at 6 months) (66.4% and 63.8%, respectively) ($\chi^2 (1, N = 336) = 16.5, p < .001$ at 4 weeks and $\chi^2 (1, N = 374) = 34.9, p < .001$ at 6 months).

Behavioural and Psychological Outcomes

The two study groups were compared in relation to breast screening behaviours (clinical breast examination, breast self-examination, and mammography). Although at the 4-week follow-up the intervention group ($n = 61, 23.0\%$) more frequently than controls ($n = 47, 15.1\%$) indicated that they were "very likely" to have an annual clinical breast examination ($\chi^2 (1, N = 576) = 8.86, p = .03$), no differences were detected at 6 months. Logistic regression analyses using baseline measures did not identify any significant predictors of intended annual clinical breast examination. Group comparisons revealed no statistically significant differences at the 4-week and 6-month follow-up for engagement in breast self-examination and intention to return for screening mammography within the recommended time interval. There were no significant differences between the groups in participants' assessment of their diet, in the number who reported making changes to their diet, and in the type of changes made at both follow-ups. No statistically significant differences were found in any of the psychological outcomes: preoccupation with breast cancer (IES, Intrusion subscale), breast cancer worry/fear, and psychological distress (POMS and CES-D) at either follow-up (see Table 2).

Women's Perception of Risk for Breast Cancer upon Receipt of MBD Information

At the 4-week follow-up, group comparison revealed no significant differences in the women's perceptions of their lifetime risk of breast cancer. However, a significant difference was found with respect to the women's relative risk perceptions (i.e., compared to other women their age)

Table 1 *Baseline Comparison of Control and Intervention Groups by Demographic/Personal Background Characteristics, Perception of Breast Cancer Risk, and Psychological Responses*

Variables	Control (n = 333)	Intervention (n = 285)	Statistics ^a	
			t	χ^2
<i>Age</i> (mean years)	65.9	66.1	-0.45	
<i>Education level</i> (%)				3.32
High school incomplete	6.4	5.6		
High school complete	23.9	27.4		
Postsecondary degree (university not included)	39.4	33.0		
Bachelor's or postgraduate degree	30.3	34.0		
<i>Years of schooling</i> (mean)	14.8	15.1	-1.26	
<i>Born in Canada</i> (no) (%)	34.8	32.3		.34 ^b
<i>Years lived in Canada</i> (mean)	38.4	39.7	-0.79	
<i>Marital status</i> (%)				.98
Married/common law	67.4	69.5		
Separated/divorced/widowed	25.9	22.8		
Single	6.6	7.7		
<i>Household income</i> (%)				3.42
< 10,000–29,000	18.2	16.7		
30,000–59,000	41.3	34.8		
60,000–89,000	22.2	29.3		
90,000+	18.3	19.2		
<i>Residence</i> (%)				.39 ^b
Urban	72.7	75.3		
Rural	27.3	24.7		
<i>Distance to mammography screening centre</i> (mean miles)	7.8	6.7		.41
<i>First-degree relatives with breast cancer</i> (%)				.57 ^b
None	81.7	84.3		
One or more	18.3	15.7		

Women's Responses to Mammographic Breast Density

Variables	Control (n = 333)	Intervention (n = 285)	Statistics ^a	
			t	χ^2
Gail lifetime risk of breast cancer (mean %)	9.1	8.7	.88	
Own lifetime risk perception (%)				.71
None at all	8.1	8.7		
Very low	25.8	22.9		
Low	36.0	36.7		
Moderate	24.5	25.8		
High	5.6	5.8		
Relative risk perception (%)				6.46
A lot lower	14.9	8.1		
Somewhat lower	34.0	36.7		
About same	40.3	43.0		
Higher	10.8	12.2		
How often worry about getting breast cancer? (%)				3.01
Not at all	32.2	30.3		
Rarely	40.7	36.3		
Sometimes	24.1	29.6		
Often to almost all of the time	3.0	3.9		
Breast cancer worry affecting mood (%)				.16
Not at all	64.9	65.5		
A little	25.8	24.4		
Somewhat to a lot	9.3	10.2		
Breast cancer worries affecting functioning (%)				.14
Not at all	92.9	91.9		
A little	4.9	5.6		
Somewhat to a lot	2.2	2.5		
POMS anxiety subscale score (mean)	15.1	14.8	.78	
CES-D total score (mean)	7.2	6.5	1.17	

^a None of the test statistics was statistically significant at $p < .05$.

^b Yates's continuity correction applied.

Table 2 Comparison of Control and Intervention Groups by Psychological Responses for Follow-up Data

Variable	Control		Intervention		Statistics ^a		
	4 weeks (n = 314)	6 months (n = 316)	4 weeks (n = 265)	6 months (n = 270)	4 weeks T	6 months T	χ^2
Impact of Events Scale, Intrusion subscale (mean)	26.1	26.2	26.2	26.0	-0.28	0.64	
How often worry about getting breast cancer? (%)					1.65		0.24
Not at all	36.6	34.5	31.7	35.2			
Rarely	43.0	44.6	45.3	45.6			
Often	20.4	20.9	23.0	19.3			
Breast cancer worry affecting mood (%)					0.01		1.82
Not at all	69.3	69.6	69.6	73.7			
A little	24.1	23.2	23.8	17.7			
Somewhat to a lot	6.5	7.2	6.6	8.6			
Breast cancer worry affecting functioning (%)					0.21		0.95
Not at all	91.3	90.3	92.3	90.3			
A little	6.6	5.3	5.5	6.9			
Somewhat to a lot	2.0	4.3	2.2	2.9			
POMS anxiety subscale (mean)	15.6	15.9	15.2	15.9	1.00	-0.09	
CES-D total score (mean)	6.9	6.8	6.8	6.6	0.14	0.33	

^a None of the test statistics was statistically significant at $p < .05$.

($\chi^2 (N = 579) = 8.00, p = .046$). More women in the control group ($n = 46, 15.5\%$) than in the intervention group ($n = 27, 10.5\%$) perceived their risk as “a lot lower.”

At the 6-month follow-up, no significant differences were found between the study groups with respect to perception of lifetime or relative risk of breast cancer (see Table 3).

Women's Advice-Seeking Behaviour upon Receipt of MBD Information

At the 4-week follow-up, the women were asked if they had received information about their risk for breast cancer. In the intervention group, 106 women (40%) recalled receiving risk information in either the SMPBC results letter or the SMPBC pamphlet. Of these women, 45 reported they had discussed their risk for breast cancer with one or more individuals, including their husband/partner (48%), physician (21%), friends (17%), and family members (13%). Only one woman reported contacting the screening program staff to discuss her results.

Variable	Control		Intervention		Statistics	
	4 weeks (n = 314)	6 months (n = 316)	4 weeks (n = 265)	6 months (n = 270)	4 weeks χ^2	6 months χ^2
Own lifetime risk perception (%)					9.27	5.39
None at all	7.7	9.4	6.7	7.9		
Very low	34.0	32.8	23.2	25.6		
Low	32.0	31.5	36.2	34.2		
Moderate	22.7	23.7	28.3	28.2		
High	3.7	2.6	5.5	4.1		
Risk perception relative to other women (%)					8.00*	5.26
A lot lower	15.5	16.7	10.5	10.6		
Somewhat lower	35.0	32.1	29.3	33.0		
About the same	38.7	42.6	50.0	45.1		
Higher	10.8	8.5	10.2	11.4		
* $p < .05$.						

Discussion

To our knowledge, this is the first study to evaluate the outcomes of a risk-notification intervention designed specifically to provide personalized information about MBD and risk-reduction strategies in the context of a population-based mammography screening program. In this study, women's knowledge of breast density as a risk factor for breast cancer was enhanced by the information provided with their mammography results letter.

Those concerned about the effect, on women's psychological well-being, of sharing MBD information in mammogram results letters should be reassured by our finding that the receipt of personalized MBD information is not associated with increased breast cancer worry, anxiety, or depressive symptoms. Although many women become anxious after being told they have an abnormal mammogram (Brett, Austoker, & Ong, 1998; Gilbert et al., 1998; Gram, Lund, & Slenker, 1990; Gram & Slenker, 1992; Lerman, Trock, Rimer, Boyce, et al., 1991; Lowe, Balanda, Del Mar, & Hawes, 1999), it appears that the women in this study did not interpret their MBD status as an abnormality. The statement we included in the mammogram results letter reassuring women with MBD that their mammogram was normal appears to have been effective.

The difficulties experienced by lay people in understanding risk-related information (e.g., probabilities or percentage estimates) are well documented. Because the MBD information was provided in the context of a mammography screening service, we wanted to be sure that it did not increase women's misunderstanding of their risk. Although at follow-up no significant difference between the two study groups was found with respect to perception of lifetime risk for breast cancer, at the 4-week follow-up fewer women in the intervention group than in the control group rated their risk for breast cancer as "a lot lower" than that for other women their age. These findings suggest that receipt of information about MBD may have increased the accuracy of risk perception by reducing the women's propensity to be optimistically biased about their personal risk for breast cancer.

Although we had hoped that providing MBD information would encourage women to engage in recommended screening practices, the only demonstrated change was a greater likelihood, at the 4-week follow-up, to report intention to undergo annual clinical breast examination. Importantly, receipt of MBD information did not appear to deter women from engaging in breast cancer screening. It is possible that the lack of change in screening intention was related to the level of commitment to breast cancer screening in this sample. All of the participants had at least one previous mammogram and were returning for re-screening.

It is possible that these women were already following recommended screening practices and that additional information about their breast cancer risk simply reinforced their actions.

We thought that dietary changes would result from the provision of information about MBD status along with recent evidence that a low-fat diet may reduce breast density and be an important risk-reduction factor. This did not appear to be the case. The majority of participants reported that their diet was "healthy" or "very healthy," in both the intervention group (90.5% at 4 weeks; 86.6% at 6 months) and the control group (90.7% at 4 weeks; 87.9% at 6 months). Although it is possible that the women did not need to introduce dietary changes such as reduced fat content because they already had a "healthy diet," a more detailed evaluation of dietary fat intake would be needed in order to tailor dietary interventions.

The findings of this study should be considered in light of several limitations. Because the study was conducted in the context of a Canadian provincial mammography screening program, the findings may not be generalizable to other settings, particularly those where free screening is not offered or re-screening reminders are not provided. The women who participated in this study all had previous screening mammograms and their current mammograms were normal. Information about MBD could have different consequences for those receiving their first screening mammogram or for those with suspicious or abnormal screening results. The period of the study did not permit long-term follow-up to assess actual participation in mammography re-screening following receipt of MBD information.

As increasingly accurate measures of MBD are introduced in clinical practice, it is likely that MBD information will be used more frequently in decision-making. Concerns that providing MBD information will result in the need for extra staff time in mammography screening programs, to address women's questions and concerns, appear to be unwarranted. Emerging evidence that breast density is hormonally responsive and may be influenced by lifestyle factors such as alcohol intake and diet (Harvey & Bovbjerg, 2004; Knight et al., 1999; Weinstein, 1999) indicates that it is important that women know their MBD status. This knowledge could influence decisions about postmenopausal hormone therapy. The majority of participants in this study believed that it was important women be informed about their breast density. Nurses and other health professionals are in key positions to support women in using personal information about MBD to understand their risk for breast cancer and to guide decisions related to risk reduction.

Conclusion

Our findings suggest that provision of information about MBD with the results of mammography screening is not associated with negative psychological outcomes and is a cost-effective way of providing women with personalized information on breast cancer risk. The effect of supplying risk information related to MBD status on women's use of screening mammography warrants further study. Further research on the relationship between understanding personal risk factors for breast cancer and changing behaviour is also needed.

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Comments or queries may be directed to Dr. Joan L. Bottorff, Faculty of Health and Social Development, University of British Columbia Okanagan, Kelowna, British Columbia V1V 1V7 Canada. E-mail: joan.bottorff@ubc.ca.

Joan L. Bottorff, PhD, RN, FCAHS, is Professor and Dean, Faculty of Health and Social Development, University of British Columbia Okanagan, Kelowna, British Columbia, Canada; and Co-director, Nursing and Health Behaviour Research Unit and NEXUS, University of British Columbia, Vancouver. Pamela A. Ratner, PhD, RN, is Professor and Coordinator, PhD Program, and Co-director, Nursing and Health Behaviour Research Unit and NEXUS, University of British Columbia. Joy L. Johnson, PhD, RN, FCAHS, is Professor, CIHR Investigator, and Co-director, Nursing and Health Behaviour Research Unit and NEXUS, University of British Columbia. T. Gregory Hislop, MDCM, MSc, is Senior Scientist in Cancer Control Research, BC Cancer Agency, Vancouver; and Clinical Professor, Health Care and Epidemiology, University of British Columbia. Jane A. Buxton, MBBS, MHSc, FRCPC, is Assistant Professor, Department of Health Care and Epidemiology, University of British Columbia. Cornelia Zeisser, MA, is a doctoral student and Senior Research Scholar in Measurement, Evaluation and Research Methodology, Faculty of Education, University of British Columbia. Weihong Chen, MSN, is a doctoral student in Nursing and Health Behaviour Research, School of Nursing, University of British Columbia. Birgit Reime, ScD, MPH, is Professor of Public Health, Faculty of Nursing and Health, University of Applied Sciences, Fulda, Germany; and Co-investigator, NEXUS, University of British Columbia.

Dresser un portrait fidèle des soins infirmiers : évaluation d'un système de classification

Margaret Ann Kennedy et Kathryn Hannah

Cette étude visait à analyser l'application de la Classification internationale de la pratique en soins infirmiers (CIPSI) au Canada, relativement à l'apport des soins infirmiers aux résultats cliniques. On s'est servi de la version bêta du CIPSI pour codifier des données rétrospectives sur les soins infirmiers extraites des dossiers de patients ayant séjourné aux soins intensifs, été admis aux soins psychiatriques, reçu des soins à domicile ou admis dans un établissement de soins de longue durée. En dépit des variations notables observées dans les pratiques de documentation, on constate une correspondance entre le CIPSI et l'essentiel des données. L'étude souligne les améliorations dont pourrait bénéficier la version bêta, notamment en ce qui concerne la granularité relative à l'usage des termes propres au langage naturel et au langage professionnel. Les auteures font certaines recommandations sur le perfectionnement de l'instrument, fondées sur la recherche axée sur les résultats attribuables aux soins infirmiers.

Mots clés : système de classification des soins infirmiers, résultats cliniques, CIPSI

Representing Nursing Practice: Evaluating the Effectiveness of a Nursing Classification System

Margaret Ann Kennedy and Kathryn Hannah

The purpose of this study was to examine the effectiveness of the International Classification for Nursing Practice (ICNP) in representing the contributions of nursing to health-care outcomes in Canada. The ICNP Beta Version was used to code retrospective nursing data extracted from patient records originating in acute care, in-patient mental health care, home care, and long-term-care practice settings. In spite of wide variation in documentation practices, ICNP achieved matches with the majority of nursing data. The study revealed areas for improvement in the ICNP Beta Version, specifically with regard to granularity related to the use of natural language terms and professional terms. Recommendations for further development through research in nursing-sensitive outcomes are discussed.

Keywords: Nursing informatics, nursing classification systems, nursing outcomes, ICNP

Introduction

For decades, nursing contributions to health-care outcomes have been excluded from the profiles of health services compiled in discharge summaries and in national data repositories. Numerous competing nursing terminologies and classifications have evolved to document and represent nursing practice in response to escalating demands and opportunities for the inclusion of nursing contributions to health care (Hannah, Ball, & Edwards, 2006, p. 174). Indeed, as Clark and Lange (1992) observe, “If we cannot name it, we cannot control it, finance it, teach it, research it or put it into public policy” (p. 109). The proliferation of health information systems and electronic health records present an opportunity for the profession to capitalize on ways to capture and represent nursing. In addition, increasing expectations related to patient safety, professional accountability, and evidence-based practice all point to the need for consistent, comparable nursing data. The Canadian Nurses Association (CNA) ([CNA] 1998, 2006) has identified an urgent need to collect consistent data using standardized languages to aggregate and compare data, as new information systems are implemented in Canada.

The CNA has endorsed the International Classification for Nursing Practice (ICNP) as the “foundational classification system for nursing practice in Canada” (CNA, 2000, p. 3). However, to date no systematic empirical research has been undertaken to determine whether the ICNP can accurately reflect the nature and culture of nursing in Canada across all of the settings in which nurses practise.

This paper presents the results of a study to examine the effectiveness of the ICNP Beta Version in representing nursing practice across multiple Canadian practice settings. This primary study extends Lowen’s (1999) focused examination of the ICNP in community health nursing by reflecting the diversity of practice settings in Canadian nursing.

The first section discusses the nature of nursing visibility and the need for nursing contributions to be represented. The second section describes the study methods and results of coding from nurses’ records and the ICNP Beta Version. Lastly, the article discusses implications for nursing and opportunities for reciprocal development between the ICNP and Canadian research in nursing-sensitive outcomes.

Literature Review

Nursing Visibility and Invisibility

The visibility of nursing contributions within the health-care system has long been a topic of interest. Sidani, Doran, and Mitchell (2004) postulate that increasing calls for accountability in the health-care system have reinvigorated calls for investigation into nursing contributions. Hannah, Hammell, and Nagle (2005) observe that the Canadian system (Canadian Institute for Health Information, Discharge Abstract database) has a *total absence* of clinical nursing data. The CNA has taken the position that “registered nurses and other stakeholders in health care delivery require information on nursing practice and its relationship to client outcomes. A coordinated system to collect, store and retrieve nursing data in Canada is essential for health human resource planning, and to expand knowledge and research on determinants of quality nursing care.... CNA believes that registered nurses should advocate and lead in implementing the collection, storage and retrieval of nursing data at the national level.” (CNA, 2001, p. 4)

The absence of nursing data standards and a common nursing language has long been acknowledged as one reason for the exclusion of nursing contributions from data summaries and a key antecedent to nursing invisibility (CNA, 1993; Graves & Corcoran, 1989; Hannah, 2005; Hannah et al., 2005, Hannah et al., 2006; White, Pringle, Doran, & McGillis Hall, 2005). In Canada, the process of capturing nursing data was initiated in 1992 after the Alberta Association of Registered Nurses

asked the CNA to host a conference intended to generate consensus on a Canadian nursing minimum data set (CNA, 1993). The nursing components of health information are known as HI:NC (Health Information: Nursing Components) and have consensus on five data elements: client status, nursing interventions, client outcomes, primary nurse provider, and nursing intensity (CNA, 2000; Hannah, 2005; Hannah et al., 2005). The CNA describes HI:NC as the “most important pieces of data about the nursing care provided to the client during a health care episode” (2005, p. 5) and recommends that if nurses are to move HI:NC forward, agreement on data standards for each HI:NC data element is essential.

Standardized Nursing Language

The need for standardized nursing data is driven partly by the advent of electronic health records and partly by the widespread emphasis on accountability in patient care. Standardized nursing data also are essential to facilitate accurate communication (CNA, 2001), which is a fundamental requirement of patient safety. White et al. (2005) and White and Pringle (2005) observe that the use of aggregated standardized data can support administrative decision-making for human resource planning as well as benchmarking and performance evaluation.

Conversely, many languages and structures of the various classification systems and taxonomies, while adopted in practice (Englehardt & Nelson, 2002; Hannah et al., 2006; Hyun, 2002), compete for representational advantage relative to nursing documentation. There are a number of obvious arguments against such diversity and competition. These include the difficulties posed when synonymous terms in competing systems conflict with each other, the lack of knowledge/applicability when used in diverse practice settings, and system redundancies and overlap (Englehardt & Nelson).

In 1990, as part of its commitment to advance nursing throughout the world, the International Council of Nurses (ICN) initiated a long-term project to develop an international classification system for nursing practice. The motivation was to support the processes of nursing practice and to advance the knowledge necessary for cost-effective delivery of quality nursing care (Ehnfors, 1999; Nielsen & Mortensen, 1999). The intent was to establish a common nursing language capable of describing nursing care, permitting comparison of nursing data, demonstrating or projecting tendencies in nursing, and stimulating nursing research (International Council of Nurses [ICN], 1993, 1996, 1999). A 1993 draft of the classification system included virtually all of the nursing classification schemes that had been developed internationally. The aim was to provide worldwide input into the construction of a comprehensive scheme that could eventually be used by nurses around the world. The

Alpha Version was released for comment and critique in 1996, followed by a Beta Version in 1999. The Beta 2, published in 2002 (ICN, 2002a, 2003), provided a version for ongoing testing and evaluation. The Beta 2 Version was used for the purposes of this study.

Subsequently, continuing development, revision, and updating based on research and experience with the ICNP resulted in the production of ICNP Version 1, which was released in 2005 at the ICN Congress in Taiwan. This is a mature product with a level of stability that can give vendors the confidence to recommend its incorporation into software products. In addition to maintaining and releasing updated versions of the ICNP, the program established formal evaluation and review processes to promote the maintenance and advancement of the ICNP (ICN, 2002b).

ICNP Beta Version

The ICNP is a classification system for nursing phenomena, actions, and outcomes. Its terminology for nursing practice serves as a unifying framework into which existing nursing vocabularies and classifications can be cross-mapped to enable comparison of nursing data (ICN, 2002b, 2003).

The initial objectives of the system were reviewed by the ICNP Evaluation Committee in 2000. These were revised in accordance with the aims of the ICNP program:

- establish a common language for describing nursing practice in order to improve communication among nurses and between nurses and others
- represent concepts used in local practice, across languages and specialty areas
- describe the nursing care of individuals, families, and communities worldwide
- enable comparison of nursing data across client populations, settings, geographical areas, and time
- stimulate nursing research through links to data available in nursing and health information systems
- provide data on nursing practice in order to influence nursing education and health policy
- project trends in patient needs, provision of nursing treatments, resource utilization, and outcomes of nursing care (ICN, 2002b)

According to the ICN (2001, p. i), the ICNP provides “a terminology for nursing practice that serves as unifying framework” for describing nursing practice and with which other nursing vocabularies and classifications can be cross-mapped. This standardized representation is intended to

enable comparison of nursing data across diverse geographical and practice settings.

Based on a system of three elements — Nursing Phenomena (assessments), Nursing Actions, and Nursing Outcomes, the ICNP is constructed as a multi-axial, combinatorial terminology that allows nurses to form a statement about each nursing element in the system using a series of eight criteria (axes) embedded in each classification. Each nursing phenomenon (nursing diagnosis) must include a term from Axis A, Focus of Nursing Practice, and a term from either Axis B, Judgement, or Axis G, Likelihood (see Appendix 1 for the Nursing Phenomena classification). By stating what must be included, the ICNP sets up a basic representation of nursing, while terms from the other axes may be used to make the diagnosis more complete. For any single diagnosis statement, the system permits the use of only one term from each axis. The Nursing Outcomes statement is also a nursing diagnosis statement, but in the ICNP this is a secondary or tertiary diagnosis that has been reassessed following some type of nursing intervention or action (see Appendix 3). The same protocols regarding Nursing Phenomena construction (required axes) apply to the construction of the outcome statements. The Nursing Actions classification (see Appendix 2) requires a term only from the Action Type axis; all other axes are optional, to expand the nursing intervention as desired. As in the Nursing Phenomena classification, only one term from each axis may be used in any single statement. Table 1 presents the various axes contained in each of the three ICNP elements.

With regard to structural granularity or basic terminological detail, the ICNP comprises a total of 2,420 codes governing every term in the classification system. Each individual label or term is assigned a unique identifying numerical code based on a hierarchical structure. Table 2 shows the distribution of terms and codes in each component of the classification system and illustrates the degree of detail in coding labels and subcategories that the ICNP employs in its effort to represent nursing.

Methods

The question to be answered in this study was *How effective is the ICNP at representing nursing practice across multiple practice settings in Canada?* Effectiveness was gauged in terms of the frequency of coding matches between the ICNP and actual nursing records.

The primary methodological approach was a retrospective qualitative analysis of nursing records. The ICNP was also subjected to structural

**Table 1 Classification Axes and Number of Codes
in ICNP Beta Version**

Element	Axes	Number of individual terms/ codes (organized by category where present)
Nursing Phenomena or Nursing Outcomes	Focus of nursing practice	Human being (273) Person (250) Group (21) Community (16) Environment (19) Biological environment (7) Human-made environment (70)
	Judgement	334
	Frequency	8
	Duration	2
	Topology	30
	Body site	133
	Likelihood	12
	Bearer	8
Nursing Actions	Action type	170
	Target	Phenomenon (6) Human (31) Body part (133) Non-body part (15) Non-human (3) Artifact (1) Appliance (152) Remedy (16) Condition (2) Signs and conditions (28) Responsiveness (8) Allergy (5) Disease (12) Reflex (3) Measure (6) Health-care structure (1) Activity (2) Habit (14) Pattern (3) Health-care service (4) Examination (9) Prevention (7)

		Therapy (29) Technique (26) Profession (11) Emergency (3)
	Means	263
	Time	22
	Topology	30
	Location	166
	Routes	48
	Beneficiary	8

Table 2 Coding Labels for Matching Nursing Data Post-extraction to ICNP Codes

Match	100% match between notation and ICNP term. Example: nursing documentation of a dressing change was coded as “changing” (2A.3.1.9) and the target as “dressing” (2B.2.1.2.2.1(a))
Conceptual Match	No exact ICNP term may exist but conceptually another term or a combination of ICNP terms captures the spirit of the notation. Example: notation recorded a client complaint of a headache that was not a migraine (which did have a code) and no code existed specifically for generalized headaches. This was coded generally for “pain” (1A.1.1.1.13.1). Example: use of packing in wound management with no existing specific ICNP code for packing, leading to code packing as “Mesh Gauze” (2B.2.1.2.2.2)
No Match	ICNP fails to communicate the notation using either an exact term or a combination of terms. Example: absence of a specific code for the term “stat,” which is a universally recognized emergency time frame
No Match, No Data	Entries could not be coded because of an absence of data in the record (versus incomplete entries that failed to conform to ICNP standards of providing all required fields).
Match-Conceptual Match	Instances of a notation containing both direct and conceptual matches. This label occurred during the coding phase in response to the nature of some notations.

analysis in terms of clarity, granularity (detail) or comprehensiveness, and application to primary health care through tertiary care settings.

Data on nursing practice were identified from nurses' charting records and then coded to the minimum concepts of Nursing Phenomena, Nursing Actions, and Nursing Outcomes as described by the ICNP. These minimum concepts were then matched to a preferred term with a corresponding numerical code in the ICNP. As Moen, Henry, and Warren (1999) note, the method of using classification systems is based on "matching the understanding of an actual phenomenon to an available term in the classification system" (p. 991). They describe this method as a "one-time data transformation" (p. 991), defined as "lossy" as opposed to lossless data transformation. Here, they are referring to losing some of the essence of the data during a linear transformation to a quantified code or word. Descriptive statistical analyses reflected the frequency of matching ICNP codes to nursing data contained in records across multiple practice domains.

Sample

Purposive sampling was used in the Canadian province of Nova Scotia to obtain client records consisting only of the nursing documentation sections. Devers and Frankel (2000) describe purposive sampling as a "strategy designed to enhance understandings of selected individuals or groups' experience(s) or for developing theories and concepts" (p. 264). They favour the selection of "information rich" cases or sampling cohort(s) that provide the greatest insight into the topic under examination. Miles and Huberman (1994), in contrast, identify typical or "average" representatives of the group as among the best options in non-probability sampling. In keeping with Miles and Huberman's definition of "average" representativeness, the sample comprised 100 anonymous client records to reflect the typical Canadian profile of nursing employment.

This method of research sampling to represent the typical practice setting in Canada was generated in order to facilitate generalizability. The Canadian nursing employment profile (CNA, 2004) indicates that almost 60% of practising nurses work in hospitals/acute care, 12.8% in public health/home care, and 10.9% in long-term care, so that these three domains account for 83.7% of Canadian practising nurses. Consequently, four practice settings — acute medical-surgical care (25%), in-patient mental health care (25%), home care (25%), and long-term care/aged care (25%) — were identified as sources of nursing records and data. The sample is thus reflective of Canadian practice settings (83.7% of working nurses), with 50% of cases in hospital-based care, 25% in long-term care, and 25% in home care. Although the number of research records for

home care and long-term care was slightly higher than represented in the Canadian profile, it was considered important to have an adequate volume of nursing data with which to evaluate ICNP effectiveness in the specific practice setting.

Data Collection

Nurses' narrative records were obtained from the participating institutions in Nova Scotia. These consisted of nursing documentation, from the time of admission to the identified service or unit, and included only the nursing narrative documentation and nursing admission databases. Patient records were collated by the institution, with all identifying patient information removed. Ethics approval was obtained from a District Health Authority, two institutional sites, and a university ethics review panel.

Records were identified by practice setting and number — for example, Acute Care #1, Acute Care #2, Mental Health #1, Mental Health #2. The unit of analysis was the nursing narrative data from five random notations (or “nursing entries”) in each patient record. The nursing data were identified and coded according to the ICNP structure. Each notation was assessed for recorded data conforming to the codes for Nursing Phenomena, Nursing Actions, and Nursing Outcomes. A total of 1,500 data elements were assessed, coded, and analyzed.

All data extractions and transformations were implemented manually. To minimize loss of meaning in the transformation process, each notation was considered in its entirety; however, only the actual content documented in the record was coded. Data extractions were assessed for term validity by a health-care researcher experienced in data coding. Interrater reliability was assessed by comparing 10 records for each practice setting; 10 was selected as the reliability sample in each practice setting based on the diversity of terms inherent in both the records and the ICNP Beta Version. Agreement ranged from 95% to 100%, with an average of 97%. Table 1 presents the coding labels for matching nursing data post-extraction with ICNP codes.

Findings

Data Analysis

Although data abstracted from the records were coded as Nursing Phenomena according to the ICNP coding structure, no single record from any practice setting presented a complete nursing assessment or nursing diagnosis in any notation using even the two minimum elements required by ICNP. Thus all data were incomplete from the perspective of the ICNP and represent a limitation of the documentation. This was considered not as a limitation of the ICNP classification system but as

Table 3 *Frequencies for Coding Nursing Data to ICNP Elements*

Matches Between ICNP and Nursing Records						
ICNP Element	Coding Label	Acute Care % (n)	Mental Health % (n)	Home Care % (n)	Long-Term Care % (n)	Combined Records % (n)
Nursing Phenomena	Match	36.8 (46)	34.4 (43)	19.2 (24)	48.8 (61)	34.8 (174)
	Conceptual Match	36.0 (45)	40.0 (50)	32.8 (41)	22.4 (28)	32.8 (164)
	No Match	0.8 (1)	1.6 (2)	2.4 (3)	18.4 (23)	5.8 (29)
	No Match, No Data	26.4 (33)	24.0 (30)	45.6 (57)	5.6 (7)	25.4 (127)
	Match-Conceptual Match	0	0	0	4.8 (6)	1.2 (6)
Nursing Actions	Match	44.8 (56)	18.4 (23)	71.2 (89)	38.4 (48)	43.2 (216)
	Conceptual Match	38.4 (48)	44.8 (56)	16.0 (20)	30.4 (38)	32.4 (162)
	No Match	0	0.8 (1)	0	0	0.2 (1)
	No Match, No Data	16.8 (21)	36.0 (45)	8.8 (11)	23.2 (29)	21.2 (106)
	Match-Conceptual Match	0	0	4.0 (5)	8.0 (10)	3.0 (15)
Nursing Outcomes	Match	8.0 (10)	7.2 (9)	4.8 (6)	13.6 (17)	8.4 (42)
	Conceptual Match	18.4 (23)	15.2 (19)	43.2 (54)	7.2 (9)	21.0 (105)
	No Match	2.4 (3)	4.8 (6)	32.8 (41)	0.8 (1)	10.2 (51)
	No Match, No Data	70.4 (88)	72.8 (91)	19.2 (24)	78.4 (98)	60.2 (301)
	Match-Conceptual Match	0.8 (1)	0	0	0	0.2 (1)

inherent in the records themselves, a conclusion that is consistent with the observations of other authors examining nursing documentation (Doran et al., 2006; Parker, Wells, Buchanan, & Benjamin, 1994).

In the absence of data conforming to ICNP standards, and in recognition of the limitation described above, all data available to the researcher in each notation were coded. Likewise, there were many instances where no assessment of any kind was documented and only a Nursing Action was documented or an action with a cursory outcome recorded. In many instances, no nursing outcome of any kind was documented, even following Nursing Actions. Every case in which the documentation provided no written record of an ICNP element, whether nursing phenomenon (assessment), action (intervention), or outcome, was coded as No Match, No Data.

Table 3 presents the frequencies for all practice settings. It reflects the frequency with which the ICNP captured or represented data, and the coding label (whether a direct match, conceptual match, etc.) under which it did so, for each classification element. The results reported in this article are intended as an overview, with examples from each of the various practice settings. A detailed examination of the results specific to each setting would exceed space limitations. Further, in the absence of extensive analytical discussion it is impossible to address the specific differences, in terms of documentation and coding results, among the settings. While there were significant differences in some cases, one cannot attribute these to variations in unit documentation standards or practices, individual practice standards or documentation styles, or institutional documentation practices, as these factors were not the focus of the study. Indeed, exploration of the factors that influence nursing documentation could form an article in itself, as this topic encompasses such current issues as workload, employer expectation, education, and nurses' individual perspectives on documentation.

With the exception of home care, the ICNP achieved either a Match or a Conceptual Match for Nursing Phenomena and Nursing Actions in more than 60% of nursing records except where no data were documented to support analysis. In contrast, no matches were achieved for Nursing Phenomena in almost 20% of long-term-care records and for Nursing Outcomes in more than 32% of home-care records. The lack of documentation in all practice settings resulted in the achievement of matches in only 20% to 50% of records.

Examples of 100% or direct matches in ICNP coding for Nursing Phenomena in acute care included pain, anxiety, restlessness, flatus, cough, crying, nausea, and respirations. Conceptual matches consisted of instances such as "taking very little fluids" being matched to "nutritional intake" and "periods of apnea" being matched to "hypoventilation." The

ICNP consequently has the capacity, either in a direct or in an indirect/conceptual way, to reflect the majority of task-related concerns that command the attention of nurses.

Examples of direct matches in Mental Health included “checks,” “encouraged,” “documented,” and “education.” Conceptual matches included entries such as “1:1 session,” which was coded as “counselling,” “removed to locked seclusion,” which was coded as “safety precaution,” and “choice to see psychologist given,” which was coded as “negotiating.”

With regard to Nursing Outcomes, ICNP performance was difficult to assess due to the lack of documentation in acute care, mental health care, and long-term-care records. There were no matches for three outcome notations: “little improvement,” “no complaints at present,” and “tolerated well” (none of which comply with ICNP guidelines for nursing outcomes). In home-care records, ICNP assessment was not significantly hampered by excessive gaps in the documentation of nursing outcomes. The ICNP was unable to capture outcomes for 41 home-care cases because no codes existed to adequately reflect the nursing outcome (32.8%), with the main challenges to the ICNP being a limited number of recurring themes in the documentation — namely “stable,” “comfortable,” and “improved.” Additionally, no match was obtained for “patient discharged from service” (although it might be argued that this could be coded as a conceptual match for “scheduling”).

Combined Records

The overall impression of ICNP performance emerges from an examination of the cumulative records. The combined records for Nursing Phenomena in all nursing domains indicate a cumulative match exceeding 70%. Only 28 cases (5.6%) could not be coded using ICNP terms, and a total of 127 records lacked nursing assessment. The frequencies for nursing actions in combined nursing domains demonstrated a cumulative match profile exceeding 78%. Only two cases (0.4%) did not achieve a match, and 106 cases (21.2%) did not document any nursing actions. Based on this performance, it is reasonable to conclude that if all records provided adequate nursing documentation, the ICNP could represent the majority of Nursing Phenomena (nursing diagnoses) and Nursing Actions. As noted above for individual practice settings, nursing outcomes were conspicuously absent in the documentation and represent a limitation of the data. It is difficult to assess the ICNP in this circumstance; however, it may be projected that, given the ICNP’s performance in Nursing Phenomena and Nursing Actions, its performance would improve with greater opportunities for coding adequate nursing outcomes documentation.

Limitations of the ICNP

As the ICNP was applied to nurses' records, it became clear that the Beta Version has a strong biomedicine perspective, as evidenced by its emphasis on the biophysical and task-based coding. Limitations of terms and codes in the ICNP became further apparent during data coding from nursing notes. The list of terms in the ICNP is not exhaustive. Undoubtedly it will continue to expand in subsequent iterations of the system. Table 4 identifies both professional and natural language terms missing from the Beta Version.

Given the incomplete documentation, it is difficult to determine whether there were limitations beyond those identified. In general, the gaps were due to a lack of "granularity" or specific detail at the terminal level, where a descriptive label is needed to accurately capture the actual nursing event (whether assessment, action, or outcome). Each term necessarily "fits" under a specific heading in each axis — for example, pastoral (or spiritual) care is missing from the Profession heading in the Target axis of the Nursing Interventions category.

Discussion

As nurses construct their records they make visible selected nursing elements, while other aspects of nursing become, or remain, invisible simply by virtue of what is and is not documented. In this study, nursing documentation was incomplete according to ICNP standards for Nursing Phenomena, Nursing Actions, and Nursing Outcomes and reflected a task orientation and a biomedical perspective. It may be argued that the absence of any outcome as a consequence of the nurse's professional interventions contributed to the invisibility of nursing. However, records from all practice settings examined in the study exhibited variable documentation gaps, from assessments to nursing actions, and this also contributes to the invisibility of nursing. As indicated earlier, there may be multiple factors affecting this issue. In a study linking interventions to outcomes in acute care, Doran et al. (2006) also encountered incomplete documentation. This lack of documentation influenced the analysis of nursing-sensitive outcomes by limiting the calculation of intervention dose or intensity, but also necessarily omitting nursing interventions when not documented.

The question of how often outcomes should be assessed may also influence future evaluations of ICNP effectiveness. Doran (2004) proposes that outcomes be measured in variable time frames depending on the specific client situation. For example, pressure ulcers would not necessarily require measurement after each intervention, whereas acute symptoms (such as pain) would be assessed frequently. The present study

Table 4 Professional and Natural Language Terms Missing from ICNP Beta Version

<p><i>Nursing Phenomena Classification</i></p>	<p>Focus of Nursing Practice</p>	<p>exudate depressed behaviour suicidal ideation challenging homicide stalking emotional abuse</p> <p>sedation affect psychosis discharge instructions self care: social interaction vs. isolation homicidal ideation verbal abuse financial abuse</p> <p>balance irritable paranoid ideation</p>
<p><i>Nursing Actions Classification</i></p>	<p>Action Type</p> <p>Target</p> <p>Means</p> <p>Time</p>	<p>consulting receiving orders orienting discharging contacting/notifying physician reviewing reassuring</p> <p>packing subcutaneous catheter razor/shaver discharge instructions pastoral care blood sugar/glucose/chem strip physical environment (temperature, noise, lighting, etc.) expand “medicines” to include at least major categories of drugs (antiemetics, beta blockers, hypertensives, antipsychotics, anxiolytics, narcotic analgesics, etc.) electroconvulsive shock therapy</p> <p>rectal tube packing personal belongings enema antiemetic (see previous comment about “medicines”)</p> <p>Stat</p>

evaluated each nursing notation for all three ICNP elements (Nursing Phenomena, Nursing Actions, and Nursing Outcomes). Doran's work offers a new perspective to inform the assessment of outcomes for the ICNP and could be incorporated either into the individual application of the ICNP at a local level or through a formal time-dimensional analysis of outcome evaluation within the tool itself.

When considering the impact of gaps in the ICNP, the risk of misrepresenting or omitting nursing practice escalates. In the case of terminological gaps in the classification system, the nurse or medical records professional entering nurses' records into the ICNP has to find an indirect or incomplete fit with an existing term in the taxonomy, instead of employing the term used by the documenting nurse. Based on the comments of Moen et al. (1999), this incomplete coding process results in the "lossy" data being recorded or data being omitted altogether, if no acceptable option exists, and thus in a skewed representation of nursing practice.

There is another consequence of using a tool that requires application of a single term from each axis and that is essentially a unidimensional, linear descriptive representation of what is necessarily a multidimensional process: it applies a deconstructionist lens to nursing practice. By focusing on task-based activities, the nurse is displaced as the central unifying "text" of nursing and the context in which skilled nursing care is delivered. We are unlikely to see the development of one classification system that fully captures the richness and synchronous complexity of nursing practice. However, Doran's work in modelling the role of nursing in achieving specific outcomes offers a mechanism for enriching the dimensionality of the ICNP (Doran, 2004; Doran et al., 2006). Doran's work might well not only lead to further refinement of coding outcomes subsets but also represent nursing as a dynamic and complex process.

Conclusions

During examination of records across the four practice settings, the fragmented documentation negatively impacted nursing representation and ICNP analysis. In spite of the limitations identified, the ICNP offers nurses a way to document their care more fully and systematically. With progressive implementation of the Pan-Canadian Electronic Health Record, the potential to incorporate the ICNP into system architecture and clinical terminologies offers nursing an opportunity to engage in documentation that encompasses Nursing Phenomena, Nursing Actions, and Nursing Outcomes. More comprehensive nursing representation is possible as research continues to inform various aspects of ICNP development. Nurses need to be active partners in determining how their

profession is best represented and in contributing to ongoing evaluative research using the ICNP across multiple practice settings.

Recommendations

The results of this study lead to a number of recommendations. The greater clarity and comprehensiveness in documenting nursing practice afforded by the ICNP can result in greater recognition of nursing's contributions. Research on ICNP integration into the Pan-Canadian Electronic Health Record could be highly informative in terms of the ICNP's representational impact on a multidisciplinary health record. We also need to further explore the area of nursing-sensitive outcomes and the timing of evaluation. Using Doran's work as a basis, it could be enlightening to explore the ICNP's effectiveness based on variable time dimensions of evaluation. Future research could also serve to generate a pan-Canadian sample of nursing records with which to evaluate the ICNP. The ability to evaluate differences in documentation could then be explored by practice setting as well as by province. Lastly, education in effective documentation and the ICNP should be provided to all nurses. It is imperative that all elements of ICNP — Nursing Phenomena, Nursing Actions, and Nursing Outcomes — be documented. Nurses should be aware that documenting all aspects of professional nursing care, including outcomes, brings significant attention to nurses' contribution to the health-care outcomes of clients. As the Pan-Canadian Electronic Health Record continues to progress, and if the ICNP is progressively integrated into the system architecture, it will be possible to create prompts or reminders for nurses to ensure that documentation is complete. It is through active, engaged partnerships that nurses will benefit most from the ICNP and that documentation will be most effectively developed.

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Authors' Note

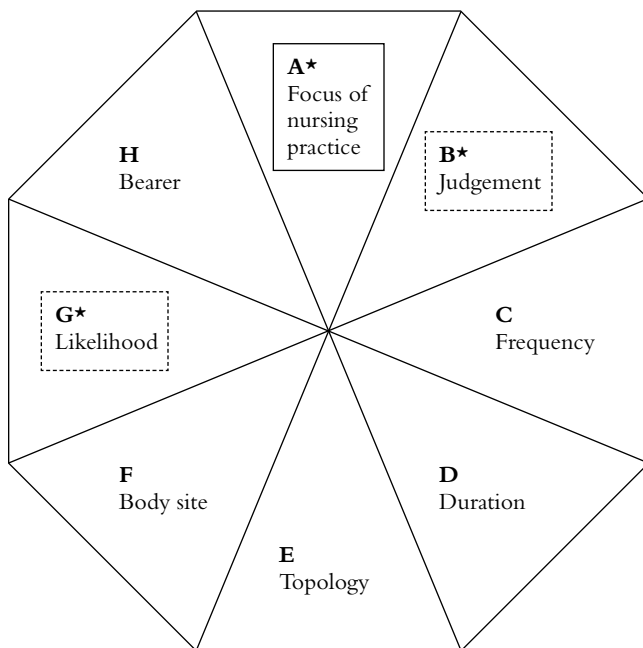
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Comments or queries may be directed to Margaret Ann Kennedy, School of Nursing, St. Francis Xavier University, 43 West Street, Antigonish, Nova Scotia B2G 2W5 Canada. Telephone: 902-867-3988. E-mail: makenned@stfx.ca.

Margaret Ann Kennedy, RN, PhD, is Assistant Professor, School of Nursing, St. Francis Xavier University, Antigonish, Nova Scotia, Canada. Kathryn Hannah, RN, PhD, is President, HECS, Inc., and Adjunct Professor, Department of Community Health Sciences, Faculty of Medicine, University of Calgary, Alberta, Canada.

Appendix 1 *ICNP Nursing Phenomena Classification*



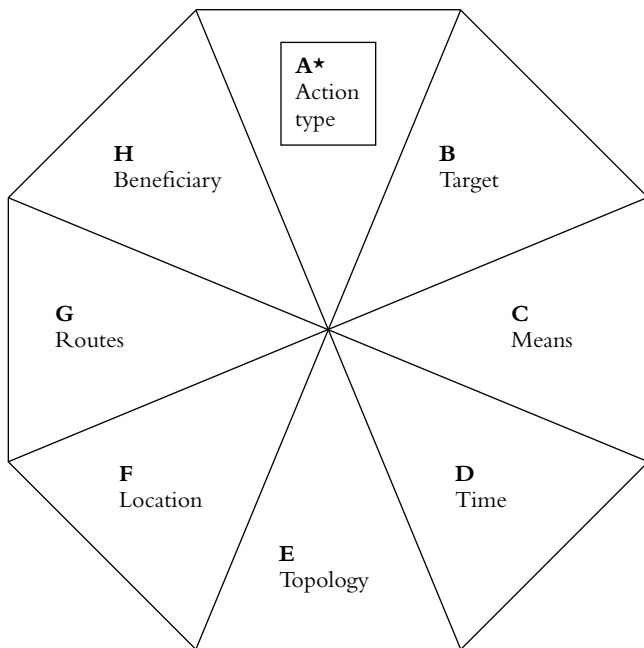
Legend

A - <i>Focus of nursing practice</i>	nursing attention (pain, body image, self-care, etc.)
B - <i>Judgement</i>	clinical evaluation of the phenomenon, including severity or intensity (enhanced, diminished, etc.)
C - <i>Frequency</i>	number of episodes/occurrences within a time frame
D - <i>Duration</i>	duration of the phenomenon (acute, chronic, etc.)
E - <i>Topology</i>	anatomical location relative to media location or extent of regional involvement (right, partial, total)
F - <i>Body site</i>	anatomical location (finger, toe, etc.)
G - <i>Likelihood</i>	probability of occurrence (risk)
H - <i>Bearer</i>	entity experiencing phenomenon (individual, family, community, etc.)

*Solid line denotes required field; dotted line denotes required field (use either field).

Source: ICN (2001), p. iii-iv. Permission pending.

Appendix 2 ICNP Nursing Actions Classification



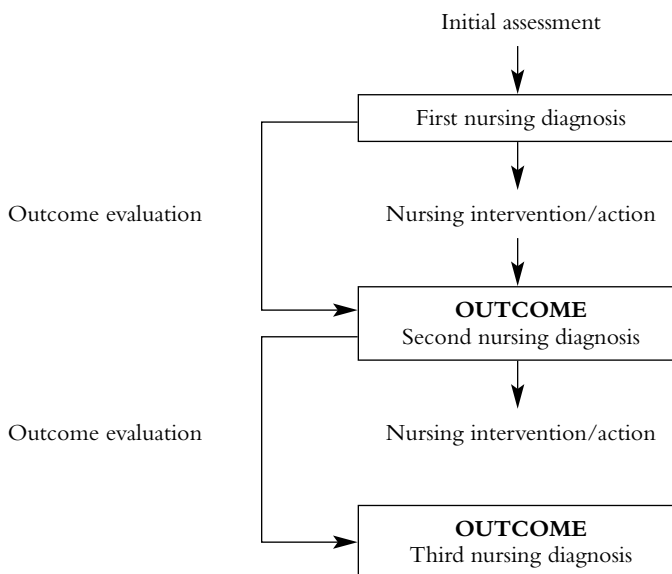
Legend

A - <i>Action type</i>	nursing activity (monitoring, teaching, etc.)
B - <i>Target</i>	recipient of nursing action (pain, individual, etc.)
C - <i>Means</i>	instruments and services used in the implementation of nursing action (dressing, pre-operative instructions, etc.)
D - <i>Time</i>	specific points in time and time intervals (pre-operative, postnatal, etc.)
E - <i>Topology</i>	anatomical location relative to media location or extent of regional involvement (right, partial, total)
F - <i>Location</i>	anatomical location and spatial orientation of nursing actions (head, shoulder, home, community centre, etc.)
G - <i>Routes</i>	pathway through which nursing action is implemented (oral, intravenous, etc.)
H - <i>Beneficiary</i>	entity benefiting from nursing action (individual, family, community, etc.)

* Solid line denotes required field.

Source: ICN (2001), p. vii-viii. Permission pending.

Appendix 3 ICNP Nursing Outcomes Classification



Nursing outcomes must:

1. include a term from the Focus of Nursing Practice
2. include a term from the Judgement Axis or the Likelihood Axis
3. include terms from other axes as necessary to expand diagnosis
4. use only one term from each axis
5. be made only after an action is completed.

Source: ICN (2001), p. iii-iv. Permission pending.

L'efficacité comparée des interventions assistées par ordinateur personnalisées et ciblées dans la promotion de l'utilisation d'un dispositif de protection de l'ouïe

**Madeleine J. Kerr, Kay Savik,
Karen A. Monsen et Sally L. Lusk**

L'objectif de cette étude était d'évaluer l'efficacité de deux interventions assistées par ordinateur et de messages incitatifs sur l'utilisation, par les travailleurs de la construction, d'une protection de l'ouïe. Des travailleurs de la construction ($n = 343$) désignés au hasard ont reçu un enseignement personnalisé (à partir de caractéristiques individuelles) ou ciblée (à partir de caractéristiques communes), avec ou sans messages incitatifs, dans le cadre d'un modèle expérimental prétest post-test comportant quatre groupes. L'appariement des messages effectué après les interventions visait à comparer la valeur de l'approche personnalisée et de l'approche ciblée. Une année après les interventions, l'utilisation d'une protection de l'ouïe chez les participants est passée de 42 à 50 % des fois où ils étaient exposés au bruit. Les différences entre les groupes n'étaient pas significatives. Cette importante amélioration dans l'utilisation d'une protection auditive démontre que les interventions peuvent avoir un impact sur la prévention de la perte d'audition due au bruit. Étant donné que les groupes ayant fait l'objet d'une intervention ciblée ou personnalisée ne présentaient pas de différences notables dans l'utilisation de la protection de l'ouïe, et que les interventions ciblées sont moins coûteuses à mettre au point, ces dernières sont plus avantageuses.

Mots clés : intervention assistée par ordinateur, perte d'audition due au bruit

Effectiveness of Computer-Based Tailoring Versus Targeting to Promote Use of Hearing Protection

**Madeleine J. Kerr, Kay Savik,
Karen A. Monsen, and Sally L. Lusk**

The purpose of this study was to evaluate the effectiveness of 2 computer-based interventions and booster messages on construction workers' use of hearing protection. Construction workers ($n = 343$) were randomly assigned to receive tailored (addressing individual characteristics) or targeted (addressing shared characteristics) education, with or without booster messages, in an experimental 4-group pretest-post-test design. Post hoc message matching compared the value of tailored and targeted approaches. Participants improved use of hearing protection from 42% to 50% of the time they were exposed to noise 1 year post-intervention. Differences between intervention groups were not significant. The significant improvement in use of hearing protection demonstrates that interventions can have an impact on preventing noise-induced hearing loss. Since targeted and tailored intervention groups did not significantly differ in use of hearing protection, and since targeted interventions are less costly to develop, targeted interventions offer greater value.

Keywords: Computer-assisted instruction, randomized controlled trial, noise-induced hearing loss, ear protective devices

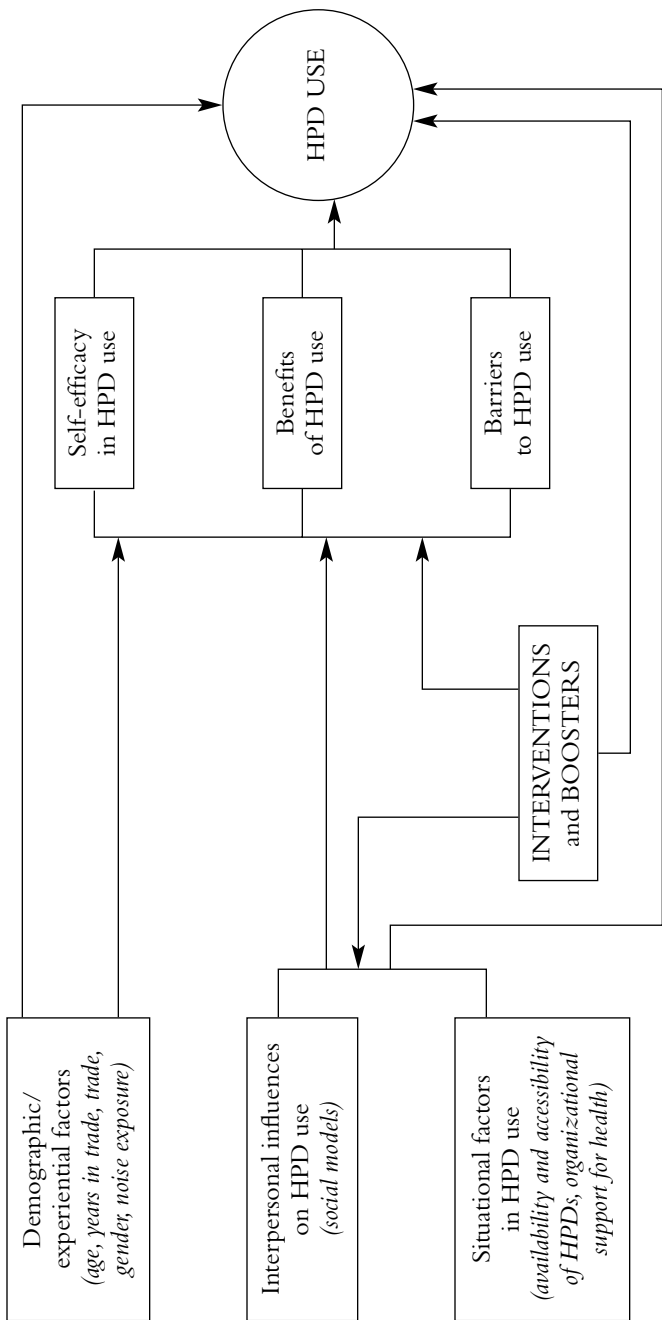
Worldwide, the prevention of occupational hearing loss is a priority for research, policy, and practice (Smith, 1998). Occupational health nurses and public health nurses are ideally positioned to address hearing loss prevention along with other health issues across worker populations. Construction workers are a population of concern because they are underserved by existing programs for hearing loss prevention (Suter, 2002). Knowledge is needed about the components of an effective hearing loss prevention program in order to inform policy and guide occupational health and safety practices. A recent Cochrane review of interventions to promote the use of hearing protection determined that there were only a few good-quality studies in this area and more randomized controlled trials are needed (El Dib, Verbeek, Atallah, Andriolo, & Soares, 2006).

We evaluated the effectiveness of a theory-based intervention designed by integrating concepts from the Predictors of Use of Hearing

Figure 1 Predictors of HPD Use

COGNITIVE-PERCEPTUAL FACTORS

MODIFYING FACTORS



Protection Model (PUHPM; Figure 1) into a computer-based educational program to promote the use of hearing protection devices (HPDs).

Background

Noise-induced hearing loss (NIHL) has been a known occupational risk for construction workers since the 1960s (Suter, 2002). Although the incidence and prevalence of NIHL are not known in Canada or the United States, isolated studies using audiometric tests have found that up to 74% of construction workers experience hearing loss (Hessel, 2000; Ringen, Seegal, & Englund, 1995; Schneider, Johannig, Belard, & Engholm, 1995; Sweeney et al., 2000). Regional estimates of the costs of NIHL in human suffering and financial resources can be found in hearing disability claims data. Provincial workers' compensation boards across Canada identify occupational hearing loss as a compensable condition (Canadian Hearing Society [CHS], 2003). For example, noise is the greatest cause of permanent disability cases settled by the Workers' Safety and Insurance Board in Ontario, with average payments as high as \$15,000 annually over a claimant's lifetime (CHS; World Health Organization [WHO], 1997). In the past decade, studies have described widespread hazardous noise exposure among construction workers in Canada (Legris & Poulin, 1998; Sinclair & Hafidson, 1995; Thompson, 1997) and the United States (Kerr, Brosseau, & Johnson, 2002; Neitzel, Seixas, Camp, & Yost, 1999). Judicious use of hearing protection is an important component of a comprehensive hearing loss prevention program for construction workers (Suter).

Consistent use of HPDs prevents NIHL (Savell & Toothman, 1987), an irreversible impairment with significant monetary and personal costs. In Canada, "not all provinces have regulations for noise exposure and hearing conservation" and some regulations are very similar to those in the United States (WHO, 1997). British Columbia revised its regulations in 1996 to require use of HPDs at an 85-decibel exposure limit (WHO). In the United States, the Occupational Safety and Health Administration mandates use of HPDs at noise levels above 90 decibels for an 8-hour daily exposure in the construction industry (US Department of Labor, Occupational Safety and Health Administration, 2005). Use of HPDs is not widespread, however, according to a review and analysis of construction noise by Suter (2002). Similarly, Lusk, Kerr, and Kauffman (1998) found that 24% of construction workers never used HPDs and only 5.3% always used them when exposed to loud noise. Worker motivation and education in HPD use are an essential part of hearing loss prevention programs (National Institute for Occupational Safety and Health, 1996). Research into the effectiveness of educational interventions is needed to

guide programs for the prevention of NIHL in the population of construction workers.

An exemplar of a successful comprehensive hearing loss prevention program for construction workers is that of the Workers' Compensation Board of British Columbia, proposed by Suter (2002) as a model for the United States in part because of its high percentage of HPD use. The program includes annual audiometric testing, training, and counselling of construction workers. Ten years of data reveal improvement in the hearing of construction workers exposed to noise to a level comparable to that of non-exposed workers (Suter). Research to discover the mechanism of this exemplary program's effect on HPD use would further the adaptation and replication of effective hearing loss prevention programs in the construction industry.

Research Employing the PUHPM

A research team of occupational health nurses led by Lusk and colleagues derived the PUHPM from Pender's (1987) Health Promotion Model (HPM) by empirically testing the HPM with factory workers (Lusk, Ronis, Kerr, & Atwood, 1994), construction workers (Lusk, Ronis, & Hogan, 1997), and Mexican-American garment workers (Kerr, Lusk, & Ronis, 2002). The HPM demonstrated utility as an explanatory model, accounting for up to half of the variance in use of hearing protection. Furthermore, exploratory forms of the HPM explained more variance. The exploratory versions allowed direct paths from all factors to the behaviour, consistent with the revised HPM (Pender, 1996; Pender, Murdaugh, & Parsons, 2002). These empirical tests of the HPM in original and exploratory forms provided the rationale for deriving the PUHPM.

As shown in Figure 1, the PUHPM includes the intervention, three types of modifying factors, three types of cognitive-perceptual factors, and the dependent variable, use of hearing protection. In the PUHPM, all factors have a direct effect on HPD use and, additionally, the modifying factors have an indirect effect on this behaviour, exerting their influence through the cognitive-perceptual factors. Interventions and informational boosters are expected to affect selected modifying factors and cognitive-perceptual factors as well as the behaviour itself.

Modifying factors. Demographic and experiential factors such as age and noise exposure at work are background factors in the model. Interpersonal influences are the social norms or expectations of significant others, social role models for HPD use, and interpersonal support for the behaviour. Situational factors include the availability of HPDs and organizational support for employee health.

Cognitive-perceptual factors. Self-efficacy is confidence in one's ability to use HPDs. Benefits refers to the expected positive effects of HPD use and barriers are the potential negative aspects of this behaviour. This model depicts the factors that are believed to influence the use of hearing protection and that provide the basis for the content and process of interventions.

Lusk and colleagues designed an intervention package for construction workers based on predictors of HPD use from a test of the PUHPM (Lusk, Hong, et al., 1999). HPD use increased from a baseline of 44% to only 52% of the time the workers were exposed to loud noise, leaving much room for improvement in achieving the goal of 100% use. The researchers recommended that future studies examine tailoring to the interests or beliefs of the individual as the next step in the development of successful theory-based interventions.

Tailored and Targeted Health Communication

Tailored and targeted interventions have been shown to be more effective than generic interventions; however, improving on generic interventions through tailoring or targeting requires assessment of population subgroups, with more extensive assessment of individuals needed for the more intensive tailored approach (Ryan, Skinner, Farrell, & Champion, 2001). Kreuter, Lukwago, Bucholtz, Clark, and Sanders-Thompson (2003) define tailoring as "any combination of information or change strategies intended to reach one specific person, based on characteristics that are unique to that person, related to the outcome of interest, and have been derived from an individual assessment" (p. 137). They define targeting as "the use of a single intervention approach for a defined population subgroup that takes into account characteristics shared by the subgroup's members" (p. 136). Revere and Dunbar (2001) reviewed 37 randomized controlled trials of computer-based tailored and targeted interventions. Of the 14 targeted intervention studies, 13 (92.9%) showed positive results. Of the 23 tailored intervention studies, 21 (91.3%) showed positive results. Ryan et al. examined the relationships between targeted and tailored interventions in a simulation study related to mammography behaviours. They quantified the similarity of an individually tailored intervention to a hypothetical group targeted intervention, and found that about 60% of the population received content in the tailored interventions that was considered a good match with that of the targeted intervention; however, 80% of tailored interventions differed in some way from message combinations developed for all other participants. Ryan et al. recommend further study to differentiate behavioural outcomes of well-targeted interventions and tailored interventions.

The purpose of this project was to (1) develop, using PUHPM, tailored and targeted interventions to increase HPD use among construction workers; (2) evaluate these by contrasting the effectiveness of tailored and targeted interventions; (3) assess the effect of a booster intervention; and (4) test the utility of PUHPM as a model for changing behaviour with regard to HPD use. We hypothesized that the tailored intervention plus booster would be the most effective intervention.

Methods

Design and Sample

Ethics approval for the study was obtained from the University of Minnesota Institutional Review Board: Human Subjects Committee. The four-group pretest-post-test experimental design contrasted the effect of a tailored with that of a targeted intervention on construction workers' HPD use and, additionally, tested the effect of a subsequent informational booster on workers' HPD use (Campbell & Stanley, 1963). Individuals were randomly assigned to one of four groups: tailored intervention, tailored intervention plus booster, targeted intervention, and targeted intervention plus booster. We faced a series of decisions in operationalizing the control group design. According to Barkauskas, Lusk, and Eakin (2005), in designing comparison interventions, researchers must consider "the conceptual framework, content and dynamics of the experimental intervention." Because construction workers are underserved by standard hearing loss prevention programs, we considered the no-intervention control group ethically unacceptable. A usual-treatment model was not feasible because at our sites education in hearing protection was variable, was of minimal quality, and differed too greatly from the computer-delivered intervention to be an adequate comparison (Barkauskas et al.). We turned next to a devised control model by designing a comparison intervention that applied the same conceptual framework to the content and differed only in the dynamics of applying the concepts using targeting instead of tailoring. In this way, the comparison intervention represented a strong approach in the field and provided a rigorous evaluation of tailoring. Participants who were randomized to the booster condition received a booster consistent with the tailored or targeted intervention they received.

Construction workers were recruited through the health and safety educational programs of one municipal employer and two large union apprenticeship programs in metropolitan areas of the American Midwest. The organizations were willing to offer their workers an innovative educational program. Workers who declined to participate in the research received the targeted educational program with no data collected. An

initial pre-intervention sample of 723 construction workers included apprentice carpenters ($n = 399$), municipal construction labourers ($n = 175$), and apprentice roofers ($n = 149$). A final sample of 343 construction workers completed the post-intervention session approximately 1 year later.

Instruments to Measure the Model

The electronic survey was integrated into the computer-based educational program following an electronic informed-consent process. Questions to measure components of the PUHPM (Figure 1) were developed in prior research to determine the predictors of HPD use among factory and construction workers (Lusk et al., 1994; Lusk, Kerr, Ronis, & Eakin, 1999). Most concepts were measured on three-item scales and had Likert-style response formats (1 = strongly disagree; 6 = strongly agree). In this study, reliability using Cronbach's alpha ranged from .54 to .88. Reliability for most scales was above the .70 generally considered acceptable (Nunnally & Bernstein, 1994): benefits minus barriers, .81; social models, .85; availability and acceptability, .89; organizational support, .82. The self-efficacy scale had an alpha of .69. The dependent variable use of hearing protection was measured by workers' self-report of the percentage of time (0%–100%) they used hearing protection when exposed to loud noise in their most recent job, the job before that, and in the preceding 12 months. A scale combining the three variables was created, with a resulting alpha of .90.

Intervention

The computer-delivered educational interventions were theory-based using concepts from the PUHPM. For example, health messages were designed to increase perceptions of self-efficacy and benefits of using HPDs while decreasing perceptions of barriers to HPD use. The interventions included the Occupational Safety and Health Administration content requirements for factory worker education: use of HPDs, effects of noise on hearing, and meaning of audiometric testing. Each worker began by answering questions about current HPD use, predictors of use from the PUHPM, and perceptions of noise exposure and hearing ability.

The single-session educational interventions comprised an 8-minute introduction including a consent section, a 15-minute survey, and a 40- to 50-minute educational program. The survey and educational program were in an interactive multimedia game-type format presented with an espionage storyline in which participants were engaged in the mission of foiling a noise villain by using their HPDs. The targeted version gave a standard, generic message incorporating these concepts, whereas the tailored intervention individualized the health messages based on worker

responses to questions assessing the components of the model. Six months after the computer-delivered educational session, participants randomized to the booster condition received a mailing at the home address they provided. The mailing included an informational handout and a plastic pouch with five different pairs of earplugs. The colourful informational handout reflected either the tailored or targeted messages the participant received during the computer-delivered education session. The booster handout also reminded the participants of the session by reinforcing the “espionage game” theme and replicating the appearance of the session handout.

Statistical Analysis

Descriptive statistics are presented as percentages, means and standard deviations, or medians and ranges. A summary measure of HPD use was computed from the mean of three measures: percentage use in the current job, in the previous job, and over the preceding year. Comparison of the three trade groups or those who did and did not complete the study was done using a chi-square test of association for categorical data and ANOVA or *t* test for interval data. If assumptions of parametric tests were not met, groups were compared using Kruskal-Wallis ANOVA or Mann-Whitney *U* test. The distribution of the summary measure of HPD use was skewed. However, the post-measure of HPD use adjusted for the baseline measure was not markedly non-normal. Therefore, comparisons between HPD use at baseline and follow-up data used a Wilcoxon Matched-Pairs Signed-Rank test and comparisons of HPD use between tailoring groups and booster groups used a Mann-Whitney *U* test. Comparisons between the four groups created by the possible combination of tailoring and booster used a Kruskal-Wallis ANOVA.

The multivariable model assessing which variables in the theoretical model explained a significant amount of the variance in follow-up HPD use was constructed using stepwise regression. Baseline use of HPDs was included as a covariate. Bivariate associations between independent variables and post-HPD use were assessed using Spearman’s correlations or ANCOVA (with baseline HPD use as a covariate), depending on the level of measurement of the independent variable. Variables associated with post-HPD use at a $p < .1$ level were considered candidates for multivariable analysis. Appropriate regression diagnostics gave no indication that any assumptions of multiple regression analysis were violated. Final results were considered significant at $p < .05$.

Post hoc Analysis of Tailored Versus Targeted Content

Ryan et al. (2001) describe an innovative method for examining differences between tailored and targeted intervention content through the use

of match scores, which they piloted using hypothetical targeted data. The present study employed the match-scores method with actual tailored versus targeted message data. Two content experts independently compared messages, at each of 11 tailoring points, to the corresponding targeted message and rated their judgements of similarity using a match score of 0 (poor fit), 0.5 (close fit), or 1 (nearly exact fit). The content experts compared their match-score ratings and reached consensus through discussion. Using these ratings, match-score sums were then computed for each participant in the tailoring group ($n = 163$) to estimate the fit of their individually tailored message combination with the targeted message combination.

Results

Description of Sample

As shown in Table 1, the percentages of men and women differed significantly among trade groups, with labourers representing the most women (19%). The trades differed significantly in education level, with labourers having the lowest percentage of high-school graduates (78%). Age and tenure in the trade differed significantly among the trades: labourers were the oldest (42 years) and had the most longevity (14 years). The trades reported similar exposures to noise but differed significantly in variables representing HPD use, hearing-test history, and reported hearing-test results. Of the three trades, labourers reported the highest median pre-intervention HPD use, percentage of recent hearing testing, and percentage with fair or poor hearing ability (34%).

Retention rates from baseline to post-test were 77% for labourers, 42% for carpenters, and 31% for roofers; therefore follow-up data were available for less than half of participants ($n = 343/723$). Baseline and follow-up participants were similar with respect to noise exposure, education, and ethnicity, but those lost to follow-up were significantly more often men (94% vs. 90%), were younger (31 vs. 33 years), had fewer years in construction (4 vs. 5 years), and used HPDs less (20% vs. 50% in preceding 12 months). These differences can be accounted for by the higher attrition rates of the apprentices (roofers and carpenters) compared to the more stable group of labourer employees.

Intervention Effects

Overall, participants' HPD use rose significantly between time one and time two ($p < .001$, Wilcoxon Matched-pairs signed-rank test); the median reported use of HPDs was 42% at time one and 50% at time two. On average, tailored participants improved their HPD use by 8.3% ($sd = 30.2$), while targeted participants improved their use by 6.1%

Table 1 Sample Demographics and Noise and Hearing Variables

	Carpenters n = 161	Labourers n = 135	Roofers n = 47	p Value
Gender male	161 (100%)	109 (81%)	45 (96%)	< .001 ^a
Education high school graduate	157 (98%)	105 (78%)	39 (87%)	.003 ^a
Ethnicity White versus all others	139 (86%)	120 (89%)	38 (81%)	.38 ^a
Asian	4 (2.5%)	2 (1.5%)	1 (2%)	
Black	9 (6%)	8 (6%)	2 (4%)	
Hispanic	7 (4%)	2 (1.5%)	3 (6%)	
American Indian	2 (1%)	3 (2%)	3 (6%)	
Age (mean, SD)	27.1(6.9)	42.4 (8.3)	30.6 (4.6)	< .001 ^b
Years in trade (median, range)	2 (0–28)	14 (0–35)	4.5 (1–16)	< .001 ^c
Exposed to noise (median, range) (1 = never; 5 = always)	3.0 (2–5)	3.0 (2–5)	3.0 (2–5)	.16 ^c
HPD use (%) (median, range)				
Most recent job site	25 (0–100)	75 (0–100)	0 (0–100)	< .001 ^c
Job site before that	30 (0–100)	50 (0–100)	0 (0–70)	< .001 ^c
Past 12 months	33 (0–100)	75 (0–100)	0 (0–75)	< .001 ^c
Last hearing test (%)				
< 2 years	16.3	1.5	8.7	
2–5 years	64.4	98.5	71.7	
> 5 years, never	19.4	0	19.6	< .001 ^a
Reported hearing test results (%)				
Don't know	33.1	8.9	36.4	
Good	56.7	57.0	54.5	
Fair, poor	10.2	34.1	9.1	< .001 ^a

Note: Percentages may not add up to 100% due to rounding.

^a Chi-square test of association; ^b ANOVA; ^c Kruskal-Wallis ANOVA.

($sd = 29.8$) ($p = .51$, Mann-Whitney U test). Concurrent with the improved HPD use, four variables specified in the PUHPM showed significant improvement over baseline: benefits minus barriers, self-efficacy, social models of HPD use, and availability of HPDs ($p < .01$, Wilcoxon Matched-pairs signed-rank test).

There was no significant difference in the effects of booster and non-booster conditions ($p = .24$). Booster participants improved their HPD use by 9.5% ($sd = 28.9$) and non-booster participants improved their use by 5.6% ($sd = 30.6$). The tailored intervention plus booster, hypothesized to be the highest-intensity intervention, improved HPD use by 12.6% ($sd = 28.7$, $p = .13$ vs. all others, Kruskal-Wallis ANOVA).

Testing of the Model

In preparation for multivariate analysis, a high correlation ($\rho = -.54$) between scales was remedied by subtracting the mean barriers to use scale score from the mean benefits of use score, creating a single scale measuring perceived benefits minus barriers. Bivariate associations between independent variables and post-intervention HPD use are shown in Table 2. Several variables were eliminated from the model because of non-significant associations with p values $> .10$: noise annoyance, tailored versus targeted intervention, booster versus no booster, and gender. Post-intervention HPD use was regressed on the remaining nine independent variables. As shown in Table 3, 58% of the variance in post-intervention use of hearing protection was explained by three variables: baseline HPD use, social models of HPD use, and benefits minus barriers.

Post hoc Analysis of Tailored Versus Targeted Content

Match-score sums ranged from 2 to 9 out of a possible 11, with a mean of 5.5. For participants in the tailored group, a higher match score showed a positive correlation with a change in hearing protection use ($r = .17$, $p = .03$). This suggests that the researchers successfully created an effective targeted message intervention for construction workers.

Discussion

Occupational health nurses face considerable challenges in promoting the use of hearing protection among construction workers. Initial results confirmed low use of HPDs in these workers, emphasizing the need for interventions to promote use. The significant differences in reported hearing tests, hearing ability, and use of HPDs among the three trade groups included in this study suggest that construction workers cannot

	Correlations ^a			p Value
Age	.23			< .001
Years in trade	.27			< .001
Noise annoyance	.004			.94
Social models of HPD use	.60			< .001
Availability of HPD	.45			< .001
Organizational support	.24			< .001
Self-efficacy in HPD use	.14			.01
Benefits of/barriers to HPD use	.55			< .001
HPD use baseline	.64			< .001
		No	Yes	
Tailored intervention ^b		48.7 (2.0)	50.5 (2.1)	.54
Booster ^b		48.0 (1.9)	51.9 (2.3)	.19
Gender male ^b		45.3 (5.2)	49.9 (1.5)	.39
Trade ^b	Carpenters	Labourers	Roofers	
	48.0 (2.1)	56.6 (2.5)	34.6 (4.2)	< .001

^a Spearman's correlations.
^b ANCOVA, means (SE) post-HPD use adjusted for baseline HPD use reported.

Variable	β (se)	Standardized Beta	p Value
HPD use pre-intervention	.37 (.04)	.37	< .001
Social models of HPD use	11.9 (1.5)	.33	< .001
Benefits/barriers	5.6 (.85)	.27	< .001

Note: Statistics for the entire model: $f_{3,339} = 154.4$; $p < .001$; $R^2 = .58$.

be treated as one group and that researchers should consider the individual trades when designing and delivering interventions.

While overall use of HPDs increased to 50% at time two, it did not approach the 100% use necessary for workers exposed to high noise levels, which points to the difficulty in achieving behaviour change among this population necessary for prevention of NIHL. To ensure high ethical standards with respect to providing essential information to all participants in the targeted and tailored groups, the targeted intervention protocol was designed with the needs and attitudes of construction workers in mind, resulting in a theory-based, well-targeted intervention. This intervention was as effective as the tailored one. Hence, because tailored interventions are more time-consuming and expensive to develop, in this case targeted interventions would be the better value. Receipt of boosters did not result in significantly increased use, suggesting a need for further studies to identify effective combinations of interventions and boosters to increase use.

Multiple regression showed significant relationships of theoretically specified variables with post-intervention HPD use, demonstrating the utility of the PUHPM. The most important predictors from this model were comparable to those in previous research for three other groups of construction workers (Lusk et al., 1997) and for factory workers (Lusk et al., 1994), and the variance in HPD use accounted for by the model was similar. The PUHPM serves as a robust guide for designing interventions to promote use of hearing protection. Occupational health nurses, public health nurses, and other clinicians can apply these findings by focusing their interventions on the strongest determinants of change in hearing health behaviour identified in this study: social models of HPD use and perceived benefits of and barriers to HPD use. Findings from this test of the PUHPM can be used to plan revisions in the prototype computer-delivered educational program in order to maximize and simplify messages to target these important influences. Because social models of HPD use are interpersonal influences in the work environment, further development of the concept would inform the design of future interventions at the organization or system level to complement educational programs for workers.

This study examined tailored versus targeted messages post hoc and determined that the control intervention had been well targeted to address the overall responses of construction workers. We concur with the conclusion of Ryan et al. (2001) that “our challenge is to be able to develop parsimonious theoretical models outlining what is worth tailoring for what types of people and in what sociocultural contexts” (p. 556). Our results suggest that hearing protection research with construction workers should focus intervention tailoring on the key concepts of

social models and benefits versus barriers with regard to the PUHPM. Tailored intervention testing will contribute to the development of a targeted message that can be translated for broad dissemination in the construction field.

Several limitations of this study must be acknowledged. First, although the design made use of random assignment to the four intervention groups, the sample itself was not randomly selected from the population of construction workers. Our convenience sample of workers from construction trade unions may not adequately represent non-union workers, a large segment of the labour force. Next, the low retention rates from baseline to post-test may have biased the results so that they do not represent those lost to follow-up, specifically younger workers with less experience and lower use of hearing protection. Finally, the three trades were combined in analyses even though several variables differed significantly across trade groups. We addressed this limitation by assessing these variables as possible confounders in the multivariate analysis.

In conclusion, further study is needed to determine the most effective combination of boosters and interventions and to contrast targeted and tailored interventions. However, based on the results of this study, when costs (in time and money) are considered, targeted interventions offer the better value. No workers should have to lose their hearing in order to earn a living. With the negative effect of hearing loss on quality of life, it is essential that effective interventions be provided to increase use of hearing protection. The interventions tested in this study were effective in increasing use of hearing protection, the first step in preventing noise-induced hearing loss.

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Comments or queries may be directed to Madeleine J. Kerr, Associate Professor, School of Nursing, University of Minnesota, 5-140 Weaver-Densford Hall, 308 Harvard Street SE, Minneapolis, Minnesota 55455 USA. Telephone: 612-625-2669. Fax: 612-626-2359. E-mail: kerrx010@tc.umn.edu.

Madeleine J. Kerr, PhD, RN, is Associate Professor, School of Nursing, University of Minnesota at Minneapolis, United States. Kay Savik, MS, is Research Fellow, School of Nursing, University of Minnesota at Minneapolis. Karen A. Monsen, PhD, RN, is Adjunct Assistant Professor, School of Nursing, University of Minnesota at Minneapolis; and Program Manager, Washington County Department of Public Health and Environment, Stillwater, Minnesota. Sally L. Lusk, PhD, RN, FAAN, is Professor Emerita, School of Nursing, University of Michigan at Ann Arbor, United States.

L'exploration des réponses psychoneuroendocriniennes à la menace de cancer : réflexions à partir d'une tâche réalisée en contexte d'imagerie mentale dirigée assistée par ordinateur

Zhenfeng Ma, Aida Faber et Laurette Dubé

Il est proposé que les ordinateurs puissent servir à examiner l'expérience subjective des patientes face à la menace de cancer. Cette étude fournit une validation initiale d'une tâche assistée par ordinateur inductrice de stress en examinant les aspects psychologiques et relatifs aux systèmes nerveux autonome et endocrinien liés à l'expérience subjective vécue par une personne face à la menace de cancer, à l'occasion d'un examen de dépistage par mammographie. Un modèle d'analyse par mesures répétées a été employé. Un total of 38 femmes en bonne santé ont effectué une tâche induisant un stress (se rapportant à la mammographie) et une tâche témoin (se rapportant à la prévention de l'ostéoporose), réalisée chacune un jour différent, et les réactions d'ordre psychologique et relatives aux systèmes nerveux autonome et endocrinien de ces femmes ont été contrôlées. Comparativement à la tâche témoin, la tâche induisant un stress a entraîné des réactions plus importantes du système nerveux autonome (variabilité de la conductance cutanée et du rythme cardiaque) et du système endocrinien (sécrétion de cortisol salivaire), mais aucune détresse psychologique. De plus, tant la réaction du système nerveux autonome (conductance cutanée) que les réactions endocriniennes à la menace de cancer ont été modérées par la maîtrise, trait reconnu pour ses effets régulateurs de stress. Mais cet effet modérateur n'a pas été observé au chapitre des indices psychologiques de stress, c'est-à-dire de l'humeur. Les implications de ces constatations pour la recherche et les interventions en soins infirmiers font présentement l'objet de discussions.

Mots clés : stress, tâche induisant un stress, mammographie, imagerie

Exploring Women's Psychoneuroendocrine Responses to Cancer Threat: Insights from a Computer-Based Guided Imagery Task

Zhenfeng Ma, Aida Faber, and Laurette Dubé

It is proposed that computers could be used to examine patients' subjective experience in the face of cancer threat. This study provides initial validation of a computer-based stress task by examining the psychological, autonomic, and endocrine aspects of an individual's subjective experience of cancer threat surrounding mammography screening. A repeated measures design was used. A total of 38 healthy women performed a stress task (pertaining to mammography) and a control task (pertaining to osteoporosis prevention) on separate days during which psychological, autonomic, and endocrine reactions were monitored. Compared with the control task, the stress task induced higher autonomic responses (skin conductance and heart rate variability) and endocrine responses (salivary cortisol) but not psychological distress. Further, both the autonomic (skin conductance) and endocrine responses to cancer threat were moderated by mastery, a trait known to have a stress-buffering effect. Yet such a moderating effect was not observed for psychological indices of stress — that is, mood. Implications for nursing research and interventions are discussed.

Keywords: Stress, stress task, mammography, psychoneuroendocrine model, imagery

Over recent decades, developments in information-processing and communication technology have opened up broad-ranging possibilities in various aspects of health care. The Internet and computers are now playing an important role not only in providing health information but also in building virtual communities and facilitating nursing and other health-care interventions (Robinson, Patrick, Eng, & Gustafson, 1998; Rogers & Chen, 2005). In the present work, it is proposed that the power of technology can be harnessed further to examine patients' emotions and other aspects of their subjective experience when they are faced with threats to their health and well-being. Careful consideration of patients' emotions is critical to the success of nursing care, in particular when it comes to health communication and disease prevention/detection (Dubé, 2003; Dubé, Ferland, & Moskowitz, 2003; Thorpe et al.,

2006). In this study we provide the first validation of a computer-based stress task designed to capture the various psychophysiological facets of stress experience in the face of cancer threat.

Studies have found that for many women the perceived cancer threat is particularly salient surrounding a mammography procedure (Brett, Bankhead, Henderson, Watson, & Austoker, 2005). In addition to the fear of pain and discomfort associated with mammography, women report fear and anxiety about a possible finding of cancer, with significant health consequences (Stewart-Brown & Farmer, 1997; Wardle & Pope, 1992). Although both the fear of the procedure and the fear of cancer detection may contribute to women's stress experience, the stress task that we report on here focuses on women's stress experience arising from intensified fear of cancer detection.

The subjective experience of cancer threat has typically been measured by self-report of physical and/or psychological distress taken at different points over the course of detection procedures. An important limitation of self-report is that it captures only the psychological part of subjective experience, the part that is accessible to consciousness (Tomarken, 1995; Wright, 1980). Yet it is well known that subjective experience, in particular stress, is also shaped by neurophysiologic and endocrine responses to one's environment. This multifaceted view of stressful experience has been encapsulated in the psychoneuroendocrine (PNE) model of stress (Ursin & Eriksen, 2004). Research has found that the three components of stress experience — psychological, autonomic, and endocrine — do not necessarily evolve in tandem and that each component has a distinguishable impact on information processing and decision-making, as well as on health outcomes (Porter et al., 2003; Schommer, Hellhammer, & Kirschbaum, 2003). In real life and actual time, however, the measurement of these three components of the subjective experience becomes a challenge due to the extended time boundaries of diagnostic procedures as well as the functional and technical constraints attached to the measurement of the neurological and endocrine components of stress in the midst of everyday life.

In the present study we examine the possibility that, beyond its extremely useful application in providing health information, the computer can be used to examine the different facets of emotional experience of cancer threat that are particularly salient during anomaly screening. We draw from recent developments in mental imagery as a valid way to simulate subjective experience (e.g., Roffe, Schmidt, & Ernst, 2005), in order to develop a computer-supported laboratory task that simulates the subjective experience of being exposed to cancer threat with benign outcomes. We will show that the neuroendocrine components of the stressful experience in the face of breast cancer threat are

more easily elicited than self-reported subjective feelings of distress. We will further show that the computer-based guided imagery task, akin to robust evidence in field settings (Holmes & Mathews, 2005; Mathews & Mackintosh, 2000; Mathews & MacLeod, 2002; Roffe et al.), is able to capture the buffering effect of mastery over stress response intensity.

Theoretical Background

The PNE Approach to Stress

Studies across various domains are converging to suggest that stress is essentially an integrated PNE process (for a review, see Ursin & Eriksen, 2004). Specifically, exposure to aversive stimuli triggers psychological, autonomic, and endocrine responses. The psychological responses are manifested in various discrete subjective feelings such as anxiety and depression. The autonomic responses include changes in electrodermal properties (e.g., skin conductance) and cardiovascular activities (e.g., heart rate). The endocrine responses include increased secretion of certain hormones, such as cortisol. The PNE view of stress has received robust theoretical and empirical support from various fields, including animal studies (Toates, 2004), human psychology (Ursin & Eriksen), and neuroscience (LeDoux, 1995).

Although a stress response typically involves changes in all PNE components, research evidence suggests that the different response modes are mediated through relatively distinct neural pathways (LeDoux, 1995). Thus the PNE stress responses may not be highly correlated (Cohen, Scribner, & Farley, 2000; LeDoux; Schommer et al., 2003) and may uniquely predict behavioural/attitudinal change under stress. The relative independence of the PNE components suggests that stress responses are ideally measured using an integrated protocol that traces autonomic and endocrine as well as psychological changes.

Stress Experience Associated with Mammography Screening

Numerous studies have investigated the impact of mammography screening on women's emotional well-being. Overall, the preponderance of research evidence suggests that, partly due to the temporarily salient perception of cancer threat, a mammography procedure is associated with considerable psychophysiological stress responses, even when the outcome is benign (Britton, 2005; Grossi, Ahs, & Lundberg, 1998). However, most of the studies have focused on the psychological aspects of the stress experience surrounding mammography (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004; Heckman et al., 2004). Some studies also looked at the physiological aspects of stress responses to mammography or other cancer screening procedures, particularly

endocrine reactivity before or after such procedures (Gustafsson et al., 1995; Porter et al., 2003). For example, Porter et al. found that, in women without cancer history, mean daily cortisol levels increased around the time of mammography compared with baseline levels. Gustafsson et al. examined men's reaction to prostate cancer screening and found that, for examinees as a whole, serum cortisol levels at the examination were higher than corresponding levels of a comparable sample of men during normal daily activities.

Findings from these studies, in particular those that focused on the psychological aspect of stress, suggest that the stress experience is contingent upon the outcome of the screening procedure. Specifically, mammography screening with negative results, equivocal results, false-positive results, or delayed results has consistently been found to trigger stress (Kahn & Luce, 2003; Lerman et al., 1991; Lindfors, O'Connor, & Parker, 2001). However, some studies did not find elevated stress levels following a screening procedure with immediate benign results (Lerman et al.; Lindfors et al.), which is the focus of the present study. In addition, these studies have typically relied on self-report as a measure of stress, which may have failed to capture the stress experience in its totality.

Use of Mental Imagery to Evoke Emotions

Mental imagery is a technique that exploits the mind's ability to form representations of objects, places, or situations, which are perceived through one's senses, to simulate subjective experience (Post-White & Fitzgerald, 2001; Wilson & Barber, 1978). Researchers have long assumed that there is a link between mental imagery and emotions (Holmes & Mathews, 2005; Lang, 1979), and psychotherapists often use mental imagery to treat emotional disorders such as anxiety and phobia (Wolpe, 1958). Recent experimental studies provide evidence that mental imagery can induce emotion (Holmes & Mathews; Mathews & Mackintosh, 2000; Mathews & MacLeod, 2002). For example, Holmes and Mathews found that participants who had imagined unpleasant events experienced increased negative emotions such as anxiety. One technique widely used in psychotherapy and nursing care is guided imagery (Roffe et al., 2005), whereby the practitioner "guides" the individual through a mental experience in order to access physical, emotional, and spiritual dimensions of imagery for the purpose of inducing bodily change (Achterberg, 1985). In a guided mental imagery session, the practitioner typically leads the individual through imagery by following a script or asking the person to imagine himself or herself experiencing a situation as vividly as possible, with the imagery unfolding in a predetermined sequence that reflects the naturally occurring event.

The Moderating Effect of Mastery

Oncologists have stressed the importance of personality characteristics and psychological resources in patients' responses to nursing interventions (e.g., Loiselle, 2001). Research findings suggest that an individual's stress responses to cancer threat may be influenced by certain personality traits. One consistently observed moderator of stress experience is mastery, which refers to "the extent to which one regards one's life-chances as being under one's own control in contrast to being fatalistically ruled" (Pearlin & Schooler, 1978). Studies in both nursing care and psychotherapy have found mastery to be an important psychological resource for buffering stress in times of adversity. People with a weaker sense of mastery generally experience a higher degree of psychological distress and endocrine reactivity in stressful situations, whereas a strong sense of mastery generally attenuates such stress responses (e.g., Britton, 2005; Grossi et al., 1998; Kim, Han, Shin, Kim, & Lee, 2005; Mausbach et al., 2006). However, few studies have investigated the moderating effect of mastery on autonomic responses, conceivably due to functional or technical constraints in measurement.

The present study was designed to develop and validate a computer-based guided imagery stress task. The stress task was validated using a PNE measurement protocol, concurrently measuring an individual's psychological, autonomic, and endocrine responses to cancer threat perceived during a mammography procedure. It was hypothesized that, given the consistently observed stress-buffering effect of mastery, the validity of the stress task would be further supported if individuals' PNE responses to the task were moderated by mastery in a way that is consistent with its stress-buffering effect.

Methods

Overview

The stress task was validated through an experimental study using a one-factor (experimental condition: stress vs. control) repeated measures design. Each participant performed two health-related imagery tasks: one control task and one stress task. The two tasks were performed on separate days roughly 2 weeks apart. The control task, pertaining to osteoporosis prevention, was performed during the first session and the stress task, pertaining to mammography screening with a benign outcome, during the second session. During both tasks, participants' PNE reactions were continuously measured. The study was approved by the ethics committee of the institution.

Participants

A total of 38 healthy women ($M_{\text{age}} = 58$, $SD = 7.83$) were recruited from the community through newspaper advertisements. When potential participants phoned in they were screened by the research assistant on several selection criteria. Only post-menopausal women were selected, in order to control for the effect of menstrual cycle on endocrine responses (Kirschbaum & Hellhammer, 1989). Other criteria were Body Mass Index < 30 ; no prior cancer history; and no drug, alcohol, or nicotine addiction. These factors potentially affect PNE reactions to stressors (Kirschbaum & Hellhammer).

Procedure

All experiments were conducted in individual sessions between 1 pm and 7 pm in a well-ventilated room. Participants sat in a high-back chair in front of an IBM-compatible computer. Two baseline salivary samples were obtained, at 5 and 10 minutes after the participant's arrival, followed by measurement of baseline mood. Next, participants were connected to the equipment for measurement of physiological responses. After a 2-minute rest period, they began performing either the control task or the stress task. They were instructed to concentrate on the respective task and minimize their body movements. Autonomic responses — skin conductance and heart rate — were continuously measured during the imagery tasks. Endocrine reaction — salivary cortisol — was sampled three times: at 6, 13, and 20 minutes into the task. Upon completion of the task, the physiological sensors were removed from the participant and post-task mood was measured. Two post-task endocrine measurements were taken: at 5 and 10 minutes after completion of the task. After the first session the women were given a questionnaire containing various measures, including the mastery scale, to take home. At the second session they returned the questionnaire, completed the imagery task, were thanked and debriefed, and left the laboratory. All participants received an incentive of \$75 for taking part in the study.

Computer-Administered Guided Imagery Tasks

Stress was manipulated using the technique of guided mental imagery administered via computer. The control task pertained to osteoporosis prevention and the stress task pertained to mammography screening. Each task lasted 20 minutes and consisted of several phases replicating real-life screening and diagnostic procedures. The stress task began with an introduction to breast cancer, followed by the two critical steps of detecting a suspicious lump in the breast and undergoing mammography screening. In the final phase participants imagined receiving screening

results indicating a benign outcome. They were guided through the task by instructions presented via multimedia Microsoft PowerPoint slides. To enhance the vividness of the imagery, the computer instructions included audio and visual cues. For example, at the moment of waiting for the mammography results, the participants heard the sound of a pounding heart and the ticking of a clock and saw the image of a looming office door. The control condition entailed a similar sequence in the context of osteoporosis: screening and a visit to the clinic with a prescription for prevention activities such as jogging or gardening. The two conditions were carefully matched in terms of length, cognitive complexity, and number of audio and visual cues.

Measures

Subjective experience was measured using the short form of the Profile Of Mood States (POMS-SF) (Shacham, 1983), which consists of a global negative mood scale — total mood disturbance (TMD) — and six subscales: anxiety, depression, anger, confusion, vigour, and fatigue. This scale is widely used by psycho-oncologists to capture transient mood states in both clinical and non-clinical settings. Consistent with reports of previous studies (Baker, Denniston, Zabora, Polland, & Dudley, 2002), Cronbach's alpha ranging from .80 to .90 was obtained for the TMD and each of the subscales. For the TMD and each subscale, a change score was calculated to index changes from pre- to post-task level.

Autonomic responses were measured in terms of skin conductance and heart rate, using MP equipment (Model 100A), a computer-based physiological data acquisition system developed by BIOPAC® Systems, Inc. Changes in skin conductance were measured via two EL500 Ag/AgCl disposable electrodes attached to the palmar surface of the participant's non-dominant hand. Variations in heart rate were recorded via two electrodes placed in a bipolar configuration on opposite sides of the participant's body. Consequently, if the participant was right-handed, one electrode was placed on her neck, on the aorta, and the other under her left ribcage. If the participant was left-handed, the reverse applied. Two indices of autonomic response were calculated: heart rate variability (HRV) and skin conductance. HRV was analyzed on the basis of an electrocardiogram (ECG). From the ECG, inter-beat (RR) intervals or time intervals between consecutive heartbeats were spectral analyzed using the Fast Fourier Transform technique. Analysis of HRV was carried out on two frequency bands: low frequency (LF) (.04 to .15 Hz), reflecting sympathetic activity with vagal modulation, and high frequency (HF) (.16 to .40 Hz), reflecting parasympathetic activity. The LF/HF ratio was calculated as a single index of mental stress (Hjortskov, Blangsted, Fallentin, Lundberg, & Sogaard, 2004). Skin conductance was measured

in terms of mean frequency of skin conductance spontaneous fluctuations (SCSF). A spontaneous fluctuation was defined as an elevation in magnitude of skin conductance level by .05 microSiemens (μS) lasting at least 2 seconds. Final analysis of SCSF was done using response per minute (SCSF/min). The mean SCSF for the 2 minutes immediately preceding the task was taken as the baseline measure. Prior to analysis, SCSF was adjusted by baseline level — that is, by subtracting the mean baseline from the task-related levels.

Endocrine activity was measured using salivary cortisol, sampled with a device called the salivette (Sarstedt Inc., Rommelsdorf, Germany). A salivette consists of a small cotton swab placed inside a standard centrifugation tube. By chewing on the swab, participants stimulate saliva flow to rates that generate sufficient material for radioimmune assay. After sampling, the tubes were frozen until assayed. The concentration level of cortisol was determined using a commercially available radioimmunoassay kit (Kirschbaum & Hellhammer, 1989). Preliminary analysis showed that the mean basal level of cortisol concentration did not differ for the two conditions ($F(1, 38) = .65, p > .40$). The area under the curve (AUC) was derived as an index of cortisol response and was used in the final analysis (Pruessner, Kirschbaum, Meinlschmid, & Hellhammer, 2003). AUC was calculated using both the basal and the task-related cortisol concentration values.

Mastery was measured using the mastery scale of Pearlin, Menaghan, Lieberman, and Mullan (1981). The instrument consists of seven items rated on a four-point scale (1 = does not apply at all; 4 = applies completely). Previous studies have found that the scale has good internal consistency (Cronbach's $\alpha = .76$) and test-retest reliability ($r = .65$ at 1-month interval) (Reich & Zautra, 1989). A mean score for mastery was calculated and used in the final analysis.

Results

PNE Responses to Cancer Threat

The first task was to examine whether the participant's psychophysiological reactions differed for the two experimental tasks. To this end, a series of repeated measures ANOVA were performed, with the PNE response variables as the dependent variable and stress condition as the independent variable. The means and standard deviation as well as the test statistics are presented in Table 1.

As can be seen in Table 1, the stress condition is associated with higher physiological reactions to cancer threat than the control condition. Specifically, regarding the autonomic responses, participants in the stress condition evidence higher SCSF ($p < .02$) and greater HRV

Table 1 *Mood, Autonomic, and Endocrine Changes in the Control and Stress Conditions*

Dependent Variables	Control		Stress		F(1, 38)	p
	Mean	SD	Mean	SD		
Mood						
TMD	-.85	.36	-.36	1.08	.50	.48
Anxiety	-.35	.11	-.15	.19	.07	.79
Depression	-.15	.08	-.10	.24	.00	.96
Confusion	-.26	0.09	-.05	.19	.19	.66
Anger	.01	.09	-.21	.22	.55	.46
Fatigue	-.13	.11	-.01	.19	.27	.61
Vigour	-.11	.10	-.19	.17	.26	.62
Autonomic						
SCSF	2.02	.26	2.15	.24	6.28	< .02
HRV	3.37	.22	4.25	.23	8.62	< .01
Endocrine						
Salivary cortisol (AUC)	1.80	.05	1.93	.08	7.33	.01

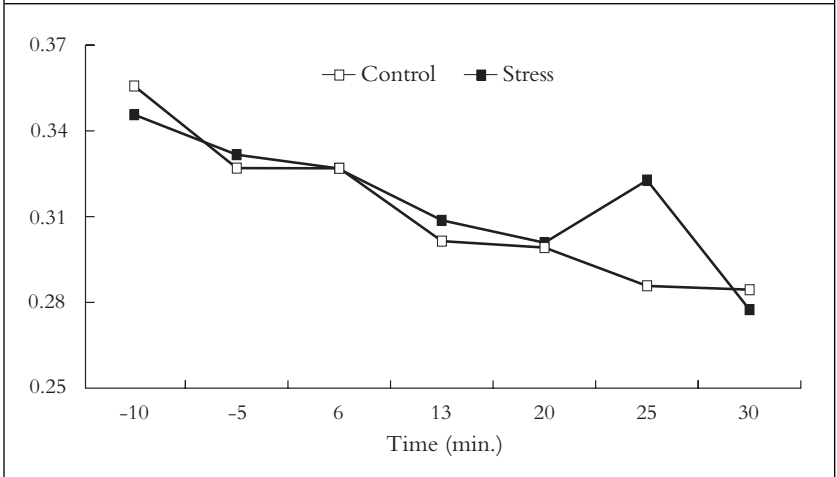
Note: Mood and autonomic responses are adjusted by baseline level; salivary cortisol is indexed by AUC. TMD = total mood disturbance; SCSF = skin conductance spontaneous fluctuation; HRV = heart rate variability; AUC = area under the curve.

($p < .01$). Compared with the control condition, the stress condition also induced higher endocrine response, as shown by the elevated salivary cortisol response ($p = .01$). Figure 1 shows the changes in cortisol concentration over time in the two conditions. Self-report measures of subjective experience, as indexed by the various POMS scales (TMD and the six subscales), did not differ for the two conditions, $ps > .40$. In other words, after receiving a benign outcome immediately following anomaly mammography screening, women did not report higher psychological distress or less intense upbeat feeling (as indexed by *vigour*; see Table 1) compared with the pre-screening level, in spite of the fact that manifestations of stress were present at the physiological and endocrine levels.

The Moderating Effect of Mastery

To investigate the potential moderating effect of mastery, a series of repeated measures analysis of covariance (ANCOVA) of the PNE response variables were performed, with the stress condition as a factor and trait mastery as a continuous covariate. The moderating effect of

Figure 1 *Changes in Cortisol Concentration Over Time in Control and Stress Conditions*

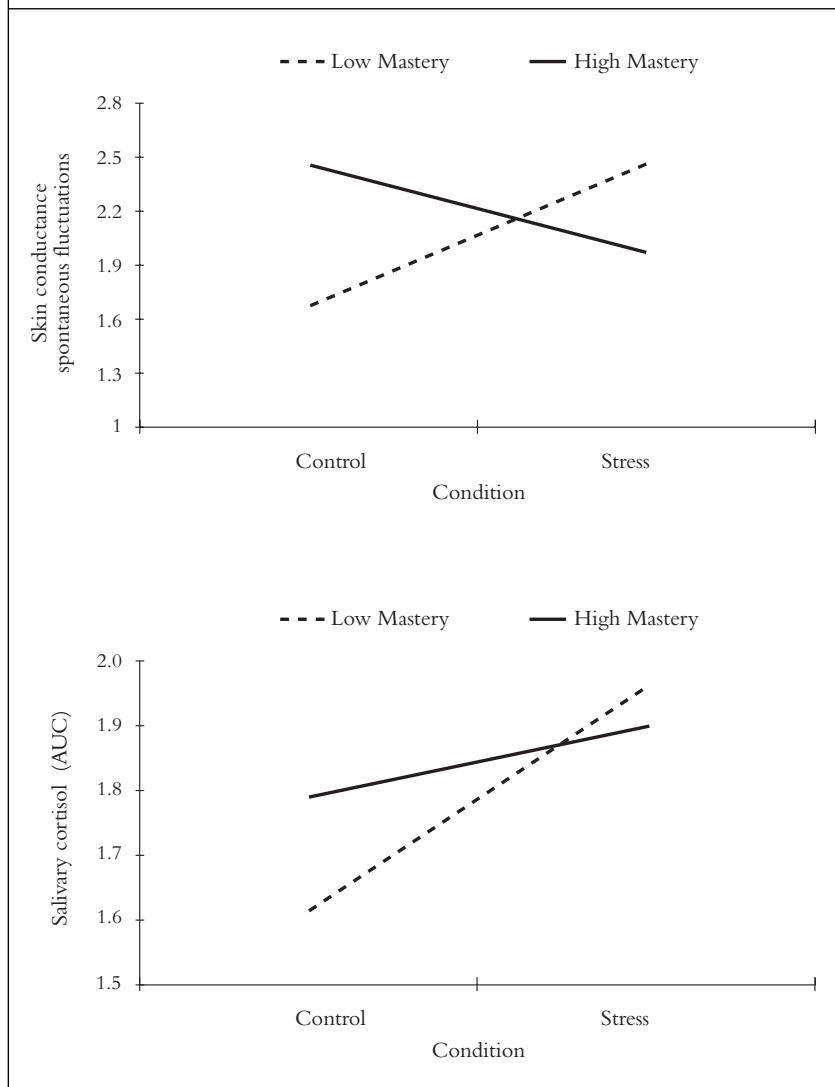


mastery could thus be detected by the presence of a significant *condition x mastery* interaction term. The ANCOVA showed a significant *condition x mastery* interaction effect on salivary cortisol, $F(2, 347) = 5.86, p < .01$, and skin conductance, $F(2, 29) = 4.9, p = .01$. However, no *condition x mastery* interaction effect was found on HRV, $p = .98$, or on any of the psychological variables — that is, POMS scores, $ps > .30$. The results also show a marginally significant negative effect of mastery on salivary cortisol, $\beta = -.02, F(1, 38) = 3.49, p = .07$, although mastery had no direct impact on any of the other psychophysiological variables.

To facilitate interpretation of the *condition x mastery* interaction effect on salivary cortisol and skin conductance, the participants were subsequently divided into high- and low-mastery groups based on a median split, $Mdn = 42$. Then salivary cortisol and skin conductance were subjected to repeated measures ANOVA, with the stress condition and mastery group as independent variables. Analysis showed a significant *condition x mastery group* interaction for both salivary cortisol, $F(2, 37) = 3.34, p = .01$, and skin conductance, $F(2, 37) = 3.11, p = .05$. Post-hoc contrast analysis showed that, consistent with the stress-buffering notion of mastery, low-mastery women evidenced increased cortisol reaction in the stress-versus-control condition, $M_{\text{stress}} = 1.96$ vs. $M_{\text{control}} = 1.61, F(1, 37) = 8.66, p < .01$. However, the cortisol responses of high-mastery participants did not differ between conditions, $M_{\text{stress}} = 1.90$ vs. $M_{\text{control}} = 1.79, F(1, 37) = .74, p = .40$. There was no difference between low- and high-mastery participants in either the control or the stress condition

($ps > .10$). Similarly, low-mastery participants showed increased skin conductance in the stress-versus-control condition, $M_{\text{stress}} = 2.45$ vs. $M_{\text{control}} = 1.67$, $F(1, 37) = 4.61$, $p < .05$, whereas high-mastery participants did not differ between conditions, $M_{\text{stress}} = 1.96$ vs. $M_{\text{control}} = 2.45$, $F(1, 37) = 1.54$, $p < .22$ (see Figure 2).

Figure 2 *Moderating Effect of Mastery on Skin Conductance and Salivary Cortisol*



Discussion

In this study we provided initial validation of a computer-based stress-induction task pertaining to the cancer threat that is typically experienced during a mammography procedure by tapping into the various psychophysiological facets of the stress experience. Compared with women in the control (low-threat) condition, those who underwent the simulated mammography procedure evidenced higher autonomic responses (as indexed by skin conductance and HRV) and endocrine responses (as indexed by salivary cortisol), although no difference in terms of psychological indices of stress (mood) was observed between conditions. The validity of the stress task was further supported by the observed stress-buffering effects of mastery on both autonomic and endocrine responses to cancer threat.

The use of a computer to capture the participant's subjective experience of being exposed to cancer threat opens many promising horizons. For example, researchers can use a modified imagery script to have patients recollect the anomaly screening experience once the benign diagnosis is known, in order to identify subgroups of patients whose stress response to the experience is most intense and who would benefit most from a stress-recovery intervention. Currently, the standard of care is that no support is given once the benign diagnosis is known. Considering the enormous impact of patient emotion on the effectiveness of nursing intervention programs, researchers can use this stress task for pilot-testing the effect of such programs, particularly in the area of health communication. In addition, the computer-supported guided imagery stress task could allow for pilot-testing and refinement of computer-supported interventions centred on the provision of health information prior to their empirical validation in clinical trials. The protocol of the stress task will also permit researchers to monitor both psychological and physiological responses to their intervention, thus having the potential to offer fresh insights into the mechanisms through which interventions influence patient attitudes and behaviours.

Although our primary purpose is to develop and validate a health-related laboratory stress task, findings from this study have several implications for nursing research and practice in general. One of our most notable findings was that after experiencing a temporarily salient cancer threat, participants evidenced stronger autonomic and endocrine stress responses but reported no change in subjective feelings (mood). Further, the stress-buffering effect of mastery was observed for autonomic and endocrine responses but not for the psychological indices of stress. Taken together, these findings clearly indicate that the psychological and physiological indices of stress experience do not always evolve in tandem. The

dissociation between the psychological and physiological measures also suggests that research that relies primarily on self-report to capture a person's experience of cancer threat may not be sufficiently sensitive to capture all facets of the emotional experience. If these facets cannot be assessed, nursing care cannot alleviate them. Thus, in future research and practice, nursing oncologists are advised to simultaneously monitor the various psychophysiological processes of patient emotional experience by employing a multi-method measurement protocol. Such multi-method measurement may be particularly useful when the subjective measures are least effective in capturing a patient's emotional experience or when dissociation between psychological and physiological measures is most likely to occur.

The stress-buffering effect of mastery observed in this study may also be interesting to nursing researchers and practitioners. Previous studies have verified the stress-buffering impact of mastery on psychological indices of stress experience. The results of this study show that mastery affects an individual's physiological stress responses as well. Since mastery has proven to be an important psychological resource in the face of adversity such as cancer threat, it is crucial that nursing oncologists and practitioners identify low-mastery individuals and promote a sense of mastery in them. For effective identification of individuals varying in mastery, here again a multi-method assessment/measurement protocol is recommended, because our findings show that the stress-buffering effect of mastery may operate differently for the different psychophysiological components of stress experience.

These results must be interpreted with due consideration of the study's limitations. The first limitation concerns our research design. We did not counter-balance the order of experimental conditions, with the control task being performed in the first session and the stress task in the second. The lack of counter-balancing is justifiable in light of the primary purpose of this study: validation of the stress task. Had the stress task been performed in the first session, the participant's reaction to the subsequent control task could have been unduly biased due to the memory of a highly emotional task. For this reason, all stress tasks were performed in the second session. Further, this experimental order helps to ensure that the observed stress responses in the stress condition are not confounded with the "novelty" effect — that is, the novelty of a new situation/task due to unfamiliarity with the situation/task. However, this experimental order does raise concerns with regard to the observed stress-buffering effect of mastery. It could introduce practice effect, which is likely to increase with level of mastery. Thus the observed buffering effect of mastery may be confounded with the practice effect. Further research is needed to replicate the findings on the stress-buffering effect of mastery

in a counter-balanced design. Also, it should be noted that the stress-buffering effect of mastery is used as a means of providing further validation to the stress task rather than as an end in itself. Thus, the observed impact of mastery on autonomic and endocrine responses should be viewed as exploratory rather than confirmatory. Further empirical evidence is needed, preferably from both field and laboratory settings, to ensure the generalizability of these findings on the stress-buffering effect of mastery.

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Comments or queries may be directed to Zhenfeng Ma, School of Business and Information Technology, University of Ontario Institute of Technology, 2000 Simcoe Street North, Oshawa, Ontario L1H 7K4 Canada. Telephone: 905-721-3111, ext. 2883. E-mail: zhenfeng.ma@uoit.ca.

Zhenfeng Ma, MA, is a PhD candidate in the Desautels Faculty of Management, McGill University, Montreal, Quebec, Canada. Aida Faber, BA, is a PhD student in the Desautels Faculty of Management. Laurette Dubé, PhD, is Professor, Consumer Psychology and Marketing, Desautels Faculty of Management.

Considérations méthodologiques sur l'évaluation des interventions en télésanté

**Huong Q. Nguyen, DorAnne Cuenco, Seth Wolpin,
Josh Benditt et Virginia Carrieri-Kohlman**

Les progrès des technologies de l'information et de la communication façonnent les attitudes des consommateurs en ce qui a trait à leur engagement face à leur propre santé et leur interface avec le système de santé. L'utilisation d'outils de télésanté est très prometteuse, car elle favorise et facilite les changements en matière de comportements touchant la santé ainsi que la prévention et la gestion des maladies chroniques. Les auteurs se penchent sur des questions liées à la conception des études, à l'application des traitements et à la mesure des résultats dans le cadre des essais en télésanté, en fournissant des exemples issus de la littérature et de leurs propres études en cours. La sélection du groupe témoin et les considérations en matière de conception à partir des préférences des participants se fondent sur l'état des connaissances scientifiques et sur les pratiques courantes dans le domaine concerné. Une conception aléatoire permet de réduire les biais de sélection, et on la préfère dans les essais visant à évaluer l'efficacité potentielle et réelle des interventions en télésanté. Selon le choix des groupes témoins, les applications en télésanté doivent être passablement solides pour démontrer leur supériorité sur le traitement de référence. Les stratégies visant à assurer la fidélité au traitement et l'engagement soutenu des participants peuvent présenter des difficultés et ne réussissent pas toujours. Les résultats rapportés par les patients se retrouvent dans toutes les études sur la télésanté. Les autres résultats, comme les coûts associés aux nouvelles applications en télésanté, sont tout autant, sinon plus importants pour les décideurs. Cette discussion vise à éclairer les futurs essais et, de ce fait, à faire progresser les connaissances en télésanté.

Mots clés : télésanté, évaluation

Methodological Considerations in Evaluating eHealth Interventions

**Huong Q. Nguyen, DorAnne Cuenco, Seth Wolpin,
Josh Benditt, and Virginia Carrieri-Kohlman**

Advances in information and communication technologies shape consumers' attitudes towards engagement in their own health and their interface with the health-care system. The use of eHealth tools holds promise for supporting and enabling health behaviour change and the prevention and management of chronic diseases. The authors review issues related to study design, treatment implementation, and outcome measurement in eHealth trials, providing examples from the literature and from their own ongoing studies. Selection of a comparison group and design considerations related to participant preferences are based on the state of the science and current practice in the particular field. Randomized designs allow for control of selection bias and are favoured in both efficacy and effectiveness trials of eHealth interventions. Depending on the choice of comparison groups, eHealth applications must be fairly robust to demonstrate their efficacy above and beyond active controls. Strategies to ensure treatment fidelity and ongoing participant engagement can be challenging and are not always successful. Patient-reported outcomes are common to eHealth studies. Other outcomes, such as the costs associated with new eHealth applications, are equally if not more important for decision-makers. This discussion is intended to inform future trials and thereby serve to advance the science of eHealth.

Keywords: eHealth, Internet, telehealth, evaluation, methodology, dyspnea, chronic obstructive pulmonary disease

Introduction

Advances in information and communication technologies continue to shape consumers' attitudes towards engagement in their own health and their interface with the health-care system (Dickerson & Brennan, 2002). These changes, combined with a greater burden of chronic illness in the population, an aging population, and escalating health expenditures, have created significant challenges. Yet ample opportunities have emerged for nurses to explore innovative ways to positively impact the health of individuals and populations (Bodenheimer, 2005). In 2001, Eng surveyed the developing landscape of information and communication technologies in health care and coined the term eHealth, defining it as "the use of emerging interactive technologies (inclusive of all media types) to enable

health improvement and health care services” (Eng, 2001, p. 1). Other terms, such as consumer health informatics (Eysenbach, 2000) and interactive behaviour change technology (Glasgow, Bull, Piette, & Steiner, 2004), emerged at the same time or soon thereafter. We will use eHealth to refer to information and communication technologies that directly engage health consumers and/or their families; discussions related to specific software applications to support health providers are beyond the scope of this article.

Notable among the eHealth tools designed to support health promotion and collaborative disease management are health-risk assessments linked to online and offline health promotion activities; applications that allow consumers to track and share health parameters; telehealth technologies that support virtual home visits and ongoing monitoring; and decision-support tools ranging from automated expert systems to evidence-based practice guidelines and online peer communities that help health consumers and their families weigh risks and benefits associated with various treatments. The use of eHealth tools in general holds tremendous promise for the support and enabling of behaviour change and the prevention and management of chronic diseases. However, a recent survey of the eHealth landscape found that, although there has been progress in the field, high-quality evidence to support the efficacy and effectiveness of these applications is still limited (Ahern, Kreslake, & Phalen, 2006).

While the methodological challenges associated with clinical studies of eHealth applications are not substantively different from those associated with evaluations of nursing interventions that do not employ technology, they can be amplified in unanticipated ways by the intersection between people and their use of technology. The purpose of this article is to review issues related to study design, treatment implementation, and outcome measurement in eHealth clinical trials and to illustrate these issues by highlighting examples from the literature and three of our ongoing studies. By bringing attention to these evaluation challenges and reporting on our “lessons learned,” we hope to inform future trials and thereby help to advance the science of eHealth.

Study Designs

As imperfect as it may be, we will use the clinical trials framework of Phase I-IV, which guides pharmaceutical research as a heuristic to illustrate the sequential steps associated with building the evidence base for eHealth applications (US Food and Drug Administration). In the context of drug trials, new pharmaceutical compounds often undergo early testing in healthy volunteers in Phase I to determine optimal intensity,

timing, mode of action or mechanism, tolerability, and safety. Similarly, short-term one- or two-group pre/post-test designs may be appropriate to determine feasibility, uncover usability and logistical issues, and establish early evidence of efficacy for trials of eHealth applications. Phase II is typically an explanatory clinical trial to determine whether a drug has the expected impact on a primary outcome. At this stage, randomized controlled trials (RCTs) with optimal testing conditions — for example, highly selected and motivated participants — are used to determine the efficacy of an eHealth application.

Once efficacy is established, the drug is administered to a larger group of participants to confirm its effectiveness, monitor side effects, and compare it to commonly used treatments (Phase III). eHealth interventions that reach Phase III are subjected to practical or pragmatic trials. These studies continue to employ randomization and are controlled, usually for community or standard alternative interventions with fewer eligibility restrictions so that the question of usefulness and generalizability can be properly addressed. Individual preferences are considered within the study design and tailored treatment algorithms (Glasgow, Davidson, Dobkin, Ockene, & Spring, 2006; Tunis, Stryer, & Clancy, 2003). Phase IV post-marketing or surveillance studies, which often employ observational cohort designs, are conducted after drugs are approved and are in broad use. Since eHealth tools are not regulated or required to undergo any formal approval process, their rapid diffusion into practice can present notable challenges to this formulaic sequential testing strategy. The framework described above informs our ensuing discussion regarding the selection of comparison groups and use of random assignment, two equally difficult and interdependent study design decisions.

Selection of Comparison Group(s)

The selection of a comparison group for studies testing a new eHealth intervention warrants serious consideration and often rests on the state of the science and practice in an area. In health care, there is frequently a standard of care against which new treatments can be compared. It should be noted that usual care is not necessarily comparable to standard care, especially since it has been found that patients receive, on average, only 50% of recommended standard care (McGlynn et al., 2003). The former question of most interest in eHealth research is whether a technology-enhanced intervention is comparable to or better than an existing standard intervention. Studies to address this question, often referred to as non-inferiority, equivalence, or comparative trials, require greater attention to study design, conduct, analysis, and interpretation. A new eHealth intervention may be expected to match the efficacy of the

standard treatment but have advantages in convenience or cost or simply be an alternative (Jones, Jarvis, Lewis, & Ebbutt, 1996). Non-inferiority designs are also appropriate for situations in which the prospect of not offering a viable treatment to all participants raises ethical concerns (Ellenberg & Temple, 2000; Temple & Ellenberg, 2000).

Various comparison conditions have been used in eHealth studies. These include usual care (Barnason, Zimmerman, Nieveen, & Hertzog, 2006), face-to-face counselling (Carlbring et al., 2005; Izquierdo et al., 2003), Web-based discussion groups (Andersson et al., 2005), and computerized assessment (Glasgow, Nutting, et al., 2004). Unfortunately, the majority of studies do not provide an explicit rationale for their selection of comparison groups. In some areas, such as smoking cessation, for which a clear standard of care exists, the studies of new eHealth tools are always compared to active behavioural interventions (Strecher, Shiffman, & West, 2005; Vidrine, Arduino, Lazev, & Gritz, 2006). In others, such as back pain, where the condition is often self-limiting and there is no clear effective therapy, usual-care controls are used (Lorig et al., 2002; Polly, 2005). Because standard of care differs across diseases and care settings and can change over time, effect sizes across eHealth studies are not always comparable and will become increasingly difficult to interpret (Murray, Burns, See, Lai, & Nazareth, 2005). The expected outcome differences between two active treatments are considerably smaller than those between active treatment and usual care.

Too often, latter-phase studies of eHealth interventions fail to perform rigorous head-to-head comparisons with standard treatments. The result is that stakeholders are left without crucial information about the relative cost-effectiveness, benefit, or risk of the new, competing treatments. An example of where an equivalence trial would have been useful is a recent study that tested the effects of an Internet-based chronic disease self-management program against usual care (Lorig, Ritter, Laurent, & Plant, 2006). The Internet program was adapted from a face-to-face program that had been widely disseminated and was considered the standard of care for patients with various chronic conditions. The new program had only modest effects on patient-reported outcomes and no impact on health-service use. The authors went on to conduct exploratory comparisons with a *historical* cohort that previously completed the face-to-face intervention and concluded that the results were similar for the two programs.

Before discussing our decision-making on a comparison group for the design of our current eHealth studies of dyspnea self-management in patients with chronic obstructive pulmonary disease (COPD), a brief overview of our work leading up to this stage is in order. Our cumulative work in understanding the symptom and coping strategies began

with early descriptive studies (Carrieri & Janson-Bjerklie, 1986; Carrieri, Janson-Bjerklie, & Jacobs, 1984), followed by two randomized trials of variations in the face-to-face dyspnea self-management program (Carrieri-Kohlman et al., 2005; Carrieri-Kohlman, Gormley, Douglas, Paul, & Stulbarg, 1996). This was followed by a Phase I study of the Internet-based dyspnea self-management program (eDSMP) using a one-group pre/post-test design (Nguyen, Carrieri-Kohlman, Rankin, Slaughter, & Stulbarg, 2005). Our DSMPs provide patient education and training on strategies for dyspnea management with a strong emphasis on independent exercise and ongoing reinforcement by a nurse.

For our first efficacy study of the eDSMP (Dyspnea Self-Management Study I), we proposed to compare the effects of the eDSMP to our “gold standard” face-to-face program (fDSMP) on the primary outcome of dyspnea with activities of daily living. We chose the fDSMP as a comparison treatment for two reasons. First, practice guidelines at the time recommended education for patients with COPD (National Heart, Lung and Blood Institute and World Health Organization, 2003). We also anticipated that the standard of care for patients with COPD would improve in the next few years and ultimately wished to build the evidence base for informed patient choice with the two programs. Second, this design provided a more stringent test of treatment efficacy and was perceived as an improvement over other eHealth studies where usual care was the comparison condition (Gustafson et al., 2001; Lorig et al., 2002; Southard, Southard, & Nuckolls, 2003).

Although our rationale for designing Dyspnea Self-Management Study I was conceptually sound subject to funding constraints, a three-arm design, which includes an attention control group, would (1) help guard against the potential of falsely concluding that the eDSMP is as efficacious as the fDSMP and that both were better than nothing, and (2) allow testing against the non-specific effects of attention, which we had not done before (Friedman, Furberg, & DeMets, 1998). In our expanded follow-up study, Dyspnea Self-Management Study II, we added a parallel control group that will receive general health education and comparable contact time. Some may view it as unethical to not provide these participants with information specific to their condition. Our rationale is that, despite national practice recommendations, structured education and skills training to manage COPD are still not the standard of care in primary care settings (Mularski et al., 2006). Moreover, participants assigned to this group will continue to have unrestricted access to online information resources available to any Internet user. Participants in the control group receive an intervention (initial home visit, six group-based health-education sessions, and ongoing telephone contact) that mimics the fDSMP, not the eDSMP.

Randomize or Accommodate Participant Preferences (or Both)?

The randomized experimental design, a cornerstone of evidence-based practice, provides the strongest evidence on the *efficacy* of eHealth interventions. It has been argued that randomized trials may be vulnerable to “preference effects” such that treatment preference and concordance could influence treatment adherence and consequently health outcomes (Sidani, 2004). With the trend towards greater patient participation in health-care decisions and the increased importance of patient-centred care (Davis, Schoenbaum, & Audet, 2005; Institute of Medicine, 2001), it has been argued that patient preferences play a key factor in determining the success of medical and behavioural treatments (Bradley, 1993; Brewin & Bradley, 1989). Efforts to foster patient involvement have been encouraged as a means to empower patients, strengthen the therapeutic alliance, optimize treatment adherence, and improve outcomes (Fisher et al., 2005; TenHave, Coyne, Salzer, & Katz, 2003). Wait-list control and group RCT designs have also been proposed by some researchers to better accommodate individual preferences while retaining randomization. However, these designs have their own limitations — for example, unacceptable treatment delays with wait-list designs and a large number of sites required for group RCTs (Gross & Fogg, 2001).

While there are hybrid designs that combine randomization and preference schemes to preserve causal inferences (Janevic et al., 2003; Noel et al., 1998), a simple preference trial that allows participants to select their treatment arm *is* a prospective observational study with its inherent susceptibility to confounding and selection biases. Partial RCT designs with a parallel preference cohort have serious problems in settings where participants have strong preferences for one treatment over another. In one study that employed such designs, an overwhelming 90% of participants selected the preference arm, leaving 10% in the randomized study (Miranda, 2004). Analyses of preference trials are inherently difficult and reports from these trials have been mixed and difficult to interpret (Bedi et al., 2000; Ward et al., 2000; Weinstein et al., 2006). Although results from these studies show that outcomes were not different for those who received their preferred treatment and those who were randomized, none of the studies was sufficiently powered to test the choice by treatment-group interaction (Bedi et al., 2000; Janevic et al.; Noel et al., 1998; Ward et al.).

Another possible alternative is a matched controlled design where random assignment is not used. Patients who choose to use an eHealth tool are compared to those who choose not to. Statistical techniques such as propensity scoring (PS) are employed to adjust for treatment selection bias in these designs. The use of PS is the observational study analogue of

randomization in RCTs (D'Agostino, 1998). A PS is a measure of the probability that a patient will receive an intervention. It is usually derived from a regression analysis of that patient's observed baseline characteristics. The PS essentially summarizes these characteristics in a single composite variable. Patients can then be stratified or matched based on this score and their outcomes compared within strata of comparable likelihood of receiving the eHealth intervention (Earle et al., 2001; Penrod et al., 2006). Although PS adjustments can balance observed baseline covariates between intervention and comparison groups, they do nothing to balance unobserved characteristics and confounders.

The US Department of Veterans Affairs has been in the forefront of testing technology-enhanced home-care services to better serve geographically distributed veterans. Propensity scoring was used to match patients who received a telecare management intervention to comparison participants (Barnett et al., 2006; Chumbler, Vogel, et al., 2005). Although health-service use was reported to be lower in the telecare intervention after 12 months compared to the matched controls, we cannot be sure if this reduction was due to the intervention itself or to some other factor that was not accounted for in the propensity-score adjustments. In another study, daily monitoring was compared to weekly monitoring for veterans with diabetes. Patients self-selected their monitoring schedule. Health-resource use was significantly lower for participants who received daily monitoring. However, baseline differences between the two groups on a number of parameters suggested marked residual confounding, which can only be addressed with better adjustments or randomization (Chumbler, Neugaard, Ryan, Qin, & Joo, 2005).

In keeping with our research question in Study I, we chose to randomize participants to one of the two treatment arms. We sought to describe treatment preferences with our sample and plan to test its association with adherence and outcomes when the study is completed. At baseline, after participants were already informed of their group assignment, they are asked about their preferences during the initial face-to-face consultation. Of the 39 participants enrolled thus far, approximately 38% said they preferred assignment to eDSMP while similar proportions preferred the fDSMP (31%) or did not have a program preference (31%). Although the data set is incomplete and perhaps underpowered, we found significant associations between treatment preferences, age, and Internet use. Participants who preferred the eDSMP ($n = 15$) were younger, 62.1 ± 8.8 , compared to those who preferred the fDSMP ($n = 12$), 70.5 ± 6.5 , or had no preference, 72.5 ± 6.6 ($n = 12$), $p = .002$. Similarly, participants who preferred the eDSMP spent more hours per week on the Internet, 31.9 ± 24.2 , compared to 8.9 ± 6.6 and 8.8 ± 4.8 for those who preferred the fDSMP or had no preference,

respectively, $p < .001$. Of note, our analyses of these first 39 randomized participants showed comparable baseline demographic characteristics and health status for the eDSMP ($n = 21$) and fDSMP ($n = 18$) arms.

If this study had been designed as a simple preference trial, we could not be certain about the degree to which age and Internet use, and also other, unmeasured, factors, would confound the findings. Younger and more experienced computer users might have differential uptake of the intervention and consequently have changes in their dyspnea that could not be fully attributed to the intervention itself. These observations lend support to our decision to use random assignment in this efficacy trial as our best measure against selection bias. No other technique has the same power to control for selection as a threat to internal validity (Cook & Campbell, 1979). Once the efficacy of eDSMP and fDSMP are established, we can proceed with a Phase III study to determine the effectiveness of intervening with patients using both modalities. Fixed adaptive designs (TenHave et al., 2003), which accommodate patient preferences for treatments with known efficacy, have been used in a number of late-phase pharmaco-behavioural and health-services trials (Activity Counseling Trial Writing Group, 2001; Berkman et al., 2003; Diabetes Prevention Program, 1999; Unutzer et al., 2002); none of these studies included an eHealth component, mainly because many technology-supported interventions are still in early-phase efficacy testing.

Treatment Implementation: Strengthening Effects and Minimizing Crossovers

Maintenance of treatment fidelity is important for all research trials. The overall goal of enhanced treatment fidelity is to increase scientific confidence that the changes in outcomes are attributable to the treatment by reducing random and unintended variability (Bellg et al., 2004). Fidelity is even more critical in the context of non-inferiority trials, since treatment crossovers will make the groups more similar than they actually are. Treatment fidelity and participant non-adherence need to be addressed in the context of the overall study design. Gross and Fogg (2001) argue persuasively that random assignment is inconsistent with the current thrust of health-care consumerism and the expectation of personal choice in matters of health and health care. They go on to suggest that the democratic balance of knowledge and power with the baby boom generation in particular will likely lead consumers to reject any efforts that restrict their options or control. These dire forecasts are more pertinent for treatments that people can access outside of a research protocol than for those interventions that are available only within a study. Unfortunately, since many technology-supported cognitive-

behavioural interventions for health promotion and disease management are readily accessible to patients, treatment fidelity can be easily compromised.

The challenges we face in communicating with our eDSMP and fDSMP participants are a good illustration of this issue. Because our research question is focused on the efficacy of the Internet as a “delivery channel” for dyspnea education and ongoing support for behaviour change, we have strategies in place to encourage participants in the eDSMP and the fDSMP to use e-mail and telephone, respectively, to communicate with the study nurse. The nurse also provides weekly and biweekly reinforcements through these two communication channels. We have provisions in the protocol to communicate with eDSMP participants via telephone should an urgent or complex matter arise. Although the nurse redirects participants by responding via e-mail or telephone according to their group assignment, a number of participants have inevitably “crossed over” and used both e-mail and telephone during the course of the study. It should be noted that although all of our participants use a computer on a regular basis, some have very clear preferences for communicating via telephone and have deliberately not answered study e-mails. The opposite has occurred with the fDSMP participants but with less frequency. These observations may be unique to our older sample; however, they raise the question of whether random assignment to a communication modality is sensible when people have preferences and will use the modality they are comfortable with.

Early studies of “stand alone” Internet-based psycho-educational interventions had disappointing results. Approximately 50% of those who initially signed up for the programs dropped out or never logged back in (Andersson, Stromgren, Strom, & Lyttkens, 2002; Clarke et al., 2002; Eysenbach, 2005). Programs that integrated live counsellors who corresponded with participants and received regular feedback were more successful (Tate, Jackvony, & Wing, 2003). In our study, all participants receive an initial face-to-face consultation with the study nurse, as a way to strengthen the eDSMP and increase participants’ commitment to the study.

It is important to note that eHealth tools targeted at relatively healthy participants for general health promotion can be successfully implemented outside of existing care relationships. However, this may not be the case for tools designed to support chronic disease management. Studies of outsourced chronic disease management often report communication challenges with patients’ health-care providers (Southard et al., 2003). We have faced similar situations in our attempts to facilitate more prompt therapy when participants report sustained worsening of their respiratory symptoms. When Shea and colleagues (2006) conducted a

Phase III study of diabetes case management for older Medicare beneficiaries using a sophisticated telemedicine system, they achieved only modest improvements in diabetes outcomes compared to usual care. The less than robust changes were somewhat expected, since the technology-enhanced case management was performed externally, not by a nurse or care manager from the practice where patients received their existing care. It is critical that testing of new eHealth interventions for patients with chronic illnesses be conducted in the context of existing care relationships.

Other implementation issues of potential import for eHealth studies include use of a “run-in” period and strategies to maintain participant engagement. In another ongoing study that tests the effects of a PDA-mediated exercise-persistence intervention for older adults with COPD (MOBILE — Mobilizing Support for Long Term Exercise), we included a 2-week run-in for prospective participants. Since this is a Phase I efficacy trial, we wanted to ensure that participants felt comfortable with the technology before they were randomized to one of the two treatment arms. Technology-supported health interventions are no different from other treatments in that novelty effects quickly wear off. Similar to findings reported elsewhere, our pilot study of the eDSMP showed a precipitous drop-off in Web-site use after the first month (Nguyen et al., 2005; Tate et al., 2003). Other researchers have used strategies such as monetary and material incentives to encourage ongoing participation (Bowling et al., 2006). Monetary incentives, even in the form of raffles or lotteries, need to be carefully crafted so as not to be perceived as coercive. Participants in our studies are issued PDA devices with data service, which allows them to access the Web for news, weather, and so forth; however, anecdotal reports suggest that, for the older cohort, these features have little appeal and are infrequently used. As with any intervention study, more creative strategies for encouraging participant engagement in eHealth interventions need to be explored.

Measuring Outcomes

Selection of outcomes in studies of technology-supported interventions is based on the most anticipated effects of the intervention, taking into account those outcomes of greatest relevance to both patients and decision-makers. Many eHealth studies use Web-based questionnaires, either singly or with other methods such as telephone and mail, to measure patient-reported outcomes (PRO) — for example, symptoms, health-related quality of life (HRQL), and satisfaction. The validity of Web-based questionnaires is no longer questioned, though it was when eHealth first emerged (Dillman, 2000; Ritter, Lorig, Laurent, &

Matthews, 2004). The science of Web-survey methodology continues to be refined (Couper, 2005). One of the exciting research areas with PRO measurement is the development of item banks and computerized-adaptive tests (CAT) for measuring symptoms and HRQOL domains (Kosinski, Bjorner, Ware, Sullivan, & Straus, 2006; Reeve, 2006). Since questions are tailored for each respondent with CAT, this approach to outcome assessment promises to increase efficiency and measurement precision, two factors that can potentially reduce the number of patients needed for clinical trials of eHealth applications without sacrificing statistical power.

Paper diaries have traditionally been the primary means of capturing outcomes or processes related to patient experiences in their daily lives. However, recent experimental findings confirm researchers' early suspicions that participants do not always adhere to diary protocols and that diary "hoarding" is common practice (Lauritsen et al., 2004; Stone, Shiffman, Schwartz, Broderick, & Hufford, 2003). In one study, electronic time-stamp records indicated that "compliance" with paper diaries was only 11% (Stone et al.). Given this knowledge, would it be appropriate to continue to use paper diaries for an active control arm in a study testing the effects of an eHealth intervention that includes an electronic diary device? If data validity is of primary import and all participants are issued devices, would the introduction of such technologies contaminate the control arm?

We were more interested in the impact of real-time data transmission on early intervention for COPD exacerbations in the eDSMP, and therefore continued to use paper diaries for the fDSMP in both of our dyspnea self-management studies. Our early experience with using a PDA/phone device to capture real-time symptom and exercise data from participants in Study I showed a mean response time of 22 hours from when queries were sent to when our servers received the data (Nguyen, Wolpin, Chiang, Cuenco, & Carrieri, 2006). We believe the delays in data submission were primarily due to the cumbersome vendor-supported hardware and software over which we had limited control. We have since developed our Web-based platform, replaced the device, and reconfigured our queries to be more parsimonious.

In contrast to other latter-phase eHealth studies that strictly rely on patient self-report and therefore can have national and even international reach (Lorig et al., 2006; Strecher et al., 2005), our efficacy studies include in-person assessments. We confirm participants' self-report of COPD with pulmonary function tests to reduce misclassification and for ongoing safety monitoring. Other studies that include daily pulmonary function monitoring as a core intervention component have given patients spirometers for self-testing at home (Finkelstein, Cabrera, &

Hripcsak, 2000). Thus, it is possible to increase the reach to target populations by modifying the data-collection approach, but this will need to be balanced with additional costs and/or testing reliability. For performance-based outcomes that require in-person testing, collaboration with existing research or practice networks may be a solution.

Economic outcomes are of considerable interest to payers and policy-makers and ideally are included in Phase III effectiveness trials of eHealth interventions (Tunis et al., 2003). A few studies have examined the cost impact of virtual home visits compared to traditional home care, with mixed success, mainly due to small sample sizes and other methodological weaknesses (Finkelstein, Speedie, & Potthoff, 2006; Hopp et al., 2006; Noel, Vogel, Erdos, Cornwall, & Levin, 2004); well-conducted parallel cost-effectiveness studies require significant resources. One such economic analysis will be forthcoming from a study testing the effects of a telecare diabetes-management intervention (Shea et al., 2006).

Conclusions

Although preliminary work has been done to promote the development of standards for evaluating eHealth applications targeted to health consumers (Eng, Gustafson, Henderson, Jimison, & Patrick, 1999), this article adds to the literature by delineating and examining in depth several key methodological challenges related to testing these technologies. We have reviewed issues related to study design, treatment implementation, and outcome assessment and have provided examples from the literature and our current work to illustrate some of the challenges. We have offered a few possible though imperfect solutions.

The design of any clinical trial begins and ends with the research question and trials of eHealth interventions are no exception. Thorough testing and evaluation of eHealth interventions require the use of many research questions, approaches, and designs. Selection of a clinically meaningful treatment alternative or comparison group and design considerations related to participant preferences will depend on the state of the science and current practice in the particular field. Nevertheless, randomized controlled designs are favoured when establishing the efficacy and effectiveness of eHealth applications. Depending on the choice of comparison groups, eHealth applications will need to be fairly robust to demonstrate their efficacy above and beyond active controls. Ensuring treatment fidelity and ongoing participant engagement can be particularly challenging and will require more creative solutions. And while more efficient methods of obtaining patient-reported outcomes are emerging, attention to other important outcomes, such as cost, will be critical in future evaluations of eHealth tools.

The advances made in information and communication technologies have undoubtedly ushered in renewed hope for and promise that such tools will facilitate positive changes in individual and population health. However, these are only promises and as such will require critical and systematic evaluations that carefully consider key methodological challenges.

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Comments or queries may be directed to Huong Q. Nguyen, University of Washington, HSB T602A, Box 357266, Seattle, Washington 98199 USA. Telephone: 206-543-8651. Fax: 206-543-4771. E-mail: HQN@u.washington.edu.

Huong Q. Nguyen, RN, PhD, is Assistant Professor, School of Nursing, University of Washington, Seattle, United States. DorAnne Cuenco, RN, PhD, is Assistant Adjunct Professor, School of Nursing, University of California, San Francisco, United States. Seth Wolpin, RN, PhD, is Research Assistant Professor, School of Nursing, University of Washington, Seattle. Josh Benditt, MD, is Professor, School of Medicine, University of Washington, Seattle. Virginia Carrieri-Kohlman, RN, DNSc, is Professor, School of Nursing, University of California, San Francisco.

Happenings

Using Interactive Health Communication Technology in a Renewed Approach to Nursing

José Côté

The use of information and communication technology (ICT) as an interactive means of transmitting information is on the increase. It appears to be the key to meeting the challenges of accessibility and continuity of care and services faced by our health-care system. ICT provides unprecedented access and exchange of the kinds of information that can ultimately transform many facets of nursing. It already supports professional practice by allowing ready access to information that is on the cutting edge of health-care knowledge — knowledge that has become indispensable for informed decision-making. Nurses can now benefit from remote continuing education, access to databases from their work stations, and interactive communication with peers through Internet discussion groups, as evidenced in virtual practice communities.

Telehealth is another field of application for ICT. We are now seeing the deployment of a multitude of innovative approaches that take advantage of technological solutions in order to provide enhanced patient follow-up. Nurses are being called upon to participate in the development of services better adapted to the needs of the population. Of particular note are telemonitoring, which allows for remote observation of patients' physiological parameters and readjustment of their therapeutic regimen as needed, and triage, which permits evaluation of a client's health status and the formulation of recommendations relative to treatment and follow-up. Additional ICT initiatives now being elaborated will make areas such as continuity, caregiving, and updating of electronic health files more efficient and effective. These new monitoring and triage approaches are changing the ways in which nurses' organize their work, making services available to a greater number of individuals.

Several innovative ICT nursing projects have been initiated in Quebec over the past 5 years. Two nurse researchers from the Groupe de recherche interuniversitaire en sciences infirmières de Montréal, whose

focus is the development and evaluation of nursing interventions, are working on the development of new ICT-assisted care approaches. Dr. Carmen Loiselle's research team from the McGill University School of Nursing is evaluating the role of ICT in the health, well-being, and health-care utilization of a diverse oncology clientele. Dr. Loiselle is also part of a team assessing the intrinsic qualities of ICT messages that optimize breast cancer screening behaviours. In addition, ICT plays a pivotal role in the academic exchanges between four universities involved in the Psychosocial Oncology Research Training program led by Dr. Loiselle and three nurse collaborators: Drs. Joan Bottorff (University of British Columbia), Lesley Degner (University of Manitoba), and Lorna Butler (Dalhousie University) (www.port.mcgill.ca).

Dr. José Côté, Research Chair for New Nursing Practice in the Université of Montréal nursing faculty, in partnership with the Département d'informatique et de recherche opérationnelle at the same institution, has developed a Web application that offers people with HIV/AIDS a virtual nursing intervention. It provides clients with the resources and support they need, when they need them and in real time, in the daily management of their therapies. This experimental approach is intended to offer this clientele high-quality individualized clinical follow-up in the context of service reorganization. Similar applications could be developed and evaluated for other clienteles managing complex health conditions.

ICT is proving to be an attractive and promising medium in nursing, for it enables access to support and information adapted to individual needs at the appropriate time, from the preferred location, at the desired frequency. While this type of intervention can never replace direct client-nurse interaction, it has its place in an array of approaches from which participants can choose according to their needs and preferences.

Interactive health communication technology is a means to an end rather than an end in itself, providing valuable support to members of the nursing community — researchers, caregivers, managers, and teachers — as they seek to develop concrete and innovative solutions to the health-care needs of the population in a renewed approach to health care.

José Côté, RN, PhD, is Associate Professor and Holder of Research Chair for New Nursing Practice, Faculté des sciences infirmières, Université de Montréal, Quebec, Canada; Clinical Researcher, Fonds de recherche en santé du Québec; and Researcher, Centre Hospitalier de l'Université de Montréal.

Les efforts de transmission de l'information sur les patients chez les infirmières en soins intensifs

Marie Edwards et Gail Donner

Cette étude descriptive et interprétative avait pour but d'explorer les moyens que prennent les infirmières en soins intensifs pour transmettre de l'information sur leurs patients aux autres membres de l'équipe soignante et en discuter. Trois questions ont été traitées : Quelle est la nature des éléments d'information transmis? De quelle façon communique-t-on ces données? À quelles fins les transmet-on? La collecte des données s'est effectuée dans un hôpital de soins tertiaires, au sein de deux services de soins intensifs, auprès de dix infirmières que l'on a observées, puis interviewées. Pour « tracer le portrait » d'un patient, les infirmières transmettent de l'information sur son état, ses réactions au fil du temps, les interventions qui lui ont été bénéfiques et sa personne. Cet aspect du travail des infirmières est facilité par leur proximité tant avec les clients qu'avec les autres membres de l'équipe, ainsi que par leur participation aux rencontres multidisciplinaires. Les résultats de l'étude comportent des implications pour l'organisation du personnel, l'aménagement des services, la structure des rencontres et l'enseignement infirmier.

Mots clés : soins infirmiers intensifs, information sur les patients, proximité

The Efforts of Critical Care Nurses to Pass Along Knowledge About Patients

Marie Edwards and Gail Donner

The purpose of this descriptive, interpretive study was to explore and describe the work of critical care nurses in sharing and discussing their knowledge about patients with other members of the health-care team. Three questions were examined: Which aspects of their understanding of patients do nurses pass along? How is knowledge passed along? To what ends is knowledge passed along? Data collection took place in 2 intensive care units in a tertiary care hospital and involved observation of 10 nurses followed by interviews. Nurses “filled out the picture” for others by passing along knowledge about the patient’s status, patient responses over time, interventions that had been beneficial, and the patient as a person. This aspect of nurses’ work was facilitated by proximity to both patients and other team members and the inclusion of nurses in multidisciplinary rounds. The results have implications for staffing patterns, the layout of hospital units, the structure of rounds, and nursing education.

Keywords: Critical care nursing, knowing the patient, communication, proximity

It has been suggested that the intensive care unit (ICU) is “a place of witness where every heart rhythm and urine output is monitored, measured, and charted” (Steinmetz, 1999, p. 14). Indeed, the ICU is a place where information from a variety of sources is of interest to a great many people, and nurses spend a significant amount of time collecting, recording, interpreting, and discussing this information. A number of events can happen in a few weeks, days, or hours in the life of a critically ill patient, and if he or she is a patient in an ICU it will most likely be nurses who witness those events as they unfold.

This interpretive study began with our interest in the knowledge that nurses gain, by any number of means, about the patients in their care. More specifically, we were interested in what nurses do with this knowledge. Benner, Tanner, and Chesla (1996) suggest that in order for patients to benefit from what nurses have learned about them through clinical contact, the knowledge must be “preserved and passed along” (p. 197) — that is, shared and discussed with or conveyed to other health-care providers. This study explored the work of critical care nurses in passing along knowledge about patients to other members of the health-care team.

Literature Review

At the outset of the study, we examined the literature related to knowing the patient and the formal mechanisms used by nurses to communicate with other health-care providers.

Knowing the Patient

Mauksch (1966), in an essay on the organizational context of nursing practice, concludes that in the hospital “the nurse comes and stays while others come and go” (p. 117). Hospital nurses spend the majority of their time in the same physical area as their patients. There are thus unique opportunities for nurses to enter into relationships with and come to know the patients and families in their care. According to Radwin (1996), a nurse’s ability to know the patient is influenced by his or her experience, time spent with the patient, and closeness to or intimacy with the patient.

Knowing the patient has been found to be important to nursing practice in studies on expertise in nursing (Benner et al., 1996; Benner, Hooper-Kyriakidis, & Stannard, 1999; Kennedy, 2002, 2004; Peden-McAlpine, 2000; Tanner, Benner, Chesla, & Gordon, 1993), clinical decision-making (Coombs & Ersser, 2004; Hurlock-Chorostecki, 2002; Jenks, 1993; Jenny & Logan, 1992, 1994; Radwin, 1995), nurse-patient relationships (Luker, Austin, Caress, & Hallett, 2000; Lundgren & Segesten, 2002; Peden-McAlpine & Clark, 2002), and ethical concerns in nursing (Liaschenko, 1993). In these studies, knowing the patient involved entering into a relationship with the patient, coming to know something about the patient in the context of his or her illness, and making choices about the patient’s care based on this knowledge.

Tanner et al. (1993), in a study of skill acquisition involving 130 critical care nurses in eight hospitals in the United States, noticed a “recurring discourse among nurses about ‘knowing the patient’ — a reference to how they understood the patient, grasped the meaning of the situation for a patient, or recognized the need for a particular action” (p. 273). This knowing represented an involved understanding, as opposed to a detached, theoretical understanding, of the patient and his or her situation. Tanner et al. identify two categories of knowing: knowing the patient’s pattern of responses, and knowing the patient as a person. Both kinds of knowing are “always specific to what can be known in the nurse/patient/family interaction and clinical context” (p. 279).

Liaschenko (1997, 1998) and Liaschenko and Fisher (1999) have found that nurses describe three types of knowledge used in their work: case, patient, and person. Knowledge about the case is biomedical knowledge: the physiology, pathology, and progression of a given disease

and its treatment. Liaschenko (1997) refers to this as “disembodied” knowledge (p. 24), as it is not specific to a particular body or person. Knowledge about the patient extends case knowledge and is specific to a particular individual experiencing a particular illness. To know the patient is to know something of the individual’s pattern of responses to his or her illness and the treatments for that illness, the patient’s medical and social history, the system and how to move patients through it, and the other health-care providers involved in the patient’s care. Knowledge about the person involves knowing “something about what it means for the individual to have a specific history, live a particular life, and engage with the world in which he or she is situated” (Liaschenko & Fisher, p. 38).

Formal Mechanisms for Conveying Knowledge to Other Team Members

There is evidence that nurses spend a significant amount of time supplying information to other health-care providers in hospital settings. Jacques (1993), in an observational study of a primary medical unit in a teaching hospital in the United States, found that approximately once every 6 minutes, or 87 times per day, nurses conveyed information relevant to patient care to other team members (e.g., physicians, clinical nurse specialists, technicians, maintenance workers). In a descriptive study that categorized and quantified the activities of nurses working in an ICU in the United Kingdom, Harrison and Nixon (2002) found that 17.7% of nurses’ time was spent observing and assessing patients, 8.06% recording observations, and 9.94% providing information to other team members.

A number of studies have examined the formal mechanisms that nurses use to pass along knowledge about patients to other team members (i.e., change-of-shift report, charting, rounds). It has been found that the main function of the change-of-shift report is to convey physiological data, information on patients’ progress, test results, treatment plans, nursing work completed, and nursing work yet to be done (Ames, 1993; Bjornsdottir, 1998; Ekman & Segesten, 1995; Hardey, Payne, & Coleman, 2000; Kerr, 2002; Lally, 1999; Liukkonen, 1993; Manias & Street, 2000; Parker, Gardner, & Wiltshire, 1992; Payne, Hardey, & Coleman, 2000; Strange, 1996). Similarly, it has been found that nurses’ entries in patient charts tend to focus on work completed, body parts and functions, treatment responses, and physiological data, including vital signs and laboratory results (Ames; Davis, Billings, & Ryland, 1994; Hale, Thomas, Bond, & Todd, 1997; Heartfield, 1996; Parker & Gardner, 1992; Street, 1992).

Few studies have examined nurses’ participation in multidisciplinary rounds (Busby & Gilchrist, 1992; Coombs, 2004; Coombs & Ersser, 2004;

Curley, McEachern, & Speroff, 1998; Hill, 2003; Mallik, 1992; Manias & Street, 2001; Whale, 1993; Zussman, 1992). Researchers have found that nurses have little involvement in rounds (Busby & Gilchrist), their contributions tending to be “reactive” (Whale, p. 160), usually in response to a problem or question introduced by another team member, often a physician (Mallik; Manias & Street, 2001; Whale; Zussman). Coombs and Coombs and Ersser, in a study of the nursing role in clinical decision-making in the ICU, found that while biomedical knowledge was the type of knowledge most frequently used by nurses and physicians during rounds, nurses also presented knowledge related to patients’ families, patient comfort, and ethical issues. “A frequent topic of conversation was the frustration experienced by nurses who ‘knew the patient’ and, on offering this information to doctors, had this ignored” (Coombs & Ersser, p. 250).

The literature provides evidence that knowing a patient can prove beneficial to that patient’s care; that nurses pass along to other health-care providers aspects of what they know about a patient, particularly physiological data, test results, nursing work completed, and work yet to be done; and that various mechanisms (e.g., reports, rounds, patient charts) are available to nurses to pass along what they know. There is also evidence that nurses have little involvement in multidisciplinary rounds. Yet to be described are the ways in which nurses think about and approach passing along knowledge, and the ends that nurses pursue in conveying what they know about patients to other health-care providers.

Research Questions

Three research questions were posed: 1. *Which aspects of their knowledge about patients do critical care nurses pass along to other health-care providers involved in the care of those patients?* 2. *How is knowledge about patients passed along to other health-care providers?* 3. *For what purposes is knowledge about patients passed along to other health-care providers?*

The phrase “passing along knowledge,” originally used by Benner et al. (1996), was viewed as an active process of conveying to and discussing with other members of the health-care team one’s knowledge about the patients in one’s care.

Methods

The specific qualitative approach used was interpretive phenomenology, as described by Benner (1994) and Benner et al. (1996). Using interviews and observations of people engaged in everyday activities, one generates and analyzes a text in order to identify its meanings. Through the interpretive process one gains an understanding of the phenomenon of

interest by making visible people's practices, actions, and concerns (Benner).

Paley (2001) draws attention to the problems associated with focusing on "what nurses say they do" rather than on "what nurses do" (p. 190). Benner and her colleagues include observations in their studies, but their work has been criticized because it does not always make clear how observational data have been used or how they add to the texts generated (Padgett, 2000). In the present study, a decision was made to begin with observations of nurses as they interacted with other members of the health-care team (through change-of-shift reports, rounds, and charting) in the clinical setting, so that insight could be gained into this aspect of nurses' practice and so that questions could be asked as nurses went about their work (Meerabeau, 1992). The observations were followed at a later date by individual or small-group interviews. An interview guide was used but the questions evolved both within the interviews and over time. Generally, participants were asked about how they approached the passing along of knowledge and their decisions regarding what information to convey to other team members.

The process of interpretation involved examining the text generated from data collection (i.e., field notes and interview transcripts) for paradigm cases and exemplars. The text was also marked or named, as described by Benner et al. (1996), to identify and organize portions of it relevant to the various lines of inquiry and identify possible themes as the interpretation proceeded. A number of strategies were incorporated into the design to ensure an interpretive account that was coherent, convincing, and applicable (Packer & Addison, 1989). These strategies included: collecting data over a number of months and from different sources (e.g., observations, interviews); exploring and clarifying observations or comments in subsequent meetings with participants; and meeting with two experienced critical care nurses to discuss and validate ideas emerging in the text.

Study Setting and Sample

The study was approved by the appropriate research ethics boards prior to recruitment and data collection. It was carried out in two ICUs in a tertiary care teaching facility in a Canadian city. One of the units was a 10-bed surgical ICU and the other a 6-bed intermediate ICU, although not all beds were open throughout the course of data collection. Ten registered nurses volunteered to take part in the study. Informed consent was obtained prior to proceeding. The mean number of years of nursing experience was 17, with a range of 6 to 28, and the mean number of years of ICU experience was 9, with a range of 1 to 18. Approximately

200 hours were spent observing participants over approximately 38 shifts and a total of 18 interviews were carried out.

Interpretation

One overall theme was identified. The participants described their efforts to first come to know patients and then pass along their knowledge as “filling out the picture”:

I feel that there is so much information that is coming to me. All of this information is related to the same individual, and all of the information is painting the picture for me, so it is making it fuller and fuller and adds more colour to it — has more colour, is more clear. (Participant 2)

This notion of the picture was discussed by eight of the ten participants. From their perspective, the picture represented all of the information and knowledge nurses and other team members were able to gather, from any number of sources, about the patient and his or her situation. Important to the development of this picture was the nurses’ contact with patients and family members resulting from their sustained presence at or near the bedside. Also important was their access to physicians and other health-care providers throughout much of the day and night. From the observations and interviews, it became apparent that the picture was made up of different types of knowledge, and filling out the picture involved making decisions about who needed to know what, and when.

Types of Knowledge Passed Along

From the viewpoint of the participants, the process of filling out the picture involved conveying information, impressions, and insights related to the patient. The participants believed that nurses are in a key position to fill out the picture, as they remain at the patient’s bedside throughout most of their shift. While some structure for interactions with other team members was provided by the systems review format (i.e., central nervous, cardiovascular, respiratory, gastrointestinal, genitourinary, and psychosocial systems), nurses still made judgements, on an ongoing basis, about what others needed to know, wanted to know, or cared about. The types of knowledge that the participants passed along to other team members can be grouped under five headings.

Knowledge about the patient’s current status. At some point in every observation, the nurse passed along information, data, or insights related to a patient’s status, particularly physiological status, at a particular moment in time, situated in the patient’s history and reason for admission to the ICU. This could include assessment data, information about the patient’s responses to illness or treatment — both physiological (e.g., vital

signs, laboratory results, test results) and psychosocial — current drug therapies, and the technological supports in use (e.g., ventilator).

Knowledge about the moving picture. The fact that nurses cared for a patient throughout an entire shift or series of shifts enabled them to get a sense of the patient's moment-to-moment responses and how these changed over time. Some of the participants described this as getting a sense of the "moving picture." This picture contrasted with the sometimes static one that other members of the team might see in their brief encounters with patients:

[The physicians] can look at them in the bed, and they might be sleeping there, but 99% of the time they are not. They are fighting the ventilator, or just out of control, or in pain.... Because sometimes you can say, "Come and look at my patient — respiratory looks a little bit distressed, their work of breathing." And they'll just kind of look — "Oh, he looks okay." But you wish you could have gotten them there after the distress with the wheezing and the Ventolin. (Participant 10)

Therefore it was important for the nurse to fill out the picture, to provide other team members with a sense of what the patient looked like at those times when others were not at the bedside — that is, a sense of how the patient was responding to treatments over time.

Knowledge about what works. An important aspect of the picture was knowledge related to interventions, treatments, or strategies that had been tried on the patient and found to work. For example, a nurse might describe to colleagues the best way to approach a dressing with a particular patient or the best way to approach weaning a patient from the ventilator. The idea that something worked usually meant that the approach taken was one that proved effective and practical while causing the patient the least amount of distress.

Knowledge that others care about. From the perspective of the participants, different team members were interested in or cared about different kinds of knowledge. This perception clearly influenced which aspects of their knowledge about patients the nurses passed along in their efforts to fill out the picture. Participants felt that all team members cared about knowledge related to patient problems, especially those problems for which they had a particular role to play in terms of treatment and aspects of the plan of care for which they were directly responsible.

It was the impression of a number of participants that knowledge about problems of a psychosocial nature was not always of interest to other team members, particularly physicians, partly because physicians were not clear about their role in addressing such problems:

[Physicians] want to know things they can fix with a medication, or things they can fix with a surgery, or things...they can investigate with a CT scan. (Participant 8)

[Physicians] care about things that they can address, from their perspective.... They may be interested from the psychosocial perspective about — does the family have enough information about the condition and what's going on here, about the plan? And how they are coping. And if there are problems there are you taking care of it?... But they are not going to do anything about it themselves. (Participant 4)

Knowledge about the patient as a person and as a family member. One aspect of the picture that nurses felt they had more knowledge about than other team members was the patient as a person and as a family member. This was partly because nurses were present at the bedside throughout their shifts and thus could engage in conversations with patients and family members:

Like if they [the patients] are really nervous about just being here and all the noises. Or [if they are] scared... And so to tell them [the physicians] that [what the patient fears] is...really important...of course we want all the systems to get better, but I think it is important that you keep in mind each patient as an individual and what they are thinking. (Participant 10)

Means of Passing Along Knowledge

The participants described filling out the picture in a variety of ways. A large number of interactions between health-care providers in the ICUs involved discussion of physiological data. A common strategy used by nurses to convey this type of knowledge was to present what could be described as bits and pieces of information or **threads of data** (e.g., the patient's current vital signs). Participants also described passing along a fuller sense of the patient's story by **tying the systems together**. This involved placing information, data, and the patient's responses to treatments in context (e.g., providing a sense of the patient's history) and then describing changes in responses as they occurred over time. When tying the systems together, participants would make links between systems — illustrating, for example, how changes in a patient's cardiovascular system had an impact on his or her respiratory system.

A third strategy used by participants to pass along knowledge was **thinking out loud**. This usually took the form of informal conversations with team members in an effort to make sense of patient information or data, particular concerns about a patient, or feelings or hunches about a patient's illness or care. This strategy might be used when there was confusion or uncertainty about a patient. One participant described it as

“bouncing ideas off each other” in order to problem-solve. When talking to others, nurses threw out ideas to see if they made sense or to see if others could build on them to clarify the situation.

Two other strategies were used by participants to pass along knowledge: **pointing** and **building the case**. Pointing involved drawing to the attention of team members, particularly physicians, specific knowledge about a patient and/or his or her family members and then making a suggestion as to what ought to be done about the issue or concern identified (e.g., seeking a specific order or recommending a particular approach to weaning from the ventilator). Usually the physician or physicians would agree with the nurse’s recommendation and the patient’s plan of care would be altered accordingly:

And nurses become very good at it — quite adept at pointing the physicians in the right direction. Nine times out of ten you’ll get what you think the patient needs. (Participant 8)

At rounds I try and convey whatever it is I want the doctors to deal with... If there’s some order I want for something, or something I want reassessed or whatever, I make sure that I point that out. (Participant 7)

Pointing was evident in an exchange between two participants during an interview:

The lady [you cared for on day shift] got a CT of her head today, and you know that she doesn’t have a cerebral bleed. You got that today. (Participant 9)

Yeah, my lady... I was concerned. Her issue is sepsis, post-op surgery, bowel cancer. She’s been weaned, but neurologically — it’s my second day with her and I just can’t really figure her out. Why doesn’t she talk to me? Why is she moaning a bit? Why doesn’t she recognize her family? So I reported all this stuff. I said, “Maybe a CT would be good — it would rule things out.” She’s had a history of coagulopathy. Platelets are 20. So we did that and ruled out a problem. (Participant 10)

Building the case involved presenting arguments to colleagues advocating for either a particular intervention or treatment for a patient or a particular approach to an intervention or treatment. This strategy differed from pointing in that it was used when there was disagreement about the plan of care and other team members required some convincing that what the nurse was proposing was indeed sound. A nurse might be required to build her or his case over time, and the arguments might not be accepted by others.

Why Knowledge Was Passed Along

Knowledge was passed along for a number of reasons: to ensure patient safety and comfort, to ensure that the wishes of patients were respected, to ensure continuity of care, to justify care decisions, or to shape or influence the plan of care. The ultimate goal in passing along knowledge, as described by the participants, was to see the patient progress to a healthier state or, when that was not possible, to ensure the provision of good palliative care.

Discussion

It was evident that the participants went to considerable lengths to know the patients in their care, make sense of what they knew, and pass along that knowledge to others. While the vast majority of observed interactions between health-care providers involved nurses conveying and discussing knowledge about the patient (Liaschenko & Fisher, 1999), also evident was the passing along of knowledge about the patient *as a person*. Important to this process was the notion of a picture, a notion discussed in two earlier studies. Peden-McAlpine (2000), in a study of expert thinking in nursing, found that nurses constructed “temporal pictures of patients’ situations where past and present understanding enabled the projection of appropriate possibilities for future action” (p. 211). Hurlock-Chorostecki (2002), reporting on a study of nurses’ decision-making with regard to pain management when weaning patients from the ventilator, uses the phrase “contemplating the big picture,” described as “getting to know the patient by stepping back to look at the whole picture” (p. 39). The participants in our study spoke of the importance of filling out the picture by interacting with the patient, family members, and other team members and passing along to other health-care providers a sense of the patient. The purpose of all of this was to promote safe care, ensure continuity of care, promote patient comfort, ensure that the wishes of patients or family members were respected, influence the plan of care, and/or justify care decisions.

Essential to this aspect of nurses’ work was proximity (Malone, 2003) to patients, family members, and other health-care providers. Closeness to other team members over time created opportunities for discussion both within and outside of the formal structure of rounds. It was because nurses were physically near other health-care providers that they could think out loud, consult others, test their ideas, point, or build cases. As nurses worked with other team members they developed a sense of what others wanted to know, what they cared about, and how they wanted to receive information. Proximity was essential for the kind of passing along of knowledge described by the participants.

The structure of the multidisciplinary rounds in the study units also proved important for the nurses' sharing of knowledge about patients. The nurses in these settings knew they were required to provide team members with the most up-to-date information on their patients at rounds and to identify current patient problems. As a result, and in contrast with the findings of previous studies (Busby & Gilchrist, 1992; Mallik, 1992; Manias & Street, 2001; Whale, 1993; Zussman, 1992), nurses' participation in rounds tended to be proactive rather than reactive. Participants commonly used direct communication strategies at rounds — for example, building or making a case, previously described by Benner et al. (1996), or pointing, two strategies that involve offering concrete suggestions for addressing patient concerns. This finding differs from that of Manias and Street (2001), who describe nurses engaging in two games (the doctor-nurse game and the game of staging) — both of which involve manipulation and indirect communication — when communicating with physicians in an ICU. The participants in our study indicated that occasions did arise where indirect communication or manipulation could prove necessary in order to get something done, but it appeared that, in these units, nurses' proximity to other team members, the inclusion of nurses in rounds, and the longstanding work relationships between nurses and other team members fostered a more direct style of communication.

Nurses in the Coombs and Ersser (2004) study described frustration at having information that had been conveyed to physicians ignored. This was much less of an issue in our study, perhaps because of the role that nurses assumed during rounds in the study units. This is not to suggest that it did not happen, but because of the frequent interactions between nurses and physicians, both within and outside of the formal structure of rounds, nurses had an opportunity to raise and discuss patient issues at various points throughout the day and night and to suggest or argue for a particular approach to care.

Implications for Practice, Education, and Research

Clearly, the work of critical care nurses in passing along knowledge about patients to other health-care providers was facilitated by four features of the study units: patient assignment, proximity of nurses to other team members, the structure of rounds, and physical layout. The process of filling out the picture was facilitated by assigning nurses to the same patients over time (e.g., two or three shifts in a row). Nurses' proximity to patients and family members over a series of shifts enabled them to know the patients in their care. This proved beneficial for nurses, patients, and families. Nurses' proximity to other team members enabled them to pass along their knowledge. It also gave the participants an opportunity

to hear multiple perspectives (Benner et al., 1999) when seeking to better understand a clinical situation and to think out loud about patients when interacting with trusted colleagues. The structure of rounds, requiring nurses to highlight up-to-date assessment data and patient problems, assured nurses a voice at these important team meetings. The open physical layout of the units and the inclusion of nurses in the bedside rounds were acknowledged as factors that promote nurses' engagement with other health-care providers.

The participants identified a need for education (e.g., within basic nursing education programs) in relation to effective interaction among members of the health-care team. They indicated that prior to coming to the ICU they had limited experience discussing patients at multidisciplinary rounds. Opportunities for students to observe skilled nurses interacting with other members of the health-care team and participating in rounds-like discussions with other members of the team would be a valuable addition to nursing education programs.

Limitations

Limitations of this study include a small sample size, the fact that data were collected in only one facility, and the fact that observation took place when participants were caring for relatively stable patients. More research is needed in this area so that we can better understand this important aspect of nurses' work. It would be useful, for example, to compare the ways in which nurses approach passing along knowledge in different types of units within one setting or in ICUs within different settings (i.e., a multicentred study). Studies with non-nursing members of the health-care team would also be useful, in order to explore what they would like to know about the patients in their care and what they expect from their nursing colleagues when interacting with them in a clinical setting (e.g., at the bedside or at rounds).

Conclusion

The critical care nurses who participated in this study described filling out the picture of the patient's story for other members of the health-care team. This involved sharing information, insights, and impressions about the patient, conveying a sense of the patient's responses over time, and identifying approaches to care that had benefited the patient. The nurses were persistent in their efforts to pass along their knowledge. Their persistence was rooted in a sense of obligation to promote patient well-being. Central to this work was their proximity to both patients and other members of the health-care team. It was also evident that there are clear benefits to ensuring that nurses have a voice in multidisciplinary

rounds. As administrators consider questions regarding staffing patterns, the structure of interdisciplinary team meetings, and the layout of hospital units, and as educators explore ways to improve nursing education, both groups would be wise to attend to the benefits — for both health-care providers and patients — of nurses' proximity to patients, more experienced nurses, and other team members and the inclusion of nurses in rounds.

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Comments or queries may be directed to Marie Edwards, Faculty of Nursing, 381 Helen Glass Centre, University of Manitoba, Winnipeg, Manitoba R3T 2N2 Canada. Telephone: 204-474-8218. Fax: 204-474-7682. E-mail: marie_edwards@umanitoba.ca.

Marie Edwards, RN, PhD, is Assistant Professor, Faculty of Nursing, University of Manitoba, Winnipeg, Canada. Gail Donner, RN, PhD, is Professor Emeritus, Faculty of Nursing, University of Toronto, Ontario, Canada.

Donner la parole aux aidants naturels qui s'occupent de personnes âgées

Pamela G. Hawranik et Laurel A. Strain

Ce projet avait pour but d'explorer les facteurs susceptibles d'influer sur la santé des aidants naturels qui s'occupent de personnes âgées, tels que l'emploi et le recours aux services de soins à domicile, ainsi que sur la capacité d'assumer cette charge et d'autres responsabilités. Vingt-six soignants ont participé à des groupes de discussion et quatre à des entretiens personnels. Les auteures ont cerné 12 thèmes qu'elles ont répartis en 5 catégories conceptuelles : santé de l'aidant naturel; relations; autonomie; emploi; recours aux services de soins à domicile. D'après les résultats, lorsqu'elle s'ajoute à d'autres responsabilités, la charge des soins peut avoir de graves répercussions sur l'état de santé du soignant. Les participants ont évoqué l'équilibre délicat qui caractérise la prise de décisions entre soignant et bénéficiaire des soins. Nombre d'entre eux ont manifesté le désir d'être intégré à l'équipe soignante proprement dite. L'article se termine sur une discussion des implications de l'étude pour les soins infirmiers.

Mots clés : aidants naturels, personnes âgées, soins à domicile, santé des aidants naturels

Giving Voice to Informal Caregivers of Older Adults

Pamela G. Hawranik and Laurel A. Strain

This study focused on the experiences of informal caregivers of older adults and explored whether employment, use of home-care services, or other factors influence the health of caregivers and their ability to manage their caregiving and other responsibilities. Focus groups conducted with 26 caregivers and personal interviews with 4 caregivers identified 12 themes under 5 conceptual areas: caregiver health, relationships, independence, employment, and use of home-care services. The findings reveal that caregiving coupled with other responsibilities can have serious health effects. Participants spoke of the tenuous balance of decision-making control between caregiver and care recipient. Many caregivers expressed a desire to be included as part of the formal health-care team. Implications for nursing are discussed.

Keywords: Caregiving, informal caregivers, older adults, home care, community service use, caregiver health

The prominent role of the family in providing care to a frail older adult is well known. Numerous studies indicate that between 75% and 90% of the care delivered in the community is provided by family members or friends (Kane, Evans, & MacFayden, 1990; Keating, Fast, Frederick, Cranswick, & Perrier, 1999). In 2003 one in five Canadians provided informal care to someone 65 years of age or older (Fast & Keating, 2001; Stobert & Cranswick, 2004).

Providing care to an older adult can affect one's physical, psychological, and social well-being (Cranswick, 2003). Raised blood pressure, immunologic deficits, musculoskeletal problems, and sleeplessness have been recorded (Atienza, Henderson, Wilcox, & King, 2001; Stobert & Cranswick, 2004). Many studies describe the psychological effects of caregiving, such as caregiver burden and depression (Chappell & Penning, 1996; Clyburn, Stones, Hadjistravropoulos, & Tuokko, 2000; Jaffe & Blakley, 2000; Schulz, O'Brien, Bookwala, & Fleissner, 1995). Keating et al. (1999) found that over half of the caregivers to the elderly were employed and a substantial number reported adjusting their work pattern, including arriving at work late, leaving early, changing their work hours, or missing work.

With changing demographics, reductions in hospital stays, and escalating health-care costs, people are being relied upon more to share or assume responsibility for the care of a family member. In the province of

Ontario, for example, family involvement is a condition for receiving home-care services (Ward-Griffin, 2001). Community nurses are increasingly expected to teach, advise, and consult with family members, who are assuming complex caregiving duties. We need more knowledge on how caregiving affects the lives of caregivers, in order for nurses to provide assistance that addresses the needs of both caregivers and elderly care recipients.

The purpose of this study was to explore the experience of caring for an older adult and whether employment, use of home-care services, or other factors influence caregivers' health and their ability to manage caregiving and their other responsibilities.

Method

This qualitative study comprised focus groups and personal interviews with informal caregivers who were providing care to an older adult in the community. Focus groups were chosen as the primary method for gathering information on caregiving experiences. This method allows for direct contact with a number of participants simultaneously, permits an exchange of experiences, and facilitates discussion of perspectives. It also allows the researchers to clarify points and probe for further information. Personal interviews were conducted with individuals who were unable to attend the scheduled focus groups. An honorarium was provided to cover transportation and parking costs. The study was approved by the University of Manitoba's Research Ethics Board.

A purposive sample of individuals caring for older adults was obtained. Inclusion criteria were: the care recipient had to reside in the community and not in an institution, the informal caregiver had to be a family member or friend, and the caregiver had to self-identify as such. Caregiving was defined by the participant; it included assistance with transportation or appointments, daily "checking in" with the care recipient, or assistance with basic or instrumental activities of daily living.

Attempts were made to include male and female caregivers, employed and non-employed caregivers, and users and non-users of home-care services. The recruitment of both male and female caregivers was considered important given the inconsistent findings on how men manage their caregiving situation, how caregiving affects one's health, and whether traditional gender roles influence the caregiving tasks that one performs (Arber & Ginn, 2002; Cranswick, 2003; Jansson, Nordberg, & Grafstrom, 2001; Lauderdale & Gallagher-Thompson, 2002; McGarry & Arthur, 2001). In terms of employment, the results of the General Social Survey (Cranswick, 2003) show that caregiving affects employment in various

ways, with some caregivers retiring early or quitting their jobs in order to provide care (Cranswick, 1997; Fast & Keating, 2001). The use/non-use of home-care services is an important factor. Unpaid caregivers tend to rely on an informal support system, with only a small proportion using formal home-care services despite the stress that is often inherent in the caregiver role (Strain & Blandford, 2003). The inclusion of both users and non-users of home-care services in the present study allowed for examination of the factors that influence the decision whether to use these services and the role that such services play in one's ability to provide care.

Recruitment was conducted by members of the research team located in the community. Posters were displayed at agencies and distributed to staff and informal caregivers who were using agency services. In addition, team members contacted individuals who met the selection criteria, and caregivers themselves were asked for names of other caregivers. Each potential participant received a description of the study, a telephone number to call for further information, and a request to verbally consent to release their name to the research assistant. The research assistant then contacted the caregiver, confirmed eligibility, and arranged for attendance at a focus group or interview at a convenient time and location.

A total of 55 informal caregivers were identified as possible participants, with 30 making up the final sample — 25 individuals were ineligible or unable to participate for the following reasons: unable to be contacted, too busy to participate, or institutionalization or death of the care recipient.

Twenty-six individuals took part in focus group sessions. Eight sessions were held, each with a range of two to five participants. Face-to-face interviews were conducted with four participants at a location and time convenient for them. The small group size and the four individual interviews were necessitated by the difficulty of scheduling a time for participants to meet due to their caregiving responsibilities and other demands.

The focus groups and interviews were conducted using a semi-structured interview guide, with open-ended questions on the influence of employment and service use on the caregiver's health and ability to manage. All sessions were audiotaped and transcribed verbatim. Thematic analysis was conducted using the constant comparative method (Glaser & Strauss, 1967). The transcripts were reviewed separately by the two researchers. Initial codes or keywords were developed to reflect meaning in the data. From these codes, themes emerged. The researchers then jointly reviewed the themes and grouped them into conceptual categories that reflected the caregivers' discussions.

Table 1 Characteristics of Caregivers and Care Recipients		
CAREGIVERS		N
Gender	Female	24
	Male	6
Age (years)	< 50	5
	50–59	10
	60–69	5
	70–79	7
	80–89	3
	range	38–88
	median	59
Relationship to care recipient	Spouse	14
	Child	13
	Other (granddaughter, daughter-in-law, friend)	3
Employment	Not employed	19
	Employed part time	5
	Employed full time	6
Co-resident with care recipient	No	12
	Yes	18
Duration of care (months)	1–24	8
	25–72	11
	> 73	11
	range	1–240
	median	60
CARE RECIPIENTS		
Gender	Female	19
	Male	16
Age (years)	60–69	5
	70–79	12
	80–89	16
	90–94	2
	range	60–94
	median	78

Results

The characteristics of the caregivers and care recipients are shown in Table 1. The caregivers ranged in age from 38 to 88 years. Of the 30 caregivers, 24 were female (of whom 5 cared for 2 individuals), 14 were spouses, 18 lived with the care recipient, and 11 were employed. The duration of caregiving ranged from 1 month to 20 years.

The care recipients ranged in age from 60 to 94 years. Of the 35 care recipients, 16 were male and 13 had some form of cognitive impairment, according to the caregiver.

The most frequently performed caregiving tasks were driving or accompanying the individual to appointments, preparing meals, shopping, and visiting/providing companionship. A total of 19 caregivers used the home-care services of a provincially funded program, the most frequently used being homemaking and personal care. Six caregivers reported purchasing foot care or housecleaning services.

Analysis of the focus group and interview transcripts yielded five conceptual areas with twelve themes. The conceptual areas were caregiver health, relationships, independence, employment, and use of home-care services.

Caregiver Health

When asked about their health, some participants described psychological, emotional, and physical changes they had experienced since assuming the caregiver role. Three themes were identified in this area. ***Deterioration in health*** was discussed by 14 participants, who identified symptoms such as sleeplessness, crying episodes, weight gain, exacerbation of arthritis, gastric ulcer pain, and sore joints/muscles. A woman who provided care to her husband with cognitive impairment stated, "I got these crying jags and that's why I thought maybe things were getting a little hard for me." This finding is consistent with those found in the literature, where it is reported that caregiving can have negative effects on the health of the informal caregiver such as stress headaches, sleeplessness, chronic back pain, depression, and emotional and physical exhaustion (Cranswick, 2003; Jaffe & Blakley, 2000). In the 1996 General Social Survey (Cranswick, 1997), caregivers reported that the most severe changes in their lives were health-related: 29% reported changed sleep patterns and 21% stated that their health had been affected.

Caregiving sometimes took a ***psychological toll***. Some participants were taking anti-depressant medication but were unable to determine whether their depression was specifically caused by the caregiving situation. Others viewed caregiving as a contributing factor in their depression, in conjunction with other life events such as change of

employment, financial troubles, health problems, or marital difficulties. While caring for a husband with cognitive impairment, one woman had surgery for cancer and a cardiac arrest. She related an experience she had had while in hospital:

I got up in the morning and I said, "Why not take it all? I've got the pills and why not just take them all?" And that's scary when you stop and think about it, so I was telling [my daughter] about it and, well, she flew down.

The daughter arranged for her mother to see a psychologist and to have a mental health worker visit her mother when she was discharged from hospital.

Another participant, a single parent, described the multiple responsibilities she had assumed — caring for her parents, helping her three adult children, and caring for an elderly aunt. All of this led to a crisis point: "Sometimes it gets to me...5 years ago I can honestly say...I was close to a nervous breakdown." She confided in her physician on a regular basis for about 6 months and has "felt fine ever since." She admitted that she had taken on more than she could manage but at the same time felt that she needed to help her family.

The third theme was the *sense of responsibility* felt by caregivers 24 hours a day. The care recipient was constantly in the back of their minds. Some participants spoke of being unable to find mental relief, always feeling anxious about the safety or health of the care recipient, even when a hired worker was with the person while the caregiver was at work or taking a break: "I feel responsible for them...I can never quite get them out of my mind. I'm always kind of on call for them."

One woman cared for her cognitively impaired mother, who lived in another community:

I can't tell you how many times we had to drive back the 60 miles. Either she didn't put the phone right on the cradle so the line is busy all the time and... Did she fall, or did she pull the phone off the hook, or what was happening?

The emotional tension persisted no matter what the caregivers were doing. Leaving the care recipients for several hours did not provide genuine respite. The literature suggests that prolonged periods of watchfulness and hyperarousal caused by ongoing problems affect one's physical and psychological health (Gottlieb, 1997).

Relationships

The conceptual area of relationships with family and friends included two themes. An *insidious loss of social ties* was described by many partic-

ipants, who spoke of the ways in which caregiving was slowly consuming their time and preventing them from maintaining their friendships. The provision of care itself and their other responsibilities were cited as causes of this insidious process. One spousal caregiver who worked part time described it as “gradual isolation. Your life and part of your activities and part of who you are get dropped one by one, and it’s because it’s too much of an effort.” Before her husband had fallen ill, the couple frequently hosted dinner parties and went out with friends. She expressed disappointment in the fact that her husband was no longer interested in seeing their friends and their friends no longer phoned them or dropped by:

Your friends go to the ball game but you don’t go because of how far it is, you don’t know where you can park and where you’re going to walk and what you’re going to do. And your friends don’t understand that.

Going out with the care recipient took a great deal of effort on the part of the caregiver and was perceived as inconvenient for friends.

One woman provided care for both of her parents:

I’ve only been doing this for a short while but I’m already tired. ...it’s causing a lot of other problems too. ...my personal relationships — I don’t have time for my friends. I’m so tired when I have a moment to myself the last thing I want to do is be on the phone talking, and I’m just really starting to ignore people.

Her caregiving responsibilities, with both parents exhibiting behaviour indicative of cognitive impairment, were time-consuming and exhausting.

These examples of the effects of caregiving on social and recreational life are supported by the findings of other studies. Caregivers may limit or discontinue their social and leisure activities and other personal pursuits in order to fulfil their caregiving responsibilities (Dunn & Strain, 2001; Jaffe & Blakley, 2000; White-Means & Chang, 1994). In a study with rural caregivers, participants directly connected the burdens of caregiving to not participating in more activities (Jaffe & Blakley).

The availability of other family members did not mean that they were necessarily called upon or considered supportive. The theme **families are not always supportive** was described differently by the participants. In most cases at least one family member lived nearby or could be reached by telephone for advice or assistance. In some situations the caregiving tasks were shared:

We...do her shopping for her and things like that. And I have a sister and brother. We all take her out once in a while, take her home for a day.

We [the caregiver and his wife] are doing, I would say, close to half of it. My sister does a lot too.

There is evidence in the general social exchange literature that positive social exchanges can dampen or buffer the distress-arousing effects of negative exchanges (Okun & Keith, 1998). Overall supportiveness of the network may buffer the adverse effects of negative social exchanges.

In other caregiving situations, the participant reported frustration and fatigue at being the sole caregiver. A daughter described her brother's lack of assistance:

I have a brother but you'd never know he was available or around. He doesn't even phone them to see how they're doing. It's a rare occurrence. He's wrapped up with his own family and there's always an excuse.

There was longstanding conflict in the relationship between these two siblings and little communication between the brother and his parents. Interpersonal conflicts have been described as a form of "chronic strain" whose long-term nature may affect health and well-being (Rook, 2003).

Other participants did not expect family members to assist with caregiving, explaining that family members have their own lives and responsibilities and therefore should not be counted on to help with the care. A woman caring for her husband said, "My daughter and her husband — they work, they've got their house to run... And I don't think you put that onto your kids."

Independence

The theme of the older adult's *desire for independence* formed the conceptual area of independence. Participants described situations in which the care recipient insisted on maintaining his or her independence despite cognitive or physical limitations, causing the caregiver distress. One woman described her mother as fiercely independent:

Under protest, she got a walker. It's sitting folded up behind her TV covered with a blanket. She also refuses to use her cane. She's very wobbly and for a long time I would grab her arm when we were walking and she would grab it away.

Another woman expressed frustration at watching her mother continue to lift her father, who was totally dependent upon others for care: "But old people say, 'Don't teach me, I know what I'm doing.'"

Those caring for a parent were often concerned about the person's health and sought to reduce the risk of injury. They proposed some

simple solutions that could reduce the risk of fall or injury but their parent maintained control, unchallenged by the caregiver. Control has been identified as a factor in a caregiver's ability to manage stress and burden, particularly if caring for a family member (Szabo & Strang, 1999; Wuest, Ericson, & Stern, 1994). While Szabo and Strang examine the experience of control by those caring for a relative with dementia, they do not discuss the challenge of caring for someone who exerts control in a potentially unsafe manner.

Employment

Two themes related to employment were evident. Nine of the eleven employed caregivers described ***employment as a resource*** and as important to their mental health. One participant put it this way: "Work is my sanity. That's my relief. I have to have something that's for me. And my job is me, and that's my outlet." Another said, "I think if I didn't go to work I would climb the wall."

Work was seen as a form of relief from caregiving, even for those whose jobs did not allow for flexible hours. These participants described their work as important to their mental health. The literature on caregiving and employment reveals conflicting findings. Some studies have found that employed caregivers experience less stress than non-employed caregivers (Edwards, Zarit, Stephens, & Townsend, 2002; Orodnenker, 1990), particularly for women with jobs that they find rewarding (Martire & Stephens, 2003).

The experiences of three caregivers can be summed up as ***caregiving and employment: a double bind***. These participants perceived their employment as essential but as a distraction from their primary role, that of caregiver, and modified their employment in order to accommodate their caregiving role. A woman caring for a mother with Alzheimer disease adjusted her work hours in order to provide the necessary assistance. Another woman selected a job that would enable her to continue caring for her parents: "I took a cut in pay but my peace of mind and having my folks — it was the best thing that could have happened to us."

The literature on the economic consequences of caregiving indicates that caregiving responsibilities may result in missed days or hours of work or in the postponement of employment opportunities (Jaffe & Blakley, 2000). The General Social Survey (Cranswick, 2003) found that 20% of female caregivers and 13% of male caregivers aged 45 to 54, and 10% of all caregivers aged 55 to 64, reduced their hours of work. A US study found that 16% of caregivers quit their job and 13% retired early (Mature Market Institute, 1999).

Use of Home-Care Services

Five themes described the conceptual area of home-care service utilization. The first theme was **reluctance to use services**. Some participants expressed frustration at the older adult's reluctance to use a service and/or their adamant refusal to accept help from anyone but the caregiver. One woman had tried to convince her father-in-law to accept night respite: "We've tried a lot of these things and he's objected. Once he's there, he's okay, but to get him there is a problem." This participant did not want to force a service on her father-in-law but would raise the topic at various times until he finally agreed. Caregivers in Strang and Haughey's (1998) study, similarly, did not agree to respite services unless the care recipient was willing, and repeatedly tried different strategies to convince the person to accept outside assistance.

Some participants were hesitant themselves to use community services. For some, a personal crisis led them to seek formal assistance. These included a woman caring for both parents:

I had to be there every day. I was running over there every day and I started to think, "Wait a minute, I'm working full time... Oh, my gosh, how much more can I take?" I arranged for her to go through the home-care system.

Some of the caregivers did not seek and obtain formal services until they reached a crisis point and were overwhelmed. Other researchers have similarly found that families often use respite services as a last resort when they are under a great deal of stress (Chappell, 1992; Strang & Haughey, 1998).

Lack of knowledge about available services was evident in the case of both novice and long-time caregivers. A participant whose husband had urinary incontinence had been doing laundry every day, unaware that pads for incontinency were available free of charge through a publicly funded home-care program. A granddaughter expressed interest in attending a support group but did not know that there were support groups for family caregivers. These caregivers apparently assumed that no assistance was available and received no information about home care from acquaintances or family members. Evidence concerning why caregivers underuse or fail to use formal services remains inconclusive (Connell, Kole, Avey, Benedict, & Gilman, 1996; Morgan, Semchuk, Stewart, & D'Arcy, 2002; Strain & Blandford, 2002).

Over half of the 19 participants who received publicly funded home care related experiences best described as **struggling to obtain the best fit**. Frequent changes of staff, lack of knowledge and inadequate training of staff about the client's health, and inconsistent performance by service

providers were frustrating for the caregiver and perceived as disruptive for the care recipient. "My biggest problem with my folks has not been my folks," said a woman caring for both of her parents, "it has been with home care; they used to send me six different people in a week." For some caregivers, use of home-care services meant being late for work because they needed to orient each new person, while other caregivers cited increased anxiety and agitation in the care recipient. The staffing situation did not change until they persistently demanded continuity (no more than two different workers per week).

A related concern was the lack of preparation of home-care staff regarding the particular client. Some participants said that staff did not know the nature of the care required nor whether the care recipient was cognitively impaired: "The girl we have now didn't know he had dementia when she came in. I had to tell her. And she doesn't really know how to handle it yet." This problem tended to be cited by those caring for a person with cognitive impairment. The worker was not aware of the cognitive impairment and did not know what to do. In the McGee, Tuokko, MacCourt, and Donnelly (2004) study, similarly, focus group participants identified a lack of knowledge and skills on the part of community-care providers in the area of dementia, understanding and managing difficult behaviours, and communication.

The fourth theme was a *good match*, or a perception that services met the needs of the care recipient and the "best" array of services was in place. Caregivers frequently saw themselves as gatekeeper, mediator, and advocate for their family member. If the caregiver felt that services did not address the needs of the care recipient, or if the care recipient did not like the worker or the services, then the caregiver tended to be dissatisfied with the home-care situation.

Finally, some participants spoke of wishing to be *part of the team* and to be included in the decision-making about the care of their family member. They saw themselves as a vital link between the older adult and the health-care system. They knew the person's needs and wished to ensure that health professionals were aware of and addressed these needs:

I always made sure we had a family meeting. We need an understanding from the health-care team. And maybe it's the system all in all that we talk about family care, whatever it may be, but nobody is walking the talk right now. It's all individualized care.

Some participants expressed anger and frustration at being excluded from assessments and care planning. They felt that vital information on the behaviours and likes and dislikes of the care recipient was being overlooked and that respectful and appropriate individualized care was not being provided. This finding is consistent with that of Morgan et al.

(2002), who report that informal caregivers in their study criticized the practice of home-care providers conducting assessments of persons with dementia in the absence of the caregiver or someone else knowledgeable about the person, especially since the person with dementia often denied having a problem. Other researchers suggest that conflicts can arise when service providers fail to recognize a caregiver's expertise (Duncan & Morgan, 1994) or when there are discrepancies in role expectations (Ward-Griffin, 2001).

Implications for Nursing

The discussions with the 30 informal caregivers contain valuable lessons. Many participants spoke of physical changes and mental stress, particularly when caregiving took place concurrent with other responsibilities and various life events. This highlights the need for nurses to take caregivers' situation into consideration, by, for example, assessing their physical, mental, emotional, and spiritual health, discussing their other responsibilities, recognizing that employment can have both positive and negative effects, and outlining the potential health effects of caregiving and other responsibilities.

Several issues emerged with regard to the use of home-care services. Caregivers' reluctance to use services and lack of awareness about their availability demonstrate the importance of reaching out to individuals who are caring for older adults in the home setting. Some participants expressed frustration with their exclusion from assessment and care planning. Further research is needed to determine if and when caregivers wish to be part of the planning team and the nature of their potential involvement. Our findings suggest that nurses should ask caregivers if they would like to be involved in the decision-making process. In addition, the caregiver's assessment of the situation should be considered. Role negotiation between the nurse and the caregiver, with clear delineation of roles and responsibilities, may be necessary. The policies of community agencies may need to be modified to address the potential dual role of the caregiver as a client and as a member of the planning team. Nurses, as client advocates and agents of health promotion, can play an important role in modifying the focus of the system and of agency policies to include greater input by caregivers and clients.

Some participants raised the issue of control. This area requires further exploration by both practitioners and researchers. The balance between the desire for the care recipient to maintain control and independence and the need for the caregiver to encourage or assume control should be discussed with the caregiver. Certainly, independence and self-care ought to be encouraged. However, the safety of the older adult and perhaps the

caregiver as well must be considered and assessed. It may be that informal caregivers are aware of and accept the self-reliance and independence of the current generation of older adults and are prepared to respect and honour them. Nurses should assess the delicate balance between the need for older adults to maintain control and the need for them to relinquish control. Nurses may have to help the informal caregiver to identify which decisions can safely and realistically be made by the care recipient. Research examining the point at which the caregiver decides that the care recipient cannot or should not exert control, and situations in which the caregiver overrides the recipient's insistence on maintaining independence and control, would increase our understanding of the dilemmas faced by the caregiver as the recipient progresses from independence to dependence.

While the findings of this research shed light on important issues from the perspective of caregivers, the limitations of the study must be acknowledged. The sample size was small and the caregivers volunteered to participate because they wished to share their experiences. Few male caregivers were recruited, which is consistent with the difficulties encountered in other studies (Neno, 2004). The type of experiences discussed by the caregivers in this study should be explored further with larger and more diverse samples.

The findings highlight a number of important issues raised by informal caregivers of older adults and offer insight into caregivers' perceptions and their desire for more consideration and control. Nurses and other health-care providers ought to listen to informal caregivers, for these people play a key role in the care and well-being of the elderly and constitute a vital link between older adults and the health-care system.

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Comments or queries may be directed to Pamela G. Hawranik, Faculty of Nursing, University of Manitoba, Winnipeg, Manitoba R3T 2N2 Canada. Telephone: 204-474-9317. Fax: 204-474-7682. E-mail: pam_hawranik@umanitoba.ca.

Pamela G. Hawranik, RN, PhD, is Associate Professor, Faculty of Nursing, University of Manitoba, Winnipeg, Canada. Laurel A. Strain, PhD, is Director, Alberta Centre on Aging, and Professor, Department of Sociology, Faculty of Arts, University of Alberta, Edmonton, Canada.

« À l'intérieur et à l'extérieur » : perspectives de femmes sikhes en matière de dépistage du cancer du col de l'utérus

Nelly D. Oelke et Ardene Robinson Vollman

Des tests de dépistage effectués régulièrement permettent de détecter le cancer du col de l'utérus à un stade précoce. La documentation suggère que le taux de dépistage de ce type de cancer chez les femmes immigrantes, une population croissante au Canada, est inférieur à celui recensé chez la population générale, puisque les immigrantes sont moins nombreuses à subir le test. Il existe peu de services de dépistage culturellement sensibles à l'intention des immigrantes. Une étude qualitative descriptive a été réalisée auprès des femmes appartenant à la communauté sikhe urbaine vivant au Canada, afin d'explorer leurs perspectives sur le dépistage de cette maladie. Des entrevues approfondies (13) et des groupes de discussion (3) ont été menés en vue de cerner les défis inhérents au dépistage de ce type de cancer. Les chercheuses ont identifié un thème prédominant, celui du concept « d'intérieur et d'extérieur ». Selon cette notion, les femmes se sentent emprisonnées dans leur communauté et éprouvent de la difficulté à aller « à l'extérieur », dans la société canadienne, pour bénéficier d'un test de dépistage. Le manque de connaissances concernant l'importance de la prévention, l'influence de la famille et de la communauté, et les problématiques liées aux professionnels soignants influent sur leur accès au dépistage. Les résultats aideront le personnel infirmier à mieux planifier et dispenser des services de dépistage auprès des femmes sikhes.

Mots clés : dépistage du cancer du col de l'utérus, dépistage du cancer, la santé des femmes

“Inside and Outside”: Sikh Women’s Perspectives on Cervical Cancer Screening

Nelly D. Oelke and Ardene Robinson Vollman

Cervical cancer can be detected at an early stage through regular screening. The literature suggests that cervical cancer in immigrant women, a growing population in Canada, is less likely to be detected early than it is in the general population, as immigrant women tend not to take advantage of screening. Culturally appropriate screening services for immigrant women are few. A qualitative descriptive study was conducted with female members of an urban Sikh community in Canada to explore perspectives on cervical cancer screening. In-depth interviews (13) and focus groups (3) were carried out to uncover challenges to cervical cancer screening. The researchers identified a prevailing theme of “inside/outside” whereby the women felt confined to their community, finding it difficult to move “outside” into Canadian society in order to participate in screening. Lack of knowledge about the importance of prevention, influence of family and community, and health-provider issues affected the women’s access to screening. The results will be helpful for nurses planning and delivering screening services to Sikh women.

Keywords: Cervical cancer screening, cancer screening, women’s health, South Asian

Cervical cancer is an important woman’s health issue; it is a disease that can be detected in its early stages when women participate in regular screening. The immigrant population in Canada has increased in recent years and the trend is predicted to continue. The South Asian immigrant population, which includes the Sikh community, is no exception. Cervical cancer is less likely to be detected early in immigrant women than in the general population, as immigrants tend not to take advantage of screening opportunities and there is a paucity of culturally congruent screening services. The literature includes little information on the screening behaviours of Sikh women, particularly with regard to cervical cancer. Such information is critical for program development and outreach strategies targeting Sikh women living in urban areas.

Literature Review

Canada’s population is changing, with an immigration increase of 14.5% between 1991 and 1996 (Statistics Canada, 2002). The South Asian community accounts for 2.3% of Canada’s total population and Punjabi

is one of the country's fastest-growing second languages (Statistics Canada). The health of immigrant groups, including the Sikh community, is an important focus for health professionals. Barriers, such as language difficulties or cultural factors, affect immigrants' access to health services.

Most cases of cervical cancer can be detected early with regular screening (Health Canada, 1998); best practice guidelines recommend annual Pap testing for all women between the ages of 18 and 69 who have ever been sexually active (Alberta Clinical Practice Guidelines Program, 2000). Nevertheless, it was estimated that in 2005 in Canada 1,350 new cases of invasive cervical cancer would be diagnosed and the disease would result in 400 deaths (National Cancer Institute of Canada, 2005). In the province of Alberta in the year 2000, 154 women were diagnosed with invasive cancer and 38 women died of the disease (Alberta Cancer Board, 2004).

Of the women who participated in the Canadian National Population Health Survey, 13% had never had a Pap test and 28% had not been screened in the preceding 3 years (Maxwell, Bancej, Snider, & Vik, 2001). Groups at highest risk for non-participation in screening included women who were single, older, born outside Canada, and non-English-speaking; had low levels of education; and did not routinely participate in prevention activities.

Hislop, Deschamps, Band, Smith, and Clarke (1992) compared South Asian women and the general population of women in the province of British Columbia for incidence of cervical cancer. Rates for South Asian women were 1.8 times higher than those for the general population, and in some age groups as much as 4.5 times higher. The authors speculate that the higher rates were due to South Asian women's inadequate participation in screening and inadequate follow-up of abnormal Pap tests. Choudhry, Srivastava, and Fitch (1998) and Bottorff et al. (1998), in their respective studies, found that South Asian women's level of proficiency in English and length of residency in Canada were significantly related to their breast cancer screening behaviours. The role of women in the family and society, modesty, and screening in the absence of symptoms were factors in their screening behaviours. Clearly, there are challenges in screening access among South Asian women as an immigrant group. What is unknown is the extent to which information about breast cancer screening practice applies to cervical cancer screening as well.

Research Purpose

The purpose of this qualitative study was to explore the knowledge, understanding, and perceptions of cervical cancer screening on the part

of Sikh women, a subgroup of South Asian women, living in a large Canadian city. Data collection and analysis were guided by the question *What are Sikh women's perspectives on cervical cancer screening and Pap testing?*

Methods

As little is known about Sikh women and their perspectives on cervical cancer screening, naturalistic inquiry (Lincoln & Guba, 1985) was considered an appropriate approach for the study. Purposive, maximum-variation sampling (Polit & Hungler, 1999) was used to ensure broad representation of urban Sikh women. Inductive analysis was employed to negotiate interpretations between participant and researcher (Lincoln & Guba). Study protocols were approved by the University of Calgary Conjoint Health Review and Ethics Board.

Participants

A varied group of Sikh women were recruited to participate in the study ($n = 53$): women in different age groups with different lengths of stay in Canada (< 10 years and 10+ years) and different screening practices. This mix of participants was based on evidence that screening behaviour varies according to age group (Maxwell et al., 2001) and that recent immigrants have lower screening rates (Goel, 1994). Both screeners and non-screeners were included in the study.

Phase 1: Interviews

Posters in English and Punjabi calling for participation in the study were placed in various locations in the community: the *gurdawara* (Sikh temple), a community agency, public health clinics, and a breast cancer screening venue. In addition, posters were distributed to key contacts in the community and the study was publicized on Punjabi radio. A presentation was made to a senior women's group to specifically recruit women aged 50 and over. The snowball method was also used (Polit & Hungler, 1999): referrals by participants in earlier interviews or by key members of the community. Recruitment continued until a fairly balanced representation was achieved with regard to age groups, length of residency in Canada, and screeners versus non-screeners.

Women volunteering to participate from various recruitment sources were telephoned by the researcher or the interpreter, who then described the study and established eligibility. Informed consent was obtained at the initial interview. Consent forms were available in both English and Punjabi. Most of the women using the Punjabi consent form were able to read the information. If they had difficulty understanding it, the interpreter helped them to complete the form. In-depth interviews were

conducted in the woman's home, *gurdawara*, or place of work. The women were asked about themselves (age, length of time in Canada, their own and their family's screening practices), the purpose of the Pap test, the benefits of screening, barriers to screening in their community, influence of family members on screening, and reasons why they had not had a Pap test. For women who spoke little or no English, an interpreter was used. Most of the interviews were audiotaped; in other cases detailed notes were taken to capture the participant's responses. Field notes were taken during all interviews in order to summarize non-verbal communication and context.

Phase 2: Focus Groups

Once the interviews were nearing completion, focus groups were commenced in order to extend and validate the findings. Focus group participants were recruited through a community service agency and English classes. Focus group organizers contacted all potential participants, described the study, and solicited their participation. At the beginning of each focus group, the study was reviewed and a consent form (English or Punjabi) was completed by each woman. As with the interviews, participants who were unable to read or understand all parts of the form received assistance. The focus groups were led by a skilled Punjabi-speaking facilitator. The researcher observed all focus groups and took detailed notes on context and non-verbal communication.

The women were provided with key themes identified in the interviews. Discussion followed on the purpose and benefits of the Pap test for the participants themselves and for other women in their community as well as barriers to participation in screening. They were also asked how cervical screening resources and services might best be delivered to women in their community. Over and above validating the interview data, the focus groups served as an opportunity for triangulation of the study's data-collection methods (Polit & Hungler, 1999).

Confidentiality among women in a close-knit community can be an issue. The confidential nature of the subject matter in the study was discussed at the beginning and end of each focus group. Recruitment of participants for the focus groups was not a difficult process; in fact two of the three focus groups had as many as 16 participants. For the last focus group, held at the *gurdawara*, women were eager to participate. The women believed they had the right to receive information that could be beneficial for them. By attending focus groups and interviews in a public place, the women may have been afforded privacy that would be impossible in the home context.

Data Analysis

Audiotapes of English-language interviews were transcribed verbatim. Audiotapes of Punjabi-language interviews and focus groups were translated and transcribed verbatim. Detailed notes of non-taped interviews, focus group observation notes, and field notes were also transcribed.

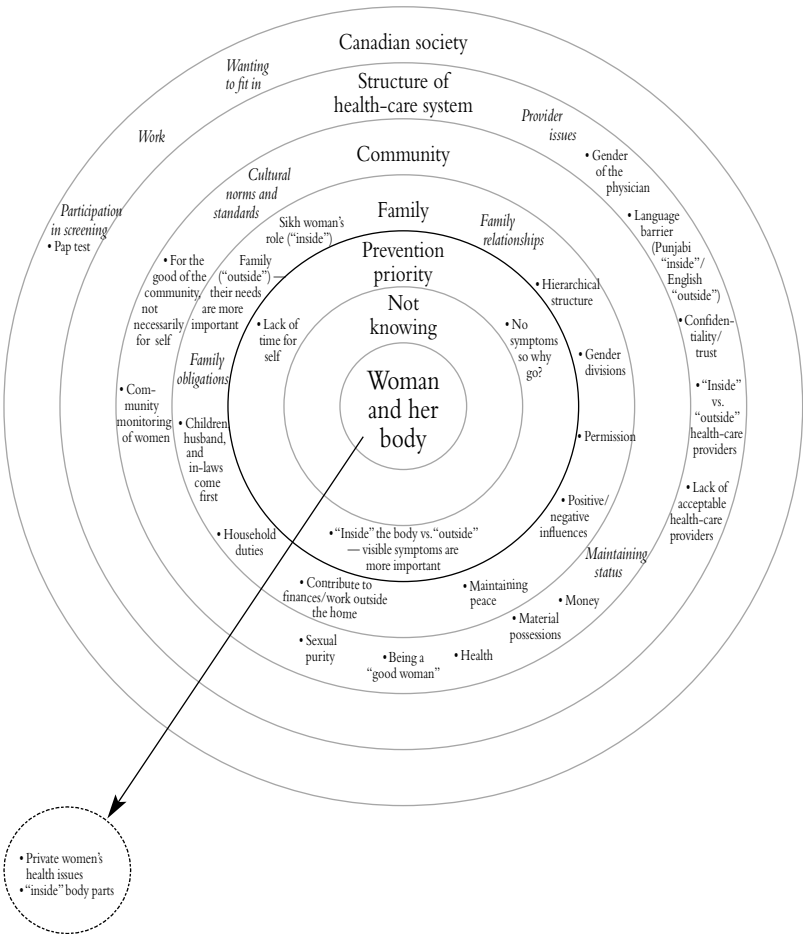
Inductive data analysis was used as a means of making sense of the data (Lincoln & Guba, 1985), facilitated by the N5TM computer program. Common themes with broad categories and patterns were identified and compared. This information helped to inform questions for further interviews and focus groups. Upon completion of all interviews and focus groups, a final round of data analysis was conducted. Trustworthiness of the results was ensured through member checking with three participants and by following audit methods outlined by Lincoln and Guba — that is, through process, confirmability, and dependability auditing.

Results

Thirteen interviews and three focus groups were conducted with a total of 53 women. Demographic information was collected for all participants. They ranged in age from 21 to > 65 years. Approximately two women from each 10-year age group (21–30 years, 31–40 years, etc.) participated in an interview. One participant was born in Canada. The others were born in India and had immigrated to Canada from 6 months to 32 years previous to the study. Most had been in Canada less than 15 years. All participants spoke Punjabi and had a range of abilities in English. They revealed a wide range of education levels, from Grade 9 to completion of postsecondary education.

Among the women who were interviewed, the overarching theme identified was the concept of “inside” and “outside.” The women’s screening behaviour was based on influences “inside” their own bodies, “inside” their personal sphere of influence, and “inside” their cultural norms and behaviours. The women faced numerous challenges to their moving “outside” into Canadian society in order to participate in cervical cancer screening. Figure 1 outlines a woman’s issues as an individual (her body, lack of knowledge about cervical cancer screening, lack of a focus on prevention), family and community influences, and health-system barriers. The process is layered from the “inside” to the “outside” in the same way that women negotiate the barriers to obtaining a Pap test. Details of the findings are presented below, followed by a discussion of the results.

Figure 1 *Issues for Sikh Women in Cervical Cancer Screening*



Individual Circle: “Inside” Our Bodies

For the interviewees, the cervix was an unseen or unknown part of the body: “It is for something you cannot see, a problem or anything inside.” The participants often stated that they knew about cancer but were not aware that one could have cancer of the cervix. Most did not know what the cervix was or where it was located in the body.

The cervix was viewed as part of the “inside” of the body and thus as less important than the more visible “outside” parts. This speaks to the very private nature of women’s health issues for Sikh women, particularly

those issues that concern sexual and reproductive health. The participants were strongly encouraged by family or community members to keep such matters to themselves, within their own bodies. This contrasts with Gadow's (1980) interpretation of women as seeking meaning of their bodies through its relationship to the "outside" world.

Knowledge Circle: "A Lot of the Time No One Knows"

Many of the interviewees had minimal knowledge of the Pap test and no ready access to information on it. Their lack of knowledge kept them from participating in "outside" screening activities and from fully participating in the "outside" world — Canadian society. Fewer than half the interviewees regularly screened; one had never had a Pap test, while others reported having one from time to time.

Focus group participants were not asked specifically about their personal screening behaviours but it was evident that many of them were not regular screeners: "I did not know anything about it till I came here [the focus group] and I have never had it done." Older women tended to know the least about the Pap test. Participants indicated that new immigrants were less likely to know about cervical cancer screening because women do not generally participate in screening in India. For those women who were aware of the test, their knowledge ranged from recently learning about it to not knowing its purpose despite having been screened.

Many of the interviewees also did not realize that annual screening is necessary: "I had it done and then I felt relaxed and I do not think about going again." The women believed that if they had the test once and it was normal they did not need to return.

These results indicate that there is limited knowledge within the Sikh community; for members of this community, knowledge about screening and the purpose of the Pap test exist in the "outside," external world. This finding is corroborated by those of other researchers. Gupta, Kumar, and Stewart (2002) found that among South Asian women lack of knowledge created a barrier to screening. Maxwell et al. (2001) and Goel (1994) found that age and length of stay in Canada were two consistent variables related to screening, with older women and new immigrants less familiar with the Pap test.

Prevention Circle: "My Body Is Perfect — Why Should I Go to the Doctor?"

The participants believed that seeking health care in the absence of symptoms is unnecessary and sometimes inappropriate. This lack of focus on prevention caused them to remain "on the inside," confined to their own community, and prevented them from readily participating in

routine screening: “You only have to go to the physician when you have [a] certain problem. If you’re fine, then you’re wasting your time.” Participants suggested that the cost of health care in India prohibited regular checkups and prescribed screening. Some women were confused about insurance coverage in Canada. Further, they were simply unaware of the Pap test and its recommended frequency.

As acknowledged by participants, India’s health-care system differs significantly from Canada’s. Private health-care spending in India is among the highest in the world, and the focus of the health-care system is curative as opposed to preventive and health promoting, as in Western countries (World Bank, 2001). This difference influences the health decisions and screening behaviours of Canadian Sikh women.

The interviewees stated that there was a lack of focus on health promotion in the Sikh community, posing another challenge with regard to cervical cancer screening. When they became aware of the need for Pap tests, participation was still minimal if no visible external (“outside”) symptoms were present. The results of this study confirm the finding of earlier research that lack of a focus on prevention is a barrier to both cervical and breast cancer screening in the South Asian community (Bottorff, Balneaves, Sent, Grewal, & Browne, 2001; Choudhry et al., 1998).

Family Circle: “Sacrifice for the Family”

The interviewees indicated that family structure and relationships can influence a Sikh woman’s ability to get to the “outside” to see a doctor for cervical screening. The Sikh woman’s role in the family (caring for family members, cooking, housekeeping) and family obligations are demanding and time-consuming. Male and elderly community members tend to dominate in the Sikh community: “It is a male-dominated society, and we accept that.” Likewise, decisions by senior family members must be respected: “All young people are actually dominated by the elderly of our society. We have to accept what they say... I can’t go against my parents’ wishes.” Participants often stated that permission for medical appointments may have to be granted by a husband, another male family member, or mother-in-law. For some women, their family was a positive influence for screening, encouraging them to see the doctor for an annual physical. For other women, their children, husband, in-laws, household duties, cultural obligations, and work outside the home came before their own needs: “My health...it’s not important”; “Women tend to ignore things and put her needs on the back burner.” For many of the women, time was also a factor, especially with regard to preventive practice in the absence of symptoms.

Cultural values and family expectations place considerable constraints on the behaviour of Sikh women and ultimately affect cervical cancer screening. The findings of this study confirm those of studies with the broader South Asian community (Bottorff et al., 1998; Choudhry et al., 1998).

Two significant themes were identified in the data regarding the family's influence on women: patriarchy and respect. The interviewees tended to live within a more traditional patriarchal society, with decisions generally being made by the head of the household. As suggested by other studies with South Asian women (Bottorff et al., 1998; Lynam, Gurm, & Dhari, 2000), the participants took care of others and fulfilled their other responsibilities before looking after themselves.

The second theme relates to respect for elders within the family and within the Sikh community. Sometimes a participant disagreed with a position taken by a respected elder but abided by the elder's guidelines in order to avoid conflict in the family and in the community. The relationship between mother-in-law and daughter-in-law is an important one in all families, particularly for extended families living within the same household. To avoid family conflict, this relationship was strongly protected, sometimes at great cost to the daughter-in-law. The custom of respect for elders and the hierarchical household structure is supported in the literature (Bottorff et al., 1998; Choudhry, 2001; Lynam et al., 2000). For many of the interviewees, the impact of family dynamics on cervical cancer screening was clear. The challenges posed by the "inside" (i.e., family) seemed not worth the effort required to reach the "outside," especially when "only" a checkup was at stake.

Community Circle: "Our Culture Is about Honour and Morals"

The interviewees stated that cervical cancer screening was a topic not to be discussed among women in the community. Such topics are kept "inside," in order to preserve the reputations of the woman and her family: "Nobody talks about this. Women don't tell each other." All participants, regardless of age or length of time in Canada, agreed that the Pap test is a private matter.

Lack of knowledge about the Pap test appeared to be closely connected to the lack of conversation about women's health concerns: "Maybe that's why people don't know...you just don't talk about [it]. How do you discuss something when nobody knows that it should be done?" Participants commented that in their families there was little intergenerational conversation, between mothers and daughters and mothers-in-law and daughters-in-law. Lacking knowledge about the disease and appropriate screening, they were unable to pass along important information to family members and other women in the

community: “The lack of knowledge and the shyness...go hand in hand...it is a vicious circle.”

Participants often spoke of the Pap test and cervical cancer in terms of sexuality and therefore as an inappropriate topic for discussion: “I was not allowed to talk about sex, and this is all about having babies or inner parts of [a] woman. That is not appropriate”; “It is a shame on you to be talking about these things in public...you don’t want people to have wrong thoughts so you keep your mouth shut.” Women’s health issues were discussed only with relatives or very close friends and then only if necessary.

The participants indicated that Sikh women live “inside” their community, their activities and actions monitored by others. A number of issues emerged related to preserving the honour and status of both the individual and the family within the Sikh community, ensuring that life was normal, at least in appearance.

The women had few opportunities for dialogue about female reproductive health, particularly issues linked to sexuality. They were strongly discouraged from talking about such issues for fear of bringing dishonour or shame upon the family. This lack of discussion resulted in large gaps in knowledge and considerable misinformation. Other researchers have similarly found that modesty and the preservation of family honour play a critical role in breast health practices (Bottorff et al., 1998) and that difficulty discussing such issues can serve to compromise women’s health (Gerrish, 2001).

Health-Care System Circle: Health-Practitioner Issues

The health-care system presented a number of challenges for the Sikh women who sought to move “outside” their community to obtain screening, particularly for those women who were unfamiliar with the system or spoke minimal English. These challenges included the sex of the physician, language barriers, trust, confidentiality, and a dearth of acceptable health practitioners.

Provider issues were of particular concern. Many participants had not been made aware of the Pap test and its importance by their family physician. They may have seen the physician for another problem but were seldom advised to have an annual physical, including a Pap test. “Why do the women not know about this?” said one participant. “I feel this is the responsibility of the doctors.” Participants felt that some Punjabi-speaking physicians did not take enough time with women, who therefore did not receive information or have a Pap test. Participants stated that embarrassment about this topic was apparent both for the health practitioner and for the woman.

There were differences of opinion about the importance of the sex of the physician. Some women believed that the main criterion was a qualified, competent doctor. Nevertheless, most of the participants felt more comfortable with a female health practitioner and, if given the choice, would select a female physician. Privacy and embarrassment were often cited as barriers for women seeing a male physician.

Language was a concern for many of the women. Most of the interviewees suggested that a female, Punjabi-speaking physician was the ideal choice although few such physicians were available: "They want to go to their physician, their own community people... They want to speak the language." The participants indicated that use of an interpreter when discussing private health matters could cause problems within the family or the community. The interviewees were divided on whether an Indian physician was preferable to a physician from outside the community. The women were concerned about trust and confidentiality. Many did not truly believe that their medical data would be held in confidence within the Sikh community. They described the Sikh community as small and close-knit.

When asked for suggestions on how to reach women in the Sikh community for cervical screening, many participants recommended the use of trained Punjabi-speaking nurses to carry out Pap tests. This would address health-practitioner issues to do with language and gender.

The interviewees reported that their physicians were not informing them about the Pap test and its importance. This is a common barrier to cervical cancer screening; the literature shows that the main reason why women do not obtain screening is that their doctor never recommended it (Fox, Siu, & Stein, 1994) and that a physician's recommendation of mammography is a cue for action in the South Asian community (Choudhry et al., 1998).

The participants' expressed preference for a female health-care provider when dealing with women's health issues is not unique to this population subgroup. Women in general prefer to have a Pap test conducted by a woman (Ahmad, Gupta, Rawlins, & Stewart, 2002). Many participants found it difficult to ask a physician, whether male or female, for a Pap test. Some Punjabi-speaking Indian doctors were themselves uncomfortable talking to women from their own community about Pap tests. Thus cervical cancer screening remains hidden "inside" the community and women are not being screened.

Difficulty with the English language made seeing a physician "outside" the Sikh community an additional challenge. Several researchers (Bottorff et al., 2001; Freeman et al., 2002) have reported on the advantages of having available first-language health practitioners

who possess cultural knowledge. However, the participants balanced these advantages with their concerns about confidentiality.

Discussion

Due to lack of participation in cervical cancer screening, the threat of cervical cancer appeared to be hidden both in the bodies of the Sikh women and in the Sikh community. The participants revealed layers of challenges to their becoming involved in screening activities. They frequently referred to the concepts of “inside/outside,” having to negotiate many obstacles in order to fully participate in the “outside” Canadian society and be screened for cervical cancer. For these women there remained a tension between themselves as individuals and their family and cultural traditions.

Participants in the study were “insiders” in their own community, wishing to be accepted into the larger Canadian society and to participate in health screening. The desire of immigrant women to belong and to have a connection with Canadians is also described by Lynam (1985), while Abouguendia and Noels (2001) found that, despite the strong desire of South Asian immigrants to participate more fully in Canadian society, there are still many factors preventing them from doing so.

What do the results of this study mean for cervical cancer prevention in Sikh women? The interviewees did not feel free to discuss the need for screening and many did not know about Pap testing. They preferred to have female health practitioners for sexual and reproductive health services. Yet few such practitioners are available and those who are available may be inaccessible to Sikh women because of language barriers. There is an urgent need for nurses to rethink the types of services that are available to Sikh women, how they are delivered and by whom, and how Sikh women can become participants in the decisions about these services. The present findings may help to familiarize nurses with the sexual and reproductive health practices of Sikh women, particularly the factors that affect their cervical cancer screening behaviours. Nurses can use this knowledge to increase participation in and access to culturally congruent screening services by planning and implementing educational and screening services for Sikh women. More specifically, those nurses who work directly with Sikh women have a role to play in welcoming the women, informing them about Pap testing, and encouraging them to participate in screening. Those nurses who are involved in community development could gather specific information from particular groups in order to effect policy, protocol, and process changes that address the issues in cervical cancer screening raised in this study.

Limitations

Ethnocultural communities are not homogeneous and there is often as much variation within groups as there is between groups. Efforts were made to recruit a sample with maximum variation in age and length of stay in Canada. Despite these efforts, caution is recommended in generalizing the results to all Sikh women living in Canada.

There are often issues entailed in conducting research in another language. The same interpreter and facilitator were used for all interviews and focus groups in order to ensure consistency of data. Consent forms were back translated; interview and focus group questions were reviewed by several Punjabi-speaking women; audiotapes of the Punjabi interviews and the focus groups were carefully translated and transcribed. Audits were conducted at various points in the process. Since language interpreters do not necessarily interpret culture, other means, beyond the words of the participants, were used to understand the Sikh culture.

Conclusion

The concepts of “inside” and “outside” referred to throughout this article require further study before we can fully understand them and their relationship to Sikh women and to cervical cancer screening. Although this study was intended to explore the perspectives of Sikh women on cervical cancer screening, throughout data collection and analysis it became apparent that it was about much more. The challenges and influences that emerged paint a picture of the Sikh woman’s response to many different aspects of health. The wide range of perspectives on cervical cancer screening revealed by the participants offer much-needed information, for nurses and other health practitioners, with regard to developing programs for cervical cancer screening for Sikh women and possibly other South Asian populations or other health-care programs.

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Comments or queries may be directed to Nelly D. Oelke, Research and Evaluation Consultant, Health Systems and Workforce Research Unit, Calgary Health Region, 10101 Southport Road SW, Calgary, Alberta T2W 3N2 Canada. Telephone: 403-943-1177. Fax: 403-943-0199. E-mail: nelly.oelke@calgaryhealthregion.ca.

Nelly D. Oelke, RN, MN, is Research and Evaluation Consultant, Health Systems and Workforce Research Unit, Calgary Health Region, Calgary, Alberta, Canada. Ardenne Robinson Vollman, RN, PhD, is Health Consultant and Adjunct Associate Professor, Faculties of Medicine (Department of Community Health Sciences), Nursing, and Kinesiology, University of Calgary.

Book Review

Women's Health in Canada: Critical Perspectives on Theory and Policy

**Edited by Marina Morrow, Olena Hankivsky, and Colleen Varcoe
Toronto: University of Toronto Press, 2007. 432 pp.
ISBN 978-0-8020-3939-2**

Reviewed by Joan Bassett-Smith

This book makes an extremely important and valuable contribution to Canadian and international literature in the domain of women's health. The feminist and postcolonial perspectives are refreshing and timely, and they move the conversations about women's health forward in a way that provides important direction for research, theory, policy, and practice. Edited by Canadian academics and practitioners, the book is impressive in the breadth and depth of Canadian and international literature that it cites.

Women's Health in Canada is organized into four sections. The first section sets the background for the book, explores the Canadian health-care system, and sets a historical context for the theoretical approaches used throughout the volume. The second section presents an essential and in-depth discussion of theory and methods underpinning the remainder of the collection. The third section addresses the social determinants of health; it includes chapters on topics such as poverty, international migration, disability, negotiating sexualities, and mothering. The fourth section addresses key issues in women's health, such as drug use, mental health policy, HIV/AIDS, breast cancer, cardiovascular care, access to maternity services, hormone replacement therapy, and violence. Each chapter in the third and fourth sections sets out goals for the chapter, discusses the state of inquiry in the field, and moves discussion of the topic forward in a way that provides direction for research and practice. The text boxes and questions for discussion are useful features of the book.

The editors situate themselves theoretically, in the opening chapter, but I would have found it useful to have a short biography of the editors and the contributors included in the collection. That said, I found the book thought-provoking, stimulating, informative, and grounded in research and practice.

Chapter 1, written jointly by the three editors, clearly sets out the purpose and goals of *Women's Health in Canada* and provides a useful link

between topics discussed in the book and relevant chapters. It then discusses the stated goals of the book. For the most part there is a sense of coherency among the chapters.

The collection is organized in such a way that it is possible for the reader to either choose a single chapter pertinent to a particular topic or read the book from cover to cover. By reading only a single chapter, however, one would miss some key theoretical background material. I would suggest that the reader peruse chapters 1, 3, and 4 before proceeding with any other single chapter.

Chapter 2, "Theory and Methods," is essential reading for anyone wishing to pursue feminist and postcolonial scholarship. It reviews theoretical foundations of postcolonial and feminist theories, and in so doing illuminates and extends the critical analysis of various topics in women's health. The reader will gain a deeper understanding of how critical perspectives can inform research, expand and deepen analysis, and provide direction for political and social action with the aim of promoting social justice. This chapter will be useful for feminist and postcolonial scholars whether or not their primary research interest is women's health. The examples provided illustrate the ways in which critical perspectives can inform research and practice and provide direction for both novice and experienced researchers. Current debates and points of tension are clearly discussed. The section on intersecting influences on women's health, such as history, sociocultural positioning, racialization, culture, and gender, adds clarity to our understanding of the multiplicity of factors affecting our research and practice with women and highlights the need to analyze differences among women as well as similarities.

This book will be useful for a wide variety of professionals interested in women's health. It is a necessary and thought-provoking addition to the literature and moves the debate on theorizing and research into new territory, not only in women's health but in a general sense as well. It could be useful for academics and undergraduate and graduate students in a variety of disciplines, such as nursing, psychology, women's studies, sociology, medicine, and midwifery, as well as for practitioners and policy-makers in the field of women's health.

Joan Bassett-Smith, RN, PhD, is Associate Professor and Director, School of Nursing, University of British Columbia Okanagan, Kelowna, British Columbia, Canada.