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EDITORIAL

CJNR and Other Canadian Independent Nursing Journals Under Threat

After 42 years of continuous publication, *CJNR* (*Canadian Journal of Nursing Research*) is under threat, along with six other independent nursing and health journals. A major source of the Journal's operating funding is being withdrawn. In order to survive we need your support.

In 2009 *CJNR* marked its ruby anniversary — its 40th year of continuous publication. This would be a remarkable achievement for any journal, but it was a particularly remarkable achievement for an academic journal that is one of the few to still be housed and published by a university, in this case McGill University, in the School of Nursing.

CJNR, originally called *Nursing Papers*, was founded in 1969 as a forum for the exchange of scholarly ideas among nurses across our vast country. This was a time when nursing research was in its infancy. There were just a handful of nurse scholars and a handful of universities offering master's programs. The establishment of doctoral programs in nursing was decades away. There were no peer-reviewed journals to disseminate the work of nurse researchers in this country. In 1974 *Nursing Papers* transitioned into a nursing research journal and its name was changed to *Canadian Journal of Nursing Research*.

Over the past three decades, nursing research has grown at an exponential rate as universities have expanded their graduate programs, the number of doctorate-prepared nurses has risen substantially, and nurse scholars have developed research programs. *CJNR*, as Canada's premier nursing research journal, has capitalized on the talents, skills, and expertise of leading Canadian nurse scholars who have served as guest editors, reviewers, and authors to further the dissemination of nursing research for the betterment of patient care. For a more detailed history, see my editorial titled "*CJNR* Celebrates Its Ruby Anniversary" (Gottlieb, 2009).

The majority of research journals founded in universities have ended up in for-profit publishing houses. The journals were established by a professor or group of professors employed by a university. These were small businesses whose editors were required to have not only the academic credentials and skills necessary to select quality manuscripts but also the managerial skills needed to produce and finance a journal. One by

one, academic journals succumbed and were taken over by large, commercial publishing houses. Academics often lost control of their own journals as the publishing company moved in.

In Canada, six of the country's eight academic and professional nursing journals are published by universities or professional associations. The other two are published by small for-profit enterprises.

In the United States the situation is quite different. In that country there are 65 nursing journals and all are published by for-profit companies. However, three publishers in effect control the market.

Another significant trend in the publishing world related to the financing of journals is the move to open access. Open access means that a journal is free: One does not need a paid subscription in order to access its articles. Often, instead of readers paying to read the articles, authors are asked to pay to have their articles published. There are problems with this economic model, the primary one being that not all authors have the money to pay to be published (Gottlieb, 2005).

At *CJNR* we have remained an independent publication. Over the years we have been able to finance the Journal through subscription fees, copyright fees, and a grant from the Social Sciences and Humanities Research Council, a federal agency. Twenty-five years ago *CJNR* received its first grant from Aid to Learned Journals, an arm of SSHRC. Every 3 years since, we have been awarded the largest amount granted through this competition. In the meantime, *CJNR* has been making a significant contribution to the development of nursing research in Canada and to the understanding of the social and emotional impact of illness. The Journal plays an important role in providing scholars with a vehicle through which to disseminate their research, as evidenced by the large number of submissions we receive each year. *CJNR*'s impact is indicated by its ranking within Ingenta, a major online publisher of journals in all fields: We consistently rank in the top 30 to 50 most downloaded of Ingenta's 17,000 publications — and we are the only nursing journal in this top ranking.

Some 4 months ago, just as we were preparing for another grant competition, we were informed indirectly that SSHRC had changed its mandate and had decided that nursing and other health journals would be ineligible to compete for funding. The reason given was that suddenly nursing and health journals no longer fell under SSHRC's mandate, even though, clearly, nursing research examines issues that belong in the human and social science lines of inquiry. SSHRC argues that journals such as ours should be funded by the Canadian Institutes of Health Research, even though CIHR does not perform this function and has no intention of doing so in the foreseeable future. This leaves *CJNR* and the

other independent nursing and health journals “between a rock and a hard place,” with no source of public funding to which we can even apply.

Without the SSHRC grant, *CJNR* is in jeopardy.

In February I wrote a letter of protest to Ms. Bryde Kelly, Program Officer at SSHRC, outlining the reasons why we should be eligible for funding under SSHRC’s own mandate and, more broadly, SSHRC’s moral obligations with respect to the funding of nursing and health journals. My letter and SSHRC’s response can be found on our Web site at www.cjnr.mcgill.ca as well as on the Canadian Nurses Association’s Web site at www.cna-nursing.ca.

What to do in both the short term and the long term to ensure our viability as a research journal?

Immediate Implications for the Viability of *CJNR*

The *CJNR* board met to discuss the situation and to regroup so that we could continue to publish. The immediate task was to see where we could cut costs. *CJNR* publishes both print and online versions. This is a costly venture. The most obvious solution was to reduce and then cut the print version. Beginning with this issue, the print version of the Journal is being reduced by 30% and the remaining content is being published online only. We will be eliminating our print version entirely: Beginning with the March 2012 issue, *CJNR* will be available online only; our last print issue will be December 2011.

Planning for the Future

Looking further into the future, we will be exploring alternative business models of funding the Journal. The future is uncertain, but what we do know is that we need to find innovative, creative ways to fund the dissemination of quality, peer-reviewed research.

Last week I met with the editors of *Canadian Nurse*, official publication of the Canadian Nurses Association, the voice of 140,000 nurses. The editors of *Canadian Nurse* have offered to help mobilize our nursing community. In their current issue (June 2011) they are publishing an abbreviated form of this editorial and my correspondence with SSHRC. As a first step, we are asking CNA members to sign a letter of protest addressed to SSHRC. We ask you to do the same by consulting our Web site at www.cjnr.mcgill.ca or the CNA Web site at www.cna-nursing.ca. In the coming months we will be developing a more specific strategy and will be asking you to become involved in our lobbying efforts. Stay tuned!

Editorial

Our very viability, and the viability of all independent nursing and health journals, is at stake. Please join us. We need your support. Let the voices of nurses be heard so that we can continue in our work to give voice to yours.

Laurie N. Gottlieb
Editor-in-Chief

References

- Gottlieb, L. N. (2005). Open access: A hot topic in the publishing world. *Canadian Journal of Nursing Research*, 37(2), 5–8.
- Gottlieb, L. N. (2009). *CJNR* celebrates its ruby anniversary. *Canadian Journal of Nursing Research*, 41(1), 11–18.

GUEST EDITORIAL

Nursing Inquiry to Address Pressing Empirical and Ethical Questions

Patricia Rodney

The most basic challenge, I believe, is to continue to make the voice of nursing stronger, louder, better understood, and heard (even among our own colleagues). . . . Our primary motive should be, and must be, a conviction that what we offer is exactly what the majority of people need the most from healthcare, regardless of where on the globe they reside. (Chinn, 2009, p. 281)

As I noted in the call for papers for this issue, *CJNR* has long provided an important venue for nurses in Canada and other countries to explore research and theory related to the philosophical and ethical dimensions of nursing practice.¹ Over the past 16 years the Journal has published four themed issues related to philosophy and ethics.² The early articles in *CJNR* concerning ethics focused mostly on philosophical analyses (1995, 2000). A philosophical analytic thread has been maintained throughout the volumes, with more recent issues of the Journal also addressing specific ethical challenges such as organizational conflict and moral practice (2002, 2007). This fifth themed issue builds on that history. It includes a Discourse and three empirically informed articles addressing philosophy, theory, and ethics in unique and complementary ways. All four articles included here make an outstanding contribution to nursing knowledge, thereby taking up Peggy Chinn's challenge to make our nursing voices stronger, louder, better understood, and better heard.

In her contribution, "Advance Care Planning: Re-visioning Our Ethical Approach," Carole Robinson describes her qualitative study exploring advance care planning processes for dyads of patients and family members. Robinson tells us that the dyads in her research demonstrated a deeply relational process, and she argues for an advance care

¹ Philosophy is inclusive of ethics, epistemology, ontology, logic, and aesthetics.

² Vol. 27 No 2 (1995): Philosophy/Theory; Vol. 32 No 2 (2000): Philosophy/Theory; Vol. 34 No 2 (2002): Ethics and Values; Vol. 39 No 4 (2007): Ethics, Values, and Decision-Making.

planning approach that embraces relational autonomy. In their article, “Remote Nursing Certified Practice: Viewing Nursing and Nurse Practitioner Practice Through a Social Justice Lens,” Denise Tarlier and Annette Browne claim that the concept of critical social justice offers a useful lens through which to examine the policy, practice, and power dynamics that lie behind inequities in the access of First Nations people to health and health care. Tarlier and Browne then undertake a critical analysis of nurse practitioners’ roles and scope of practice based on the empirical, theoretical, and policy literature. While Robinson’s contribution focuses on the ethics of relationships in families, and Tarlier and Browne’s on the ethics of relationships within communities and within provincial and national policy systems, Amy Bender and her Canadian and Ethiopian colleagues extend our view to the ethics of international relationships. Their article, “International Research Collaboration as Social Relation: An Ethiopian-Canadian Example,” is a case study of the Canadian and Ethiopian authors’ collective experience in organizing an interdisciplinary forum on intimate partner violence in Ethiopia. They offer an insightful reflection on international collaboration as a manifestation of social relations and subsequently posit their reflection as a basis for improving collaborative processes and outcomes.

In his Guest Editorial and Discourse for an earlier issue of *CJNR* dedicated to ethics, Franco Carnevale (2007) claimed that nursing needs more empirical inquiry to inform our ethical theorizing. The three articles I have sketched out above do just that. They each use various sources of empirical data to inform ethical theorizing in nursing, particularly regarding concepts such as autonomy, justice, and global health. And each helps us to better understand the complex contexts within which individuals, communities, and nations struggle to address inequities in health and health care. Elizabeth Peter’s Discourse in this issue, “Fostering Social Justice: The Possibilities of a Socially Connected Model of Moral Agency,” is therefore particularly salient. Peter argues that our theorizing about ourselves as moral agents ought to be re-conceptualized and fostered as a socially connective attribute, as opposed to an individual one, if we are to address health disparities locally and across the globe. Peter’s articulation of a socially connected understanding of nursing’s moral agency offers us a powerful theoretical lens through which to address ethical challenges at all levels of health care — from the individual through to the global.

The contributions in this fifth issue of *CJNR* dedicated to philosophy and ethics reflect nursing’s growing expertise in navigating and applying complex philosophical and ethical theory, and reconciling theory with empirical findings so as to improve practice and policy.

In the first issue dedicated to philosophy and theory, in 1995, the Guest Editor, June Kikuchi, noted that many of the manuscripts she received were lacking in philosophical depth (Kikuchi, 1995). In her Guest Editorial in the second issue, in 2000, Joy Johnson challenged us to continue in our “quest for philosophical understanding” (Johnson, 2000, p. 6). It is my observation that over the past decade or so in nursing we have made significant progress in our philosophical and ethical inquiry. Indeed, we had numerous promising manuscripts submitted for this fifth issue. Those authors whose works do not appear here will be able to make effective use of the insightful feedback they obtained. The expertise of the peer reviewers we were able to call upon is another reflection of nursing’s growing expertise in navigating and applying complex philosophical and ethical theory.

It is my hope that the contributions to nursing inquiry in this issue of *CJNR* will serve to foster further philosophical and ethical theorizing in nursing. Our profession, other health-care professions, health and social policy-makers, and the public all need it. As I also noted in the call for papers for this issue, some of the most pressing empirical and ethical questions facing us today are rooted in systemic inequities in access to resources for health and health care in Canada and around the globe (Anderson et al., 2009; Canadian Nurses Association, 2009; World Health Organization, 2008a, 2008b). Further, as cost constraints proliferate in health-care delivery there are serious concomitant challenges to the moral agency of nurses and other health professionals (Canadian Nurses Association and Registered Nurses Association of Ontario, 2010; Pringle, 2009; Rodney & Varcoe, in press; Varcoe & Rodney, 2009). I believe that the next frontiers for pressing empirical and ethical questions are therefore both practical and political. The questions are practical in the sense that we need to know more about how to make progress towards better ethical practice and policy, and political in the sense that we need to know more about how to foster stronger democratic dialogue within diverse care-delivery and policy structures.

Together, as socially connected moral agents, we ought to continue to strive to actualize Chinn’s conviction that as nurses we offer exactly what the majority of people need the most from health care, regardless of where in the world they reside. This actualization requires that we support each other within and across our professional arenas — practice, education, leadership, research, and policy. It also requires the support of scholarly publishing venues such as *CJNR*. In closing I would therefore like to thank Laurie Gottlieb (Editor-in-Chief), Joanna Toti (Managing Editor), the staff at *CJNR*, and all the contributors to and reviewers for this issue of the Journal for their commitment and expertise.

References

- Anderson, J. M., Rodney, P., Reimer-Kirkham, S., Browne, A. J., Khan, K. B., & Lynam, M. J. (2009). Inequities in health and healthcare viewed through the ethical lens of critical social justice: Contextual knowledge for the global priorities ahead. *Advances in Nursing Science*, 32(4), 282–294.
- Canadian Nurses Association. (2009). *Position statement: Determinants of health*. Ottawa: Author.
- Canadian Nurses Association and Registered Nurses Association of Ontario. (2010). *Nurse fatigue and patient safety: Research report*. Ottawa: Canadian Nurses Association.
- Carnevale, F. A. (2007). [Guest editorial and discourse.] Relating the “is-ought problem” to nursing inquiry. *Canadian Journal of Nursing Research*, 39(4), 11–17.
- Chinn, P. L. (2009). [From the editor.] Healthy people beyond 2010. *Advances in Nursing Science*, 32(4), 281.
- Johnson, J. L. (2000). [Guest Editorial.] Progress in philosophical inquiry in nursing. *Canadian Journal of Nursing Research*, 32(2), 3–6.
- Kikuchi, J. F. (1995). [Guest Editorial.] Moving forward in our philosophizing and theorizing in nursing. *Canadian Journal of Nursing Research*, 27(2), 11–14.
- Pringle, D. (2009). Alert — Return of 1990s healthcare reform. *Nursing Leadership*, 22(3), 14–15.
- Rodney, P., & Varcoe, C. (in press). Constrained agency: The social structure of nurses’ work. In F. Baylis, J. Downie, B. Hoffmaster, & S. Sherwin (Eds.), *Health care ethics in Canada* (3rd ed.). Toronto: Nelson.
- Varcoe, C., & Rodney, P. (2009). Constrained agency: The social structure of nurses’ work. In B. S. Bolaria & H. D. Dickinson (Eds.), *Health, illness, and health care in Canada* (4th ed.) (pp. 122–151). Toronto: Nelson Education.
- World Health Organization. (2008a). *Closing the gap in a generation: Health equity through action on the social determinants of health*. Final report of the Commission on Social Determinants of Health. Geneva: Author.
- World Health Organization. (2008b). *World health report 2008. Primary health care: Now more than ever*. Geneva: Author.

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Discourse

Fostering Social Justice: The Possibilities of a Socially Connected Model of Moral Agency

Elizabeth Peter

The moral agency of nurses in light of practice realities has long been debated (Davis & Aroskar, 1978). Particular attention has been paid in both empirical and theoretical inquiry to everyday local realities such as power differences, conflicts among nurses and other health professionals, limited resources, and the perceived misuse of technology to prolong life, which can constrain the moral agency of nurses in reaching the ideals of practice. While these remain worthy of discussion, increasingly attention is being drawn to nurses' moral agency in relation to their ability to address broader social injustices, which demonstrates a greater recognition of health disparities both locally and across the globe. An independent global commission recently released a report that presents a future vision for the education of health professionals; the report emphasizes the significance of health professionals working together in ways that are responsive both to local needs and to the promotion of health equity everywhere (Frenk et al., 2010). Within bioethics there is also recognition that ethicists and health professions alike need to adjust their focus beyond the medical model to that of promoting social justice (Sherwin, 2011).

Within Canada, however, questions have been raised regarding what expectations are appropriate for nurses with respect to their ethical responsibilities to meet the demands of social justice in their practice and more broadly. During the process of revising the Canadian Nurses Association's Code of Ethics in 2008, divergent views related to the purposes of the Code developed between ethicists and regulators. The ethicists believed strongly that the Code should emphasize nurses' roles in promoting social justice. The regulators, in contrast, argued that statements in the Code related to social justice should not be used to evaluate nurses' ethical conduct, because the expectation was believed to be too high and too difficult to inform regulatory decisions (Peter, 2008; Storch,

2008). These debates reflect a concern that nurses may not possess the moral agency necessary to address the social injustices they encounter.

In this Discourse I argue that nurses do possess this agency, if moral agency is re-conceptualized and fostered within nursing as a socially connective attribute as opposed to an individual one. First, I discuss the shortcomings of conventional conceptualizations of moral agency in relation to addressing social injustices. While individuals alone can at times have success in making structural changes, there are many potential constraints. Second, using Young's (2006, 2011) social connection of moral responsibility and agency, I re-conceptualize moral agency as potentially connected in nature. And third, I propose educational and research strategies to foster this agency.

Conceptions of Moral Agency

Moral agency has been defined as “the capacity to recognize, deliberate/reflect on, and act on moral responsibilities” (Peter & Liaschenko, 2004, p. 221). What this means in practice is largely dependent upon how the moral world is envisioned. For example, a deontologist may regard moral agency as primarily an individual's rational ability to comprehend and fulfil universal moral obligations. A virtue ethicist may regard moral agency as character traits or virtues of an individual that enable moral recognition, deliberation, and action — for instance, a nurse who possesses the virtues of compassion and courage and is able to recognize the suffering of a patient in acute pain, consider alternative interventions, and stand up to her colleagues who do not believe the patient is in pain. With these approaches there is the potential to envision moral agency as a collective attribute with a group of individuals displaying reason or virtue, but generally these approaches view persons as autonomous and individualized.

With a feminist approach, however (which conceptualizes persons as connected and interdependent), it is possible to think of moral agency as more than a characteristic possessed by an aggregate of individuals. It is possible to think of agency as a relational or socially connected characteristic of individuals in such a way that we can, at least to some extent, recognize, reflect on, and act on moral responsibilities as a collective. This conceptualization holds clues as to how best to educate nurses to address social injustices in groups and should help to direct our future research initiatives.

With a conventional conception of moral agency, individuals can be held directly accountable for their actions as they would be by a court or a regulatory body (Young, 2006, 2011). This conception is useful when

there is a direct connection between agents and their actions, such as individual nurses' accountability for the care they provide to patients under optimal circumstances. It is less useful when considering social injustices that have only an indirect relationship to individual agents, such as nurses' responsibility for poverty and racism in their communities; while there is an element of responsibility, it is indirect.

Young's Social Connection Model of Responsibility

Because social justice concerns primarily social groups and their relative positioning, as opposed to individuals outside of group membership, a conceptualization of moral agency as a social or collective construct is useful in terms of thinking about effecting social change. Although individuals, if favourably situated, can address social injustices by initiating policy change or advocating for patients, for example, social groups are better able to make the structural changes needed to bring about the political and economic changes necessary for social justice to exist. Both the ethics of care and feminist ethics, with their underlying ontological perspective of persons as connected, permit the conceptualization of individuals as connected moral agents, not just an aggregate of individuals. Iris Young's (2006, 2011) social connection model is an example of a feminist approach that constructs moral agency in this way.

The social connection model of responsibility views individuals as having some responsibility for social injustices, because they contribute, through their actions, to the social processes and rules that bring about these injustices. This responsibility is a consequence of individuals' connections to others in a web of social relationships. While they have some responsibility, they are not liable for failing to achieve social justice (Young, 2006, 2011). This distinct feature of the model has important implications for the regulation of the nursing profession. The legalistic aspects of the regulation of nursing that result in the disciplining of nurses fall under what Young (2006, 2011) calls the liability model. This model for understanding moral responsibility derives from a legalistic framework used to establish the guilt of individuals for harms and misdeeds. Under this model, guilt is assigned when there is a clear causal connection between an individual's action and a harm — for example, when a nurse steals from a patient. Social injustices, in contrast, cannot be causally linked to individuals, because they are structural in nature and are a consequence of numerous individual actions and policies. As a result, it is not constructive to look to the past to assign blame and seek punishment. Young (2006, 2011) encourages us all to develop a forward-looking approach (as opposed to a backward-looking approach) in order to

engage in collective action to address structural injustices. To discipline nurses for failing to address social injustices would be backward-looking and in error according to the social connection model. Nursing responsibilities related to social justice in codes and standards should be forward-looking, and those who fail to meet these responsibilities should not be subject to discipline.

Forward-looking strategies are best undertaken through social connections, because they provide individuals with some power over the social structures that create injustices (Young, 2006, 2011). We therefore do not need to be passive onlookers. *It is because we are deeply connected moral agents that we are able to bring about social change, particularly when we form organized social groups.* Nurses, unlike many citizens, possess the benefit of being in organized professional groups within their own countries and have at least some global presence in associations such as the International Council of Nurses. Social connections already exist among nurses and the possibility of strengthening these connections is there. In this sense, the professionalization of nurses enables moral agency in ways unknown to many. This is not to say that nurses as a social group do not experience constraints to their moral agency, because as a social group (or perhaps as social groups) we, too, are situated by social class, gender, race, and so on. Nevertheless, our potential to act is likely underestimated.

Fostering Social Justice

How can the moral agency of nurses using a socially connected model be fostered? In other words, how can nurses' ability to recognize, deliberate on, and act to address the social injustices they encounter as a group, or a series of groups, be enhanced? The ability to recognize social injustices may be easiest developed in traditional educational settings. Codes of ethics and standards of practice need to address the importance of accepting social injustices as a collective responsibility with forward-looking elements, so that they can inform the ongoing development of moral receptivity of student and practising nurses. Sherwin (2011) suggests that theories (such as the work of Walker [1998] and Young [2006]) that focus on community and interconnected moral agents and move away from dominant models that focus on individual action are better able to direct the demands of social justice. These theories could also help us to view ourselves as connected moral agents capable of recognizing group responsibility. Further educational research could examine the usefulness of such strategies and could also explore what other kinds of educational approaches might be successful in both preparatory and continuing education.

Other authors have shed light on approaches that can enhance our ability to address social justice concerns through dialogue with both student and practising nurses. This could result in a collective mindset that fosters not only recognition of social injustices but also fruitful deliberation about them. Critical self-reflection and thinking can lead to an understanding of individuals' health concerns, difficulty accessing health services, or difficulty following medical advice as a manifestation of their social locations, as opposed to their individual failings (Anderson, Browne, Khan, Lynam, & Rodney, 2009; Pauly, MacKinnon, & Varcoe, 2009). For example, the lack of medical follow-up for the young child of a poor single mother with multiple children could be judged as a lack of caring on the mother's part instead of as an indication of her lack of transportation, child care, or health literacy. This kind of understanding could lead to deliberation about how to improve access to the social determinants of health for all, and would be a fruitful area for future nursing research. Position statements that are the outcome of group deliberation related to social justice concerns, such as poverty, racial discrimination, and access to quality education and nutrition, could support the creation of a group ethos in both student and practising nurses. This group ethos could lead to the questioning of attitudes that further the "othering" (Canales, 2010) of the less privileged and an intolerance of these attitudes in nursing.

Learning to take collective action as an end result of reflection and deliberation is ultimately the most powerful aspect of moral agency. Anderson et al. (2009) recommend engaging in moral dialogue at all levels — local, national, and global — to eliminate everyday social interactions that lead to inequities. In this way, changes can be made to health-care delivery to make it more accessible and more sensitive to those who are underserved. Exposing students to innovative settings that address the needs of vulnerable populations can help them to develop the critical reflection skills and confidence they will need to initiate actions that are directed towards overcoming health inequities (Cohen & Gregory, 2009). If the opportunity to take part in this type of practicum were to become the norm, the capacity for collective action after graduation would be greatly enhanced. Action directed towards developing health policy that addresses the social conditions that surround health problems and that is sensitive to differences in class, race, and gender could also address health inequities (Pauly et al., 2009). Organized professional groups stand to have the most success in sustained collective action at the level of policy, given the opportunities they have to pool resources of all kinds, including talent and will.

Many other collective actions are possible in relation to promoting social justice. The possibilities for change are there, but a rethinking of our moral agency is necessary so that we can capitalize on our collective strengths. This rethinking must be supported by ongoing empirical and theoretical inquiry in nursing, to ensure that the best strategies are adopted. Ultimately, a socially connected moral agency will not only enhance efforts to achieve social justice, but also strengthen nursing's sense of identity and power as a profession capable of bringing about important changes to health and health services for the populations with whom we work.

References

- Anderson, J., Browne, A., Khan, K. B., Lynam, J., & Rodney, P. (2009). Inequities in health and healthcare viewed through the ethical lens of critical social justice. *Advances in Nursing Science*, 32(2), 282–294.
- Canales, M. K. (2010). Othering: Difference understood?? A 10-year analysis and critique of the nursing literature. *Advances in Nursing Science*, 33(1), 15–34.
- Cohen, B. E., & Gregory, D. (2009). Community health clinical education in Canada: Part II – Developing competencies to address social justice, equity, and the social determinants of health. *International Journal of Nursing Education Scholarship*, 6(1), 1–15.
- Davis, A. J., & Aroskar, M. A. (1978). *Ethical dilemmas and nursing practice*. New York: Appleton-Century-Crofts.
- Frenk, J., Chen, L., Zulfiquar, A. B., Cohen, J., Crisp, N., Evan, T., et al. (2010). Health professionals for a new century: Transforming education to strengthen health systems in an interdependent world. *Lancet*, 376, 1923–1957.
- Pauly, B. M., MacKinnon, K., & Varcoe, C. (2009). Revisiting “who gets care?” Health equity as an arena for nursing action. *Advances in Nursing Science*, 32(2), 118–127.
- Peter, E. (2008). Seeing our way through the responsibility vs. endeavour conundrum: The code of ethics as both product and process. *Canadian Journal of Nursing Leadership*, 21(2), 28–31.
- Peter, E., & Liaschenko, J. (2004). Perils of proximity: A spatiotemporal analysis of moral distress and moral ambiguity. *Nursing Inquiry*, 11(4), 218–225.
- Sherwin, S. (2011). Looking backwards, looking forward: Hopes for *Bioethics'* next twenty-five years. *Bioethics*, 25(2), 75–82.
- Storch, J. (2008). Codes of ethics: Aspirational or regulatory? *Canadian Journal of Nursing Leadership*, 21(2), 31–33.
- Walker, M. U. (1998). *Moral understandings: A feminist study in ethics*. New York: Routledge.
- Young I. M. (2006). Responsibility and global justice: A social connection model. *Social Philosophy and Policy Foundation*, 23(1), 102–128.
- Young, I. M. (2011). *Responsibility for justice*. New York: Oxford University Press.

A Socially Connected Model of Moral Agency

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Planification préalable des soins : la révision de notre approche éthique

Carole A. Robinson

Cette étude qualitative a exploré l'applicabilité et l'utilité d'une intervention de planification préalable des soins (PPS), et examiné le processus de PPS. Neuf dyades (des patients et patientes auxquels on a diagnostiqué récemment un cancer du poumon à un stade avancé et un membre de leur famille) ont participé à l'intervention de PPS, ainsi qu'à des entrevues évaluatives effectuées trois mois et six mois après l'intervention. Toutes les entrevues ont été enregistrées, transcrites mot à mot et analysées à l'aide de la méthode de la comparaison constante. Il a été constaté que le processus ne préparait pas un mandataire spécial à parler en son propre nom ni à orienter les soins de santé dans la situation où une personne est incapable; il engageait plutôt les familles dans un processus relationnel très profond permettant de discuter de la signification, des valeurs et des préférences. En théorie, la PPS repose sur la notion traditionnelle de l'autonomie du patient ou de la patiente, laquelle n'est pas en harmonie avec le processus relationnel qui s'est manifesté dans cette étude. Une approche qui épouse l'autonomie relationnelle est plus congruente et fournit une base plus solide pour répondre aux besoins des familles.

Mots clés : planification préalable des soins, éthique, autonomie du patient, autonomie relationnelle

Advance Care Planning: Re-visioning Our Ethical Approach

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This qualitative study explored the applicability and usefulness of a promising advance care planning (ACP) intervention and examined the ACP process. Nine dyads (patients newly diagnosed with advanced lung cancer and a family member) participated in the ACP intervention, with evaluative interviews at 3 and 6 months after the intervention. All interviews were recorded, transcribed verbatim, and analyzed using constant comparison. The process was found not to be one of preparing a substitute decision-maker to speak for oneself and direct health care at a time when one is incapacitated; rather, the families engaged in a deeply relational process where meaning, values, and preferences were negotiated in conversation. ACP is theoretically rooted in a traditional notion of patient autonomy that is not aligned with the relational process that unfolded in this study. An approach that embraces relational autonomy is more congruent and provides a stronger foundation for meeting the needs of families.

Keywords: advance care planning, ethics, patient autonomy, relational autonomy

“Advance care planning is, at its most basic, a process of thinking ahead to treatment choices, goals of care, and/or choosing another person (proxy) to speak for oneself at a point in the future” (Romer & Hammes, 2003). While Romer and Hammes state that discussions of advance directives and advance care planning (ACP) are omnipresent in the end-of-life literature, and while these initiatives have received a great deal of attention over the last two decades in the United States, the Canadian health-care system is just beginning to systematically communicate on decision-making at end of life (Carstairs, 2005). Limited public awareness of ACP, lack of integrated services such as ACP, varying provincial legislation, lack of leadership, and reluctance to discuss death and dying — even among care professionals — present continuing challenges to care at end of life in Canada (Carstairs, 2010).

The promotion of advance directives as a way for patients to control their own medical care should they become incapacitated is associated with the 1990 US *Patient Self Determination Act* (PSDA) and subsequent accreditation standards (Emanuel, 2008; Romer & Hammes, 2003). The PSDA requires hospitals, nursing homes, and health plans to ask whether patients have advance directives and to include these in the medical record. As a result, most US health-care organizations provide some assistance with the completion of advance directives. However, the original

document-driven approach to ACP has met with strong international criticism and marked lack of success (Kass-Bartelmes & Hughes, 2003; Solomon, 1999; The SUPPORT Investigators, 1995). Two challenges have become evident: completing the documents and getting them on record, and having the stated preferences influence care (Collins, Parks, & Winter, 2006). These challenges are exemplified in the landmark Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), a large prospective clinical trial designed to improve end-of-life decision-making (The SUPPORT Investigators, 1995). The intervention included the use of specially trained nurses to facilitate conversations and information exchange among patients, families, and physicians. While demonstrating a significant increase in documented advance directives, the intervention did not improve communication, incidence, or timeliness with respect to “do not resuscitate” orders, days spent in the intensive care unit, physician knowledge of patient preferences, or level of patient pain. In other words, the intervention failed to improve end-of-life care. The document-driven approach is severely limited by a narrow focus on specific interventions and lack of attention to the broader values and goals of care that accurately predict end-of-life treatment preferences (Collins et al., 2006; Emanuel, 2008; Kaldjian, Curtis, Shinkunas, & Cannon, 2009). As well, the influence of advance directives on care continues to be limited by procedural, legal, and communication difficulties (Collins et al., 2006). Further, end-of-life values change over time and there is a risk that advance directives will not reflect related changes in treatment preferences, since the document may not be revisited (Collins et al., 2006).

In response to the failure of ACP to improve end-of-life care, the field has evolved from a legal, document-driven one to a process of engaging patients, families, and substitute decision-makers in conversations about hopes, wishes, values, and goals with respect to care. In contrast to earlier initiatives, this process orientation to ACP has demonstrated success in improving end-of-life care (Collins et al., 2006; Hammes & Romer, 1999; Lorenz et al., 2008). ACP, when done effectively, is associated with meaningful outcomes for patients, including a sense of well-being, connection with family, sense of control, peace of mind, relief of anxiety, and relief of stress for proxy decision-makers (Briggs, Kirchhoff, Hammes, Song, & Colvin, 2004; Clayton, Butow, Arnold, & Tattersall, 2005; Ditto et al., 2001; Kass-Bartelmes & Hughes, 2003; Martin, Thiel, & Singer, 1999; Sakalys, 2003; Singer et al., 1998; Stewart, 1995; Tilden, Tolle, Garland, & Nelson, 1995; Tilden, Tolle, Nelson, & Fields, 2001; Tulsy, Fischer, Rose, & Arnold, 1998). Since most of these outcomes arise from the effectiveness of the process rather than from the completion of doc-

uments (Briggs & Colvin, 2002), skilled facilitation and engagement of key decision-makers is critical (Lorenz et al., 2008).

The thinking about ACP in Canada has mirrored the shift seen in the United States (Carstairs, 2000). Further, ACP is viewed as integral to high-quality palliative care and is consistent with the values, guiding principles, and foundational concepts identified in the National Model created to guide the development of palliative care in Canada (Ferris et al., 2002). In relation to advance directives, the Senate Subcommittee to update *Of Life and Death* (see Carstairs, 2000) came to this conclusion: "If loved ones and medical professionals have engaged in a process of serious communication, the problems associated with the interpretation and application of advance directives are much less likely to arise. The passage to death is eased, the level of comfort rises, and the burden of care is lightened for the substitute decision maker." Yet, while 83% of Canadians feel it is important or extremely important to discuss their medical care wishes with family members, only 44% of those surveyed had had at least one discussion with a family member about ACP (Ipsos-Reid, 2004). The Senate report also points out that legislation pertaining to advance directives varies across Canada, which creates a set of problems, and that our orientation to advance directives as opposed to the process of ACP is associated with problems of interpretation and application in the often ambiguous situations of real life. Again, these ideas mirror the findings reported in the United States.

Despite the shift towards ACP as a process that requires the involvement of persons who are significant to the planner, the ethical foundation of ACP remains firmly rooted in individual autonomy and the right of self-determination (Emanuel, 2008; Puchalski et al., 2000). ACP is viewed as a way of extending individuals' autonomy and control over future health-care decisions at a time when they may be unable to speak for themselves (Collins et al., 2006; The SUPPORT Investigators, 1995). This practice relies on substitute decision-makers who are charged with making choices the patient would have made (Hickman, Hammes, Moss, & Tolle, 2005; Shalowitz, Garrett-Mayer, & Wendler, 2006). Yet the evidence shows that this standard is frequently unattainable and may not even be desirable from the patient perspective (Collins et al., 2006; Emanuel, 2008). Indeed, many patients want their substitute decision-makers to use their own judgement rather than strictly follow preferences stated in an advance directive (Puchalski et al., 2000).

Consideration also needs to be given to the negative consequences family members may experience as a result of their involvement in end-of-life decision-making (Haley et al., 2002; Tilden et al., 2001; Tilden, Tolle, Nelson, Thompson, & Eggman, 1999). One of the main goals of

ACP from the patient perspective is alleviation of the burden on family members (Martin et al., 1999; Singer et al., 1998), and family involvement in the process supports this goal (Tilden et al., 1999, 2001). While the importance of family involvement is evident, the role of family members in the ACP process has received little research attention beyond studies focused on the accuracy of proxy decision-making (Shalowitz et al., 2006). A model of shared decision-making has been proposed as one way to address family involvement, but it is unclear how this aligns with the foundation of individual autonomy (Collins et al., 2006; Kaldjian et al., 2009). How do we reconcile the traditional conceptualization of autonomy that values independence, self-sufficiency, and decision-making free from the influence of others (Mackenzie & Stoljar, 2000) with the recognition that ACP is dependent on an iterative process of discussion and feedback within a network of intimate relationships (Martin et al., 1999; Prendergast, 2001; Singer et al., 1998)? This apparent contradiction has the potential to cause clinical tension and raises further questions regarding the appropriate role of both family members and health-care providers in the ACP process. For example, Sahlberg-Blom, Ternstedt, and Johansson (2000) posit that “decision making concerning a dying patient can be described as a drama comprised of different conflicts concerning autonomy between a variety of actors such as the patient, the patient’s relatives, and caregivers” (p. 297). Here, emphasis is placed on competing needs that arise between independent and self-determining players rather than the interdependence that characterizes much of family life.

This article reports on an ethically and clinically important facet of a study focused on ACP in the context of a diagnosis of advanced lung cancer: the relational process. The patients and family members who took part in the ACP intervention demonstrated deep relational engagement that calls into question the ethical foundation of ACP and provides support for a shift in perspective. An approach that honours both autonomy *and* the intimate relationships in which it is embedded is discussed. The article is intended to provide insight into one way of better informing the ACP process.

The Study

The study was designed to evaluate the applicability and usefulness of a promising patient-centred ACP intervention developed by the Respecting Choices[®] program in Wisconsin (Briggs et al., 2004). The study was approved by the University Research Ethics Board.

The Intervention

A recent US development in ACP addresses special populations who, because of complex health concerns, need extra assistance and skilled facilitation in making future health-care decisions (Briggs, 2003; Briggs et al., 2004). This initiative, the Patient-Centered Advance Planning Interview (PC-ACP Interview) evolved as it became apparent that different ACP approaches are needed for different situations (Briggs, 2003; Briggs et al., 2004). Special populations include individuals with end-stage chronic illness. The hallmarks of the initiative are as follows (Briggs, 2003; Briggs et al., 2004; Hammes, 2003; Hammes & Romer, 1999):

1. A guiding ethical principle of respecting the patient's beliefs, values, and preferences.
2. A focus on relationships; thus, patients and their families are engaged together if possible. Family is defined in a non-traditional manner, to include those persons closest to the patient who would most likely offer support and be involved in decision-making.
3. Creation of an emotionally safe environment for discussion that is facilitated by a trained, highly skilled individual.
4. An educational approach whereby patients/families gain an understanding of realistic future options and associated decisions, have the opportunity to reflect on this information, work through the issues, come to decisions that are consistent with their values and beliefs, and communicate these decisions appropriately.
5. Information offered to the patient and family that is individualized to diagnosis, understanding, values, goals, and beliefs. Thus, it is disease- and situation-specific.
6. Pacing according to family direction about what will be discussed, and when.
7. A process orientation whereby discussions can be revisited over time.

A pilot study for the intervention (Briggs et al., 2004; Schwartz et al., 2003) reports the following outcomes:

1. Patients and their families were more prepared to make difficult decisions after having these discussions. Briggs (2003) found that patients were often afraid to talk to their loved ones about these issues and the intervention offered a valuable opportunity for discussion.
2. Less conflict among family members and enhanced confidence in decisions.
3. Significantly improved congruence, in specific treatment preferences, between patients and their surrogate decision-makers.

4. Significantly greater patient satisfaction with the quality of patient-clinician communication when compared to patients who had not had this level of discussion.
5. Significantly lower decisional conflict for patients about preferences for future medical care when compared to patients who had not had the intervention.

This promising evidence-based intervention was chosen because it showed potential for enhancing the quality of life and death for our chronically and terminally ill population. Further, we wanted to extend knowledge about its usefulness to persons with cancer and in a Canadian context. We were also curious about *how* it worked, since this had not been examined before.

Participants

The sample of 18 participants comprised patients newly diagnosed with advanced lung cancer and their chosen significant other. All dyads spoke and read English. Six dyads were married couples and three were parent/child (one son; two daughters); the patients in the three latter dyads were either widowed or divorced.

Of patients who are newly diagnosed with lung cancer, 80% will have advanced disease and require immediate palliative care. Those patients who are palliative from initial diagnosis often face a rapid decline in health, accompanied by an abbreviated time frame for decision-making, and early death. Median survival estimates for persons diagnosed with the dominant form of advanced lung cancer range from 5.8 to 7.3 months (Breathnach et al., 2001).

Data Collection

The PC-ACP is a structured interview with a consenting patient and a chosen significant other, delivered by a trained facilitator and lasting 1 to 1.5 hours. It is an opportunity for the patient and family member to consider the life-sustaining treatment choices the patient would make if he/she became unable to speak for him/herself. The purpose of the interview is to explore the patient's understanding of the situation, introduce new information as needed, and promote dialogue.

First, participants' experiences and beliefs about their life, illness, and treatment were explored; then the participants were led through a series of situation-specific scenarios where preferences for end-of-life care were elicited (see Briggs [2003] and Briggs et al. [2004] for a more detailed description of the interview components).

Where possible, evaluation interviews were conducted 3 and 6 months after the intervention, which itself occurred several months after

diagnosis. Follow-up did not take place with all families, for various reasons, the most common being illness progression. In total there were 15 interviews (nine PC-ACP interviews; six follow-up interviews). All of the interviews were audiorecorded and transcribed verbatim. Audiorecording of the intervention enabled in-depth exploration of the process, which had not been done before. The data also included detailed field notes.

Data Analysis

Constant comparative analysis proceeded concurrently with data collection (Glaser & Strauss, 1967). Two researchers with expertise in qualitative research independently read and reread the transcripts, identifying meaning units or themes. The codes evolved through the iterative process of constant comparison within and across transcripts and discussion between the researchers. A coding schema was developed by consensus and NVivo was used to manage the data. This article reports on the relational process of ACP.

Findings

The involvement of significant others in the ACP process was intended to enhance family members' understanding of patients' preferences so that they would be able to better speak for the patient, if necessary, at end of life and to reduce the burden of doing so. In other words, the aim was to prepare family members for their role as substitute decision-makers while also reducing the negative consequences, with the patient foreground and the family member somewhat in the background. In contrast, the relational process that unfolded was interactional, with family members actively engaged in both the narrative process and the decision-making process that followed. In each dyad, both the participants and their network of relationships were foreground.

The Narrative Process

The intervention began by eliciting the patients' narrative about their illness, including fears, past experiences with serious illness and death, and values and beliefs that were influential to their definition of quality of life. Family members spontaneously "jumped in" even when questions were explicitly directed to the patient. Family members reminded patients of things they had forgotten, finished the patients' sentences, elaborated on the narrative, initiated joint problem-solving when concerns arose, and offered their own ideas and experiences. Both members of the dyad frequently used the word "we" when referring to the illness experience — for example, "We were in hospital." The conversation

clearly showed that illness is a relational experience. In the following exchange the participants speak for each other and the relational impact of symptoms arises:

Researcher [to husband/patient]: *Any other areas of your life affected [by the symptoms]?*

Wife: *Not very much . . . he went to play poker last Wednesday night. [laughs]*

Researcher [to wife]: *And how about you? Do you see how [husband's] symptoms have affected his life?*

Husband/patient: *She has to do all the work.*

Wife: *[laughs] No, that's not true. Actually, as he says, he's back to doing stairs and we're going for walks every day.*

As this conversation illustrates, the patient-centred, individual focus of the questions was shifted towards a family-centred, relational focus by the participants. From the family perspective, the illness experience is a shared experience.

Family members often used the conversation to affirm the vitality of the ill person, to offer support, and to highlight the person's contributions to family life. This emphasis on the importance of the ill person's involvement in family life was a counterbalance to discussions about physical decline and dependence:

Husband: *One day I was out there in the yard digging and I looked in and she [wife/patient] was standing by the window there. I sneaked around after her and I came in this door and she didn't know I was coming in this way. And I walked in and the tears were going. And I said, "What happened to you?" She said, "You're doing my job." So I said, "Well, it was time. You've done it 50 years. It's my turn. You stand there and tell me what not to cut and rake."*

Researcher: *So there's been a fair bit of loss for you [wife/patient].*

Husband: *Oh, that's the problem. [pause] She still cooks a mean meal.*

In another interview, the family member was quick to point out his father's active contribution to family understanding:

Father/patient: *I don't know what I learned [from the mother's death].*

Son: *Well, you take a great deal of effort and care to make sure that everybody is informed.*

This reveals a process of mutual affirmation.

Patients also used the interview to acknowledge the closeness and importance of the relationship with their participating family members:

Mother/patient: *She [daughter] will be able to sense what I want, because we've been close . . . I'm really sorry for [my daughter] . . . I'm really glad she's here, but she's taking on a big, big job, a really big job. And she just moved here a year ago. She kind of figured we'd do a lot of things together, as we like to cross-country ski, and we did a little bit of that last year, and we were looking forward to doing things like going to hockey games and just doing things together. Now she's got my responsibility . . . she's got the full load.*

Daughter: *This is not about me, Mom. This is about you. [sobbing]*

Mother/patient: *It's about both of us.*

This conversation also illustrates how patients were worried about creating a burden for their family members, which became a point of discussion in many of the interviews.

The dyads demonstrated mutual support through family solidarity, particularly around hopes for the plan of care, as seen below:

Researcher: *Now, you [wife/patient] touched on this a little bit earlier . . . what do you hope for from your current plan of care?*

Wife/patient: *From my current plan of care . . . I'm hoping for recovery.*

Husband: *Complete.*

Wife: *Complete recovery.*

Another family said it this way:

Father/patient: *I don't think there are going to be any complications [of my lung cancer], to be quite honest. I don't.*

Son: *I'm with you, Dad.*

All of the patients identified family as what sustained them in difficult times. For most, this was the only support spontaneously identified.

Researcher: *Who or what sustains you when you face challenging times?*

Husband/patient: *For this condition I got now?*

Researcher: *For any challenges . . . if you think back . . .*

Husband/patient: *My wife of 50 years.*

When questioned further, some participants expanded their answer to embrace a network of relationships:

Wife/patient: *I've had a lot of friends that are praying for me, and it makes me feel good to know that these people out there are all trying to support me . . . and that they're all rooting for me.*

Another facet of the PC-ACP focuses on what it means to the patient to live well. This is designed to begin the discussion about key elements underpinning quality of life from their perspective. Again, all of

the patients focused on family and meaningful activities with close friends. One participant stated it this way:

Wife/patient: *Living well means for me to be with my family and kids and see them growing up and getting married and having children — my grandchildren.*

Another patient described the importance of continuing to care for his family as part of living well. Just as he drew strength from his wife, she drew strength from him:

Researcher: *I'm also hearing you say [that] part of living well for you at this time includes not only visiting your family but caring for them and to some degree protecting them.*

Husband/patient: *Definitely.*

Wife: *That's what he's doing, making it easy for everyone in whatever ways he can . . . If he weren't of the strength and calmness that he has been, I'd be a lot worse off. Like I said, he's trying to make it easy on me.*

The interactional process was slightly different when the dyad was husband and wife versus parent and child. Well spouses tended to take a more active part in the process than children, and husbands in particular often responded to questions by voicing their thoughts, values, and beliefs regarding their own situation. This led to a dual focus on the spousal partners and sometimes a dual planning process. Children tended to engage in the process by maintaining the focus on the ill parent. While the children offered ideas and posed questions, these were about the parent and not themselves. Both well spouses and children were active in clarifying the perspective of the ill person, either by asking questions or offering a counterpoint that stimulated discussion and reflection. One of the explicit goals of the ill participants was to avoid burdening their family. The predominant goal for all was to avoid unnecessary suffering for the ill person, especially as the end of life approached. There was extensive discussion within all dyads about the importance of good pain management. An intimate relational process, with family at the centre, characterized not only the narrative phase of the intervention but also the decision-making phase, which is discussed below.

Decision-Making Around End-of-Life Preferences

The articulation of end-of-life preferences revolved around five explicit health-related scenarios that may realistically be faced by someone with advanced lung cancer. Discussion focused on the benefits and burdens of treatment; the probability of these benefits and burdens manifesting; and the patient's values, beliefs, and views regarding quality of life. While the intervention focused on burden for the patient, the participants often

shifted the focus to include the burden on the family:

Husband/patient: *And the burden you're putting on your family, too. I mean, I would not, with all sincerity, want my wife to come and spend hours in a hospital watching me with tubes going every which way. That's not quality of life for her and it's not quality of life for me.*

Again, family members were very active in the process. It was not a matter of quietly observing and listening to the patients think through their preferences. The process showed deep relational engagement. The following excerpt pertains to a scenario of permanent cognitive impairment and a good chance of survival:

Researcher: *So, not knowing who you are or whom you are with . . .*

Wife/patient: *Ah, forget it.*

Husband: *Yeah.*

Researcher: *So which would be your choice?*

Husband: *That would be number two — stop all efforts to prolong my life.*

Researcher [to wife/patient]: *That's what you're saying?*

Wife/patient: *Mm hmm. We are real clear on that.*

Husband: *Exactly.*

Note the wife's use of the word "we," which so beautifully captures the joint decision-making and, in effect, joint planning.

Sometimes, family members sought clarification of the patient's position, assisted in the negotiation of meaning, and influenced a shift in perspective, as can be seen in the following exchange. Here, the researcher is trying to determine what the patient would consider a poor chance of survival:

Researcher: *We were wondering [about] low chance of survival for you, what percentage would that be?*

Husband/patient: *Five percent.*

Wife: *I guess.*

Researcher: *Would that be in keeping with what you would define as low, or would another number be appropriate?*

Husband/patient: *I think we probably would raise that to a quarter [25] percent. I say 50 percent is probably too high, because if you have a 50/50 chance, well, then, I'd try to survive . . . but below 50 percent . . .*

Wife: *You think so, Dad? Oh, I wouldn't give up that soon.*

Husband/patient: *Well, I don't know . . .*

Wife: *Well, 50 percent seems pretty high to me; five percent sounds okay to me.*

Researcher: *So for you [wife], five percent would sound right for you, but what we are hearing [husband] say is that low for him would be—*

Husband/patient: *—about five percent . . . My brother, he had 6 months to live, but he lived for 2 years . . . He got longer [than we expected].*

It was not uncommon for patient preferences to shift after discussion and reflection.

In one family, the husband was dominant throughout the interview. The following excerpt pertains to the scenario of prolonged hospitalization with a poor chance of survival. One of the strongest themes for this family was the importance of hope:

Husband: *As long as there's hope.*

Wife/patient: *As long as there's hope, even [with] five percent there's still hope.*

Husband: *Okay, if you were going to have a prolonged hospital stay, that doesn't mean permanent hospital stay — so then there's hope for survival. If there's no hope . . . like, once hope is gone . . .*

Researcher: *Here, they're saying hope for survival is really low, less than five percent.*

Husband: *I'd have to say just let her go.*

Wife/patient: *Yes, I'd say that.*

In the second scenario, that of functional impairment, the need for 24-hour nursing care, and a good chance of survival, the patient was initially uncertain about her preference. The husband led the discussion and his wife soon arrived at her choice, which she was able to explain based on the case of someone who managed well with functional impairment:

Wife/patient: *I don't know.*

Husband: *Well, you know, okay, if you can't walk, you can't talk . . . I've known a lot of people who've spent a lot of years in a wheelchair, and . . . quality of life is still there for them.*

Researcher: *I guess what we're trying to determine is, is that acceptable to you [wife/patient]?*

Wife/patient: *I think so — like, there are other ways of communicating.*

Husband: *And there are other ways of being mobile.*

Wife/patient: *Yeah.*

Husband: *Yeah, because anything less [than complete paralysis] and you can train yourself to be able to function.*

Wife/patient: *Right. You see a lot of people out there with different impairments. We have one guy [here] that has had his leg off. He's young, and, you know, he can get around better than most people, on his one leg. He's a fighter.*

This woman chose to continue all treatment to prolong life unless the functional impairment was complete paralysis. Like this participant, many patients framed their preferences in light of experiences with others, usually family members or close friends, at end of life where treatment delayed death and prolonged suffering.

In terms of decision-making should one be unable to speak for oneself, most patients wanted their family member to use his or her judgement rather than strictly follow their stated preferences. Most were committed to involving additional family members, at a minimum by providing them with a copy of the statement of preferences or via ongoing conversations. One patient got part way through decision-making and stopped, as he wanted to work through his preferences with input from his adult children. Another patient agreed to stop the discussion of scenarios at the request of his wife, who was overwhelmed and worried that her emotions would not help either of them; they agreed that it was important to have the conversation but wanted to have it privately at a later time.

For those families who participated in a follow-up interview, none had involved their health professionals in ACP in any way, despite being asked to do so. It was clear that they viewed ACP as a family affair and felt safe knowing that their wishes were clearly understood by a trusted loved one who could speak on their behalf.

All participants evaluated the intervention as difficult but helpful:

Daughter: *Well, I have to say that that interview was really, really hard for me . . . it was really, really tough, but I feel, and I know you [mother] felt, that it opened a lot of doors that I couldn't hardly bring myself to talk to Mom about. It was in the back of my mind, thinking, well, we have to talk about this . . . should I do it now or should I wait until I see how the treatment is going?*

Mother/patient: *We've come closer . . . it opened the door for us.*

This family continued the conversation over time, and at follow-up the patient reported that "everything is in order" and her daughter stated, "We are prepared." Several participants noted that the conversation brought an enhanced sense of closeness.

One participant who, based on an experience with her mother, was determined not to accept life support, had completed a living will some years prior to the intervention. She and her daughter evaluated the PC-ACP this way:

Mother/patient: *I really thought that going to my lawyer made it pretty clear how I wanted things, but there were other things that I just didn't think about.*

Daughter: *It certainly clarified things for me, because the scenario is different. You're not really aware of all the symptoms that can happen and all the decisions you'll have to make. I think this really clarifies exactly how Mum feels on all of them . . . it will help.*

Follow-up with this family occurred after the mother's death and was the only evaluation of the influence of the intervention at end of life:

Daughter: *It sure helped us a lot, especially when she was in hospice and asleep, or unconscious or whatever you call it . . . There was no question. We all knew exactly what Mum wanted. We might have wanted to prolong it for ourselves, but we knew she had made her wishes so clear that there was no question about it . . . The specific examples [we talked about] made our job so much easier. The living will . . . wouldn't have been enough to help us.*

It is clear from the family perspective that ACP is an endeavour that is deeply embedded in intimate family relationships.

Discussion

The ACP process we observed, rather than being a process for preparing a substitute decision-maker to speak for oneself and direct health care at a time when one is incapacitated, is one where people come to a shared understanding of their own preferences in conversation with loved ones. Our findings are in alignment with those of others (Martin et al., 1999; Singer et al., 1998) who found that, from the patient perspective, the primary goals of ACP are psychosocial: avoiding prolongation of death, strengthening relationships, achieving a sense of control, minimizing burden, and managing pain. Most patients wanted their family members to use their own judgement when making end-of-life decisions, rather than strictly relying on their stated preferences for care (see also Collins et al., 2006; Puchalski et al., 2000). This finding calls into question the view that ACP is successful only when a family member's decisions mirror those of the patient. Like Gardner and Kramer's (2009) participants, the patients and family members in this study had slightly different concerns, the common thread being relational attention to the well-being of the other, aimed at reducing burden and suffering.

The emphasis on ACP as a vehicle for the expression of an individualistic notion of autonomy is not in keeping with how the process is lived. While there is broad agreement that autonomy is central to bioethics, there is also recognition that the concept has limitations in practice (Bergum & Dossetor, 2005; Christman, 2004; Mackenzie & Stoljar, 2000; Sherwin, 1998). A critique of autonomy is beyond the scope of this article; readers seeking a more fulsome discussion are

referred to feminist scholars who have developed a compelling argument that autonomy be re-conceptualized in relational terms (Mackenzie & Stoljar, 2000; Sherwin, 1998). The fundamental notion here is that humans are essentially social beings, embedded in and shaped by intimate relationships, which are characterized by interdependence, and that the development as well as the exercise of autonomy is not solely an individual enterprise (Ho, 2008; Mackenzie & Stoljar, 2000; Sherwin, 1998). Interdependence encompasses the idea that we are both dependent and independent, that what we do affects others and what they do affects us (Bergum & Dossetor, 2005). The patients who participated in this study were mindful not only that they needed the support of their family to have their preferences for care at end of life honoured, but also that their preferences had consequences for family. All of the participants were vulnerable, fragile, and at risk of isolation as they worried about how to engage in a meaningful way that would not “spoil the moments” left to them. When patients adhere to an individualistic approach to end-of-life decision-making that does not acknowledge dependence on family, their demands may override the needs of caregivers and leave them inadequately prepared (Sahlberg-Blom et al., 2000). Thus, an approach to ACP that rests on individualistic conceptions of autonomy with requirements for people to make decisions separate from family carries a high risk for increasing vulnerability for all, while compromising dignity and well-being (Ho, 2006; Sherwin, 1998). As Ho (2008) argues, against the backdrop of often impersonal, fragmented institutional health care “it seems that family involvement and patients’ relational identity are more important than ever in preserving or restoring patients’ autonomous agency” (p. 131). As the participants in this study demonstrated, autonomy is lived as a relational experience (Bergum & Dossetor, 2005).

This was a small study with a narrow focus. Nevertheless, the findings suggest the need for a shift in the ethical underpinnings of ACP. An approach to ACP that is informed by relational autonomy has the potential to serve patients and families well. This approach does not deny that autonomy resides in individuals, but it supports a process that “is both deeper and more complicated than the traditional conception acknowledges” (Sherwin, 1998, p. 44).

Implications for Practice and Research

Like the patients in the study by Singer and colleagues (1998), the participants in this study did not involve health professionals in ACP. What does this mean for our participation in the process? Current recommendations focus on the development of specialized facilitation skills (Atkins, 2006) and of supportive clinician-patient relationships (Entwistle, Carter,

Cribb, & McCaffery, 2010) to enhance autonomy. Practice recommendations often position the health professional as the “significant other” in the process. Based on the findings of this study, nurses can be helpful to families by viewing family broadly as those individuals who are important to the ill person, approaching ACP from a relational perspective, developing the skills necessary to facilitate family conversations, providing accurate information regarding likely health complications during illness progression, following the family’s lead with regard to pacing, and setting aside the notion that we are central characters in the relational process. Family is at the heart of ACP.

Research is needed to determine the most effective way to implement a relational autonomy approach to ACP and to evaluate whether the outcomes of such an approach support the psychosocial goals of families and the outcomes of “good” living and dying at end of life. Kolarik, Arnold, Fischer, and Tulsy (2002) point out that determining the effectiveness of ACP has proven difficult. They state that the main problem is lack of clear and comprehensive goals. I argue that the greatest barrier is an ethical foundation that orients us to goals that are not in alignment with the relational process.

References

- Atkins, K. (2006). Autonomy and autonomy competencies: A practical and relational approach. *Nursing Philosophy*, 7, 205–215.
- Bergum, V., & Dossetor, J. (2005). *Relational ethics: The full meaning of respect*. Hagerstown, MD: University Publishing Group.
- Breathnach, O. S., Freidlin, B., Conley, B., Green, M. R., Johnson, D. H., Dandara, D. R., et al. (2001). Twenty-two years of phase III trials for patients with advanced non-small-cell lung cancer: Sobering results. *Journal of Clinical Oncology*, 19(6), 1734–1742.
- Briggs, L. (2003). Shifting the focus of advance care planning: Using an in-depth interview to build and strengthen relationships. *Innovations in End-of-Life Care*, 5(2): www.edc.org/lastacts.
- Briggs, L., & Colvin, R. (2002). The nurse’s role in end-of-life decision-making for patients and families. *Geriatric Nursing*, 23, 302–310.
- Briggs, L. A., Kirchoff, K. T., Hammes, B. J., Song, M-K., & Colvin, E. R. (2004). Patient-centered advance care planning in special populations: A pilot study. *Journal of Professional Nursing*, 20, 47–58.
- Carstairs, S. (2000). *Quality end-of-life care: The right of every Canadian*. Subcommittee to Update “Of Life and Death” of the Standing Senate Committee on Social Affairs, Science and Technology. Final report. Retrieved April 17, 2011, from <http://www.parl.gc.ca/36/2/parlbus/commbus/senate/com-e/upda-e/rep-e/repfinjun00-e.htm>.

- Carstairs, S. (2005). *Still not there. Quality end-of-life care: A progress report*. Retrieved April 17, 2011, from <http://sen.parl.gc.ca/scarstairs/PalliativeCare/Still%20Not%20There%20June%202005.pdf>.
- Carstairs, S. (2010). *Raising the bar: A roadmap for the future of palliative care in Canada*. Ottawa: Senate of Canada. Retrieved April 17, 2011, from <http://www.sen.parl.gc.ca/scarstairs/PalliativeCare/Raising%20the%20Bar%20June%202010%20%282%29.pdf>.
- Christman, J. (2004). Relational autonomy, liberal individualism, and the social constitution of selves. *Philosophical Studies*, 117, 143–164.
- Clayton, J. M., Butow, P. N., Arnold, R. M., & Tattersall, M. H. (2005). Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer*, 103, 1965–1975.
- Collins, L. G., Parks, S. M., & Winter, L. (2006). The state of advance care planning: One decade after SUPPORT. *American Journal of Hospice Palliative Care*, 23, 378–384.
- Ditto, P. H., Danks, J. H., Smucker, W. D., Bookwala, J., Coppola, K. M., Dresser, R., et al. (2001). Advance directives as acts of communication. *Archives of Internal Medicine* 161(3), 421–430.
- Emanuel, L. L. (2008). Advance directives. *Annual Review of Medicine*, 59, 187–198.
- Entwistle, V. A., Carter, S. M., Cribb, A., & McCaffery, K. (2010). Supporting patient autonomy: The importance of clinician-patient relationships. *Journal of General Internal Medicine*, 25, 741–745.
- Ferris, F. D., Balfour, H. M., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., et al. (2002). A model to guide hospice palliative care. Ottawa: Canadian Hospice Palliative Care Association.
- Gardner, D. S., & Kramer, B. J. (2009). End-of-life concerns and care preferences: Congruence among terminally ill elders and their family caregivers. *OMEGA*, 60, 273–297.
- Glaser, B. G., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine.
- Haley, W. E., Allen, R. S., Reynolds, S., Chen, H., Burton, A., & Gallagher-Thompson, D. (2002). Family issues in end-of-life decision making and end-of-life care. *American Behavioural Scientist*, 46, 284–298.
- Hammes, B. J. (2003). Update on *Respecting Choices* four years on. *Innovation in End-of-Life Care*, 5(2): www.edc.org/lastacts.
- Hammes, B., & Romer, A. L. (1999). The lessons from *Respecting your choices*: An interview with Bernard Hammes. *Innovations in End-of-Life Care*, 1(1): www2.edc.org/lastacts/archives/archivesJan99/featureinn.asp.
- Hickman, S. E., Hammes, B. J., Moss, A. H., & Tolle, S. W. (2005). Hope for the future: Achieving the original intent of advance directives. *Hastings Center Report*, 35(6), S26–S30.
- Ho, A. (2006). Family and informed consent in multicultural settings. *American Journal of Bioethics*, 6, 26–28.
- Ho, A. (2008). Relational autonomy or undue pressure? Family's role in medical decision-making. *Scandinavian Journal of Caring Sciences*, 22(1), 128–135.

- Ipsos-Reid. (2004). *Hospice palliative care study: Final report*. Ottawa: Canadian Hospice Palliative Care Association and GlaxoSmith Kline Foundation.
- Kaldjian, L. C., Curtis, A. E., Shinkunas, L. A., & Cannon, K. T. (2009). Goals of care toward the end of life: A structured literature review. *American Journal of Hospice and Palliative Medicine*, 25, 501–511.
- Kass-Bartelmes, B., & Hughes, R. (2003). Advance care planning: Preferences for care at the end of life. *Research in Action*, #12. AHRQ #03-0018. Rockville, MD: Agency for Healthcare Research and Quality.
- Kolarik, R. C., Arnold, R. M., Fischer, G. S., & Tulskey, J. A. (2002). Objectives for advance care planning. *Journal of Palliative Medicine*, 5, 697–704.
- Lorenz, K. A., Lynn, J., Dy, S. M., Shugarman, L. R., Wilkinson, A., Mularski, R. A., et al. (2008). Evidence for improving care at the end of life: A systematic review. *Annals of Internal Medicine*, 148, 147–159.
- Mackenzie, C., & Stoljar, N. (2000). Introduction: Autonomy refigured. In C. Mackenzie & N. Stoljar, *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self* (pp. 3–33). New York: Oxford University Press.
- Martin, D. K., Thiel, E. C., & Singer, P. A. (1999). A new model of advance care planning: Observations from people with HIV. *Archives of Internal Medicine*, 159, 86–92.
- Prendergast, T. J. (2001). Advance care planning: Pitfalls, progress, promise. *Critical Care Medicine*, 29, N34–N39.
- Puchalski, C. M., Zhong, Z., Jacobs, M. M., Fox, E., Lynn, J., Harrold, J., et al. (2000). Patients who want their family and physicians to make resuscitation decisions for them: Observations from SUPPORT and HELP. *Journal of the American Geriatrics Society*, 48, S84–S90.
- Romer, A. L., & Hammes, B. J. (2003). Communication, trust, and making choices: Advance care planning four years on. *Innovations in End-of-Life Care*, 5(2): www.edc.org/lastacts.
- Sahlberg-Blom, E., Ternstedt, B.-M., & Johansson, J.-E. (2000). Patient participation in decision making at the end of life as seen by a close relative. *Nursing Ethics*, 7, 296–313.
- Sakalys, J. A. (2003). Restoring the patient's voice: The therapeutics of illness narratives. *Journal of Holistic Nursing*, 21(3), 228–241.
- Schwartz, C., Lennes, I., Hammes, B., Lapham, C., Bottner, W., & Ma, Y. (2003). Honing an advance care planning intervention using qualitative analysis: The Living Well interview. *Journal of Palliative Medicine*, 6, 593–603.
- Shalowitz, D. I., Garrett-Mayer, E., & Wendler, D. (2006). The accuracy of surrogate decision makers. *Archives of Internal Medicine*, 166, 493–497.
- Sherwin, S. (1998). A relational approach to autonomy in health care. In S. Sherwin, *The politics of women's health: Exploring agency and autonomy* (pp. 19–47). Philadelphia: Temple University Press.
- Singer, P. A., Martin, D. K., Lavery, J. V., Thiel, E. C., Kelner, M., & Mendelsohn, D. C. (1998). Reconceptualizing advance care planning from the patient's perspective. *Archives of Internal Medicine*, 158, 879–884.

- Solomon, M. Z. (1999). Why are advance directives a non-issue outside the United States? *Innovations in End-of-Life Care*, 1(1): www.edc.org/lastacts.
- Stewart, M. A. (1995). Effective physician-patient communication and health outcomes: A review. *Canadian Medical Association Journal*, 152(9), 1423-1433.
- The SUPPORT Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *Journal of the American Medical Association*, 274, 1591-1598.
- Tilden, V. P., Tolle, S. W., Garland, M. J., & Nelson, C. A. (1995). Decisions about life-sustaining treatment: Impact of physicians' behaviors on the family. *Archives of Internal Medicine*, 155(6), 633-638.
- Tilden, V. P., Tolle, S. W., Nelson, C. A., & Fields, J. (2001). Family decision-making to withdraw life-sustaining treatment from hospitalized patients. *Nursing Research*, 50(2), 105-115.
- Tilden, V. P., Tolle, S. W., Nelson, C. A., Thompson, M., & Eggman, S. C. (1999). Family decision-making in foregoing life-extending treatments. *Journal of Family Nursing*, 5(4), 426-442.
- Tulsky, J. A., Fischer, G. S., Rose M. R., & Arnold, R. M. (1998). Opening the black box: How do physicians communicate about advance directives? *Annals of Internal Medicine*, 129, 441-449.

Acknowledgements

This project was funded by the British Columbia Medical Services Foundation and the Canadian Nurses Foundation Nursing Care Partnership Program, grant #BCM04-0018.

I would like to thank Bill Nelems, MD, Michael Humer, MD, Terri-Lynn Kent, MSW, and Kamilla Bahbahani, PhD, for their assistance with the study. The study was also supported by Linda Briggs of the Respecting Choices advance care planning program in LaCrosse, Wisconsin.

Financial disclosure: none.

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Le programme de pratique infirmière en régions éloignées : la pratique infirmière et le personnel infirmier praticien considérés sous l'angle de la justice sociale

Denise S. Tarlier, Annette J. Browne

Le programme de pratique infirmière agréée en régions éloignées [Remote Nursing Certified Practice (RNCP)] a été créé en 2010 dans le but de réglementer la pratique infirmière dans les collectivités éloignées de la Colombie-Britannique, au Canada, qui sont formées en grande partie de Premières nations. Ces collectivités vivent souvent des inégalités en matière de santé et de soins de santé. Les infirmières et les infirmiers sont généralement les principaux fournisseurs de soins de santé de ces collectivités. À l'aide d'une grille d'analyse critique se fondant sur la justice sociale, les auteures explorent les répercussions cliniques et éthiques de la RNCP sous l'angle de l'accès à des soins de santé primaires équitables et de haute qualité. Elles examinent la correspondance entre le niveau et l'étendue des services de santé fournis par le personnel infirmier autorisé qui travaille conformément à la RNCP et les besoins de santé des collectivités des Premières nations en région éloignée. Ce faisant, elles font des comparaisons d'une part entre les infirmières praticiennes et les infirmiers praticiens (IP) et d'autre part les infirmières et les infirmiers en régions éloignées jouant le rôle d'IP qui ont été employés historiquement pour fournir des soins de santé dans ces collectivités. Les auteures concluent en demandant qu'une réglementation de la pratique infirmière soit adoptée afin de soutenir la prestation de soins primaires équitables de grande qualité à toute la population de la Colombie-Britannique.

Remote Nursing Certified Practice: Viewing Nursing and Nurse Practitioner Practice Through a Social Justice Lens

Denise S. Tarlier, Annette J. Browne

Remote Nursing Certified Practice (RNCP) was introduced in 2010 to regulate nursing practice in remote, largely First Nations communities in British Columbia, Canada. These are communities that often experience profound health and health-care inequities. Typically nurses are the main health-care providers. Using a critical social justice lens, the authors explore the clinical and ethical implications of RNCP in terms of access to equitable, high-quality primary health care. They examine the fit between the level and scope of health services provided by registered nurses working under RNCP and the health needs of remote First Nations communities. In doing so, they draw comparisons between nurse practitioners (NPs) and outpost nurses working in NP roles who historically were employed to provide health care in these communities. The authors conclude by calling for nursing regulations that support equitable, high-quality primary care for all British Columbians.

Keywords: Aboriginal health, health disparities, nursing roles, primary health care, rural and remote health care, vulnerable populations

In 2010 a new category of registered nurse (RN) regulation was implemented in the province of British Columbia, Canada, created specifically to regulate the practice of RNs employed in remote communities: Remote Nursing Certified Practice (RNCP). As of March 31, 2010, nurses employed in remote First Nations communities in British Columbia are required to be RNCP-certified. The RNCP initiative was preceded by the implementation of the nurse practitioner (NP) role in British Columbia following legislative and regulatory changes made in 2005.

As formal recognition of the NP role has been rolled out in recent years through legislation and regulation in jurisdictions across the country (Canadian Institute of Health Information, 2010), most jurisdictions have recognized the need to ensure that the residents of remote communities continue to have access to nurses who have advanced¹ and

¹ *Advanced nursing practice* is defined by the College of Registered Nurses of British Columbia (CRNBC; 2011a) as “an umbrella term to describe an advanced level of

expanded scopes of practice and who are well prepared to provide high-quality primary care² within primary health care (PHC) settings.³ Such nurses are now identified and regulated as NPs in all Canadian provinces and territories. The educational preparation; knowledge, skills and competencies; and scope of practice are much broader for NPs in all jurisdictions than for RNs working under RNCP in British Columbia. However, few NPs are employed in British Columbia's remote First Nations communities. These positions are instead filled by RNs with RNCP designation.

It seems paradoxical that, now that highly qualified NPs are formally recognized and licensed to practise in British Columbia as primary care providers, RNCP has been implemented as a new regulatory model that, we argue, may in fact obfuscate the need for nurses in remote settings to have NP-level competencies and scope of practice — thereby perpetuating the inequities in access to high-quality primary care historically experienced by First Nations people in remote communities. We wish to be clear that we support the principle of ensuring that nurses providing health services in remote communities are adequately educated and prepared to deliver high-quality primary care while concurrently working in a community health role. We appreciate the critical importance of ensuring that standards for nursing competencies are met. We are not critiquing the quality of nursing care or the competency of nurses working in RNCP, nor are we dismissing RNCP as unimportant. However, in the context of remote First Nations communities in British Columbia, and using the lens of critical social justice, we believe that the scope of

registered nursing practice that maximizes the use of in-depth nursing knowledge and skills in meeting the health needs of clients (individuals, families, groups, populations, or entire communities). In this way, advanced nursing practice extends the boundaries of registered nursing's scope of practice and contributes to nursing knowledge and the development and advancement of the profession."

² *Primary care* is defined by the CRNBC (2011a) as "the first point of contact with a health care provider for diagnosis, treatment and follow-up for a specific health concern."

Primary care providers are defined as "health professionals who take primary responsibility for an established group of patients for whom they provide: longitudinal person-focused care; comprehensive care for most health needs; first contact assessment for new health care needs; and referral and coordination of care when it must be sought elsewhere. A primary care provider is ideally chosen by an individual to serve as his or her health care professional to address a wide variety of health issues including health promotion, illness and injury prevention, and the diagnosis and treatment of illness and injury."

³ *Primary health care* is defined by the CRNBC (2011a) as "essential health care (promotive, preventive, curative, rehabilitative, and supportive) that focuses on preventing illness and promoting health with optimal individual and community involvement. It is both a philosophy and an approach that provides a framework for health care delivery systems. The five principles of PHC are accessibility, public participation, health promotion, appropriate technology and intersectoral collaboration."

RNCP is inadequate to support safe, equity-oriented primary care. It is therefore timely to take a critical look at what we see as the implications of RNs working under RNCP.

This article is intended to contribute to a dialogue on the implications of implementing the recently established RNCP for RNs working in remote First Nations communities in British Columbia. In forming our analysis we draw on philosophical and ethical perspectives grounded in notions of critical social justice. The concept of critical social justice offers a useful lens through which to examine the policy, practice, and power dynamics that lie behind inequities in the access of First Nations people to health and health care (Anderson et al., 2009; Browne & Tarlier, 2008; Reimer Kirkham & Browne, 2006). Although discourses of social justice have become commonplace in the nursing and health-services literature, critical analyses of how nurses' roles and scope of practice articulate with social justice issues have received little attention (Browne & Tarlier, 2008). Critical interpretations of social justice shift the analysis beyond distributive paradigms of justice to issues of equity versus equality in health-care access, access to health care as a human right, the role of neoliberal policies in health-care planning and policy decisions, and the social and political contexts that shape health and health-care inequities (Browne & Tarlier, 2008; Reimer Kirkham & Browne, 2006). With epistemological roots in critical, feminist, and postcolonial theoretical perspectives, a critical social justice lens facilitates the development of contextual knowledge, which is "crucial to fostering the planning of socially just and equitable healthcare across different population groups" (Anderson et al., 2009, p. 287). A critical social justice lens in relation to nursing and NP roles raises morally significant questions (Sherwin, 2002) such as the following: Why do health and health-care inequities persist for certain groups or populations such as Aboriginal peoples? What is the role of nursing in responding to persistent inequities? What health-care planning and policy decisions will be useful in addressing such inequities? The concept of critical social justice thus provides an ethical lens through which to consider inequities in the resources needed for health, as well as inequities in decisions affecting health-care access. In this article, we apply this lens to consider the implications of introducing new regulations regarding RN practice in remote First Nations communities in Canada.

Our purpose in writing this article is to examine the fit between the level and scope of health services provided by NPs compared to RNs working under RNCP and the health needs of remote First Nations communities in British Columbia. We specifically focus our arguments on RNCP in the context of remote First Nations communities, recognizing that other certified practices such as Reproductive Health and

RN First Call may be well suited to a variety of other practice contexts. Our arguments are presented with a view to opening up a dialogue around an initiative that has both practical and ethical implications for equitable health-care delivery and therefore the health of First Nations people residing in remote BC communities.

The Context of Nursing Practice in Remote First Nations Communities

Renewal of and investment in PHC continue to be identified as key pathways to achieving health equity, particularly for populations experiencing health inequities (Starfield, 2006; World Health Organization [WHO], 2008a, 2008b). In Canada, nurses have been providing high-quality PHC and filling a gap in health-care access in remote First Nations and Inuit communities for decades. The role of nurses working and living in indigenous communities has particular significance, given the long history of health and health-care inequities that continue to affect indigenous peoples in Canada and globally (Adelson, 2005; Reading, Marsden, Kurbanova, & Link, 2009). These inequities have their roots in colonial policies and practices, systemic racism and discrimination, and limited access to the resources needed for health: income, employment, self-determination, education, adequate housing, and, notably, health care (Bourassa, McKay-McNabb, & Hampton, 2004; Kubik, Bourassa, & Hampton, 2009; WHO, 2008a). Moreover, inequities in access to needed health services and resources persist and continue to challenge the health of many indigenous people in Canada (Adelson, 2005; Health Council of Canada, 2008; Luo et al., 2010). First Nations and Inuit residents in remote, isolated, and northern communities are often further marginalized in terms of access to health resources and providers, and their health outcomes are still often among the poorest in Canada. For example, a recent study of birth outcomes and infant mortality in rural and remote populations in Manitoba found that First Nations populations in that province still experience a relative risk of infant mortality (one of the most sensitive indicators of population health) almost twice that of non-First Nations populations (Luo et al., 2010). This finding echoes the results of a similar study conducted in British Columbia several years ago (Luo et al., 2004) and confirmed in 2009 (British Columbia Provincial Health Officer [BCPHO], 2009).

These historical and current social and political realities form the backdrop against which nurses have traditionally worked to provide PHC services in many First Nations communities. Nurses working in remote communities across Canada have traditionally been referred to as “outpost” nurses. This outpost nursing role has, in the Canadian context

and prior to the recent formalization and regulation of NP roles in Canada, historically been identified as that of an NP. For example, in a 2009 position statement on NPs, the Canadian Nurses Association (CNA) acknowledged the outpost nursing roots of contemporary Canadian NPs:

The origin of the NP role in Canada lies in the work of nurses who, decades ago, provided care that was otherwise unavailable in rural and remote areas. The first education program for NPs was developed to prepare nurses to work in nursing stations in remote areas of northern Canada. Nurses working in these northern communities were pioneers, and their work was integral to the evolution of the NP role as NPs began to be employed in other parts of the healthcare system. (CNA, 2009)

Thus, even going back several decades, outpost nurses were identified as NPs. When possible (given the shortage of NP education programs at the time) such nurses were prepared as NPs, to fulfil a role that was viewed as that of an NP.

Filling a Gap in Health-Service Access: Early NP Roles in Northern and Remote Canada

Traditionally, nurses working in an expanded nursing role have provided PHC, including primary care services, in northern and remote First Nations and Inuit communities. In these communities access to physician services has been, and continues to be, typically on an intermittent “visiting” doctor basis, with the bulk of ongoing primary care provided by nurses who reside in the community.⁴ Thus, nurses employed in the outpost nursing role filled a critical gap in access to needed health services by functioning in an expanded scope of practice that demanded competency in primary care as well as public health and urgent/emergent acute care (Tarlier, Johnson, & Whyte, 2003). Moreover, the everyday contexts of nursing practice in remote First Nations communities impelled experienced outpost nurses to integrate broader PHC perspectives into their practice, to better address the social determinants that influenced health in the communities in which they lived and worked (Brumwell & Janes, 1994; Doucette, 1989; Tarlier et al., 2003). In these

⁴ Notably, most of the few positions that do exist for NPs to work with remote First Nations communities in British Columbia appear to be following this “visiting” doctor model, wherein the NP visits communities, while RNCP RNs live in the community and attend to the day-to-day health needs in the community. This in itself may have significant implications for the ability of the NP to build the trusting, reciprocal relationships with community residents that are integral to both client-centred and community-centred care (Tarlier et al., 2003; Vukic & Keddy, 2002). However, a full discussion of these implications is beyond the scope of this article.

ways, outpost nurses operated from a social justice stance in relation to working with communities to address community-defined priorities (Brumwell & Janes, 1994; Tarlier et al., 2003). For example, nurses worked with community members to advocate for local stores to carry nutritious foods, worked closely with Community Health Representatives on health promotion and prevention activities that were contextualized to the needs of the community, and advocated for families to have access to adequate housing and clean water.

Tarlier et al. (2003) found that experienced outpost nurses shared the domains and competencies of NP practice identified by Brykczynski (1989) in her influential study of NP practice competencies, which built on Benner's (1984) foundational work describing the domains and competencies of nursing practice. For example, the experienced outpost nurses who participated in Tarlier et al.'s (2003) study described competencies comparable to the domain of NP practice competencies, Management of Patient Health/Illness in Ambulatory Care Settings, identified by Brykczynski (Tarlier, 2001). As Tarlier et al. (2003) note, the findings of this study suggest "that outpost nurses share domains and competencies of practice with NPs, as identified by Brykczynski, a finding that may have relevance for the development of the NP role in Canada" (p. 183). However, in the same study Tarlier (2001) identified a domain of outpost nursing practice that did not appear in Brykczynski's NP framework. The new domain was described as "caring for the community" and included the following competencies: building and maintaining responsive relationships with communities; partnering with the community (collaborating, facilitating, negotiating; facilitating community action); and working over the long term (Tarlier, 2001, p. 104). These competencies were described by study participants as integral to the PHC orientation that evolved through experience in the outpost nursing role (Tarlier et al., 2003).

Ideally, nurses had the benefit of intensive, high-quality post-basic education beyond their basic nursing programs, to prepare them for the requirements of this complex, challenging nursing role. While not every nurse employed in an outpost setting received additional education, many of those who did were educated in the available NP programs of the time. These included the program offered at Dalhousie University, which opened in 1967 (Nurse Practitioner Association of Ontario, 2010), and the several universities (including McGill and the Universities of Alberta and Toronto) that offered the Clinical Training of Nurses Program from 1972 until the early 1980s (University of Alberta Faculty of Nursing and Faculty of Medicine, 1980). For example, the program offered at the University of Alberta in the early 1980s was officially named the Nurse Practitioner Program. Thus, historically, and up until very recent times

and the advent of formal regulatory mechanisms, the Canadian outpost nursing role was widely recognized in Canada as an NP role (CNA, 2009; De Witt & Ploeg, 2005).

Lacking the legislation required to enable regulation and autonomous practice, outpost nurses functioning in these early NP roles formally practised under medical delegation and by protocol. In reality, isolation and remoteness imposed a high level of autonomy and independent decision-making, which nurses often were initially unprepared for in taking up the role but became comfortable with as they developed the competencies required for primary care practice (Tarlier et al., 2003; Vukic & Keddy, 2002). A consulting physician, for example, might be located several hundred kilometres away and have little familiarity with the local community context. This meant that the nurse was de facto responsible for interpreting and modifying medical advice to ensure that it was implemented in a locally acceptable and appropriate manner. Additionally, even today, in the age of satellite-based telecommunication, communication is notoriously unreliable in some remote communities, as is transportation in and out of many communities (Tarlier, Browne, & Johnson, 2007), thus imposing a high level of independence in practice. In other words, those employed in the traditional outpost nursing role functioned in an autonomous role that demanded independent clinical decision-making, knowledge on how to influence the social determinants of health in local contexts, and knowledge of how to work with communities in ways that conveyed respect for cultural protocols (Tarlier et al., 2003; Vukic & Keddy, 2002). This practice was consistent with what we now recognize as NP-level competencies. Moreover, the isolated nature of practice in remote communities has not changed significantly and continues to demand practitioners who are well prepared to engage in independent practice and clinical decision-making and who are committed to fostering equity by providing primary care that is consistent with the principles of PHC, as NPs are prepared to do (Browne & Tarlier, 2008).

An Overview of Contemporary NP Roles in Canada

Alberta was the first province to pass legislation recognizing NP roles, in 1996, and Yukon was the last jurisdiction, in December 2009 (Canadian Institute for Health Information, 2010; Yukon Registered Nurses Association, 2009). While it has taken 15 years, NP roles are now recognized and legitimized through legislation in all provinces and territories. Although the requisite level of educational preparation and licensing for NPs continues to vary across the provinces and territories, there is a commitment on the part of most jurisdictions to move towards consistency at the pan-Canadian level (Canadian Nurse Practitioner Initiative,

2006). For example, while there is now a commitment to recognize master's-level nursing education as the standard for advanced practice, including NP practice (CNA, 2008), many jurisdictions formalized the NP role back when post-BSN preparation was the standard expectation for NPs in community-based roles. This discrepancy across jurisdictions may reflect the evolutionary nature of nursing education in general — not unlike the inconsistency experienced as jurisdictions moved towards the BSN as the standard for entry to practice.

In British Columbia, legislative changes in 2005 opened the door to NP regulation and practice. Nurses seeking NP licensing in the province are required to be master's-prepared. The College of Registered Nurses of British Columbia (CRNBC) introduced a rigorous licensing process for master's-prepared NPs that includes an Objective Structured Clinical Examination as well as a written examination (CRNBC, 2011b).

Currently there are approximately two hundred NPs licensed to practise in British Columbia (CRNBC, 2011f). A significant number of NPs registered in the province remain unemployed or underemployed in NP roles, largely due to a lack of provincial funding to create new NP positions through the six health authorities (Watts, 2010). The province lacks alternative reimbursement mechanisms for NPs, meaning that there are few options for employment outside of the funded health authority positions (Watts, 2010). In British Columbia, in contrast to regions such as Manitoba, First Nations, Inuit and Aboriginal Health (the federal government department that is the largest employer of health providers in remote First Nations and Inuit communities) has not developed NP positions independent of the health authorities. Thus, most licensed NPs in British Columbia practise in urban or suburban settings, while the bulk of health care in remote First Nations communities continues to be provided by RNs functioning in an NP-like role, now regulated under the RNCP. Notably, British Columbia is the only jurisdiction in Canada to have implemented this new regulatory model.

British Columbia: Remote Nursing Certified Practice

RNCP is one of three certified practices developed by CRNBC in response to the 2001 recommendation of the Health Professions Council of British Columbia (2001) that “legislative or regulatory mechanisms be established to enable [CRNBC] to develop a formal regulatory system” for advanced practice and primary care nursing. Reproductive Health and RN First Call⁵ are the two other areas of certified practice. The rec-

⁵ RN First Call is defined by the CRNBC (2011a) as “nursing practice that occurs in small acute care hospitals, diagnostic and treatment centres and other settings where there is physician service available in the community.”

ommendation arose from the Council's concern regarding inconsistency in the education of RNs for advanced practice and primary care roles. One outcome of the recommendation was the creation of a new class of CRNBC registrant: RN certified practice. Certified practice provides a regulatory mechanism for RNs to carry out a certain number of the restricted activities that are included in the NP scope of practice but are not within the RN scope of practice (CRNBC, 2011e). While all three certified practice areas require nurses to undertake some additional training and to rely on Decision Support Tools (DSTs) to guide their clinical decision-making, RNCP is significantly broader in scope, and in fact encompasses both the Reproductive Health and RN First Call certified practices (CRNBC, 2010b). CRNBC began the process of certifying RNs for RNCP in late 2009, with a mandate to ensure that all nurses practising in an expanded role in remote communities (which in British Columbia comprise mostly First Nations communities) be certified by March 31, 2010. There are currently about one hundred RNs certified in RNCP.

In response to the recommendation of the Health Professions Council of British Columbia (2001), in 2005 the CRNBC also developed and implemented the regulatory process to approve NP licensure, education, and educational programs. Thus, in British Columbia there now exist two standards of educational preparation and two different regulatory models to regulate nurses functioning in what we assert are substantively similar scopes of practice: NPs, and RNs in remote First Nations communities working under RNCP. No other province or territory in Canada has so far seen a need to follow British Columbia in implementing a certified practice model of regulation for nurses practising in remote areas. Rather, other jurisdictions actively recruit NPs to work in remote First Nations communities (e.g., Health Canada, 2010).

The Health Professions Council of British Columbia (2001) mandated a formalized process for regulating nurses in advanced practice and primary care nursing roles. However, it is not clear why, in British Columbia, this nursing role has been conceptualized as two distinct roles requiring different levels of preparation and different regulatory processes. In other jurisdictions the advanced practice primary care nursing role is conceptualized as a single role — that is, the NP role. Implicit among the questions we pose in this article are the following two: Why is British Columbia the only jurisdiction to have implemented the certified practice model? What are the assumptions underlying this initiative?

A comparison of the CRNBC RNCP (CRNBC, 2009) and NP competency (CRNBC, 2010a) statements suggests that both NPs and RNCP RNs assess, diagnose, interpret laboratory data, implement treatment, and make decisions about drug therapy (see Table 1). Thus, the two

Table 1 Comparison of RNCP and NP Competencies and Level of Accountability in Practice

RNCP Competencies	NP Competencies
<ul style="list-style-type: none"> • Assessment • Diagnosis • Interpreting laboratory reports • Treatment • Administering and dispensing drugs (CRNBC, 2009) 	<ul style="list-style-type: none"> • Assessment • Diagnosis • Interpreting laboratory reports • Treatment • Prescribing drugs (CRNBC, 2010a, 2011d)
<ul style="list-style-type: none"> • “Certified practices are carried out independently and the registered nurse is solely accountable for the diagnosis and treatment of the client. Certification allows registered nurses to: <ul style="list-style-type: none"> – Diagnose some diseases and disorders (as set out in decision support tools) – Carry out some restricted activities independently (as set out in decision support tools) that would otherwise require an order (e.g., administering, compounding or dispensing Schedule I medications)” (CRNBC, 2011c) 	<ul style="list-style-type: none"> • “Nurse practitioners diagnose and manage diseases, disorders and conditions within the limits of the nurse practitioner’s legislated scope of practice, individual competence within that scope of practice, and the stream in which the nurse practitioner is registered to practice (family, adult or pediatric).” (CRNBC, 2011d, p. 13) • “Nurse practitioners are solely accountable for their prescribing decisions.” (CRNBC, 2011d, p. 20) • “Nurse practitioner practice is grounded in the five World Health Organization principles of primary health care: accessibility, public participation, health promotion, appropriate technology and intersectoral collaboration.” (CRNBC, 2010a, p. 7) <p>Advanced Practice Competencies (CNA, 2008)</p> <p>An advanced practice nurse integrates extensive clinical experience with theory, research, and in-depth nursing and related knowledge to:</p> <ul style="list-style-type: none"> • develop multiple advanced assessment and intervention strategies within a client-centred framework for individual clients, communities, and populations

	<p><i>An advanced practice nurse demonstrates leadership by:</i></p> <ul style="list-style-type: none">• advocating for individuals, families, groups, and communities in relation to treatment, the health-care system, and policy decisions that affect health and quality of life• advocating for and promoting the importance of health-care access and advanced nursing practice to nurses and other health professionals, the public, legislators, and policy-makers• contributing to and advocating for an organizational culture that supports professional growth, continuous learning, and collaborative practice• evaluating programs in the organization and the community and developing innovative approaches to complex issues• understanding and integrating the principles of resource allocation and cost-effectiveness in organizational and system-level decision-making• identifying gaps in the health-care system and developing partnerships to facilitate and manage change• developing and clearly articulating a vision for nursing practice, influencing and contributing to the organization's and the health-care system's vision and implementing approaches to realize that vision• advising clients, colleagues, the community, health-care institutions, and policy-makers on issues related to nursing, health, and health care• identifying problems and initiating change to address challenges at the individual, organizational, or system level• understanding legislative and sociopolitical issues that influence health policy and building strategies to improve health, health-care access, and healthy public policy
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roles require the same basic primary care competencies — and, by extrapolation, individuals presumably would need the same level of education and clinical experience to engage in such competencies. Moreover, both NPs and RNCP RNs carry out these competencies independently and with sole accountability for their practice, as shown in Table 1 (CRNBC, 2010a, 2011c). NPs licensed in British Columbia base their practice on an extensive theory and knowledge base (i.e., one that supports clinical competencies in primary care) developed through substantive additional graduate education (i.e., usually a master's degree in nursing in an NP program). Similar to physicians, NPs utilize clinical practice guidelines and “best evidence” to inform clinical judgement and decision-making. In addition, as part of the NP graduate education, NPs are prepared at an advanced level (i.e., beyond the baccalaureate level) to engage critically with literature, be exposed to ideas related to cultural safety and the philosophy of PHC, and practise with an awareness of how profoundly the social determinants of health affect health and health-care inequities. In contrast, the RCNP educational preparation is one six-credit course taken over 18 weeks (University of Northern British Columbia, 2010). RNCP RNs follow DSTs that have been developed by CRNBC to direct their practice (CRNBC, 2010b). NP practice is significantly broader in scope than RNCP, and, as we argue, a broad scope of practice is fundamental to the provision of safe, effective — and in other words, ethically defensible — community-based primary care.

To illustrate the breadth of primary care that is required of providers in remote First Nations settings, we draw on the example of respiratory system diagnoses. Within the respiratory system, NPs may independently diagnose and manage a wide spectrum of common diseases, as supported by their broad knowledge base as well as personal competency (CRNBC, 2011d). In comparison, under RNCP a RN may (relying on the DSTs) diagnose only one condition of the respiratory tract: acute bronchitis (CRNBC, 2011c). Yet the reality is that there is a high prevalence of respiratory ill health in many remote First Nations communities (BCPHO, 2009; Reading, 2009) — in large part due to the inadequate housing and crowded living conditions in some on-reserve communities (Adelson, 2005; BCPHO, 2009). This raises the question of how a narrow scope of RNCP would allow nurses, as the main primary care providers in a community, to adequately address the wide range of respiratory conditions they are likely to encounter in their practice. Similarly, none of the DSTs for RNCP addresses the prenatal or postpartum primary care of women or infants, yet recent research suggests that this continues to be a critical area of health inequity in First Nations populations (Adelson, 2005; BCPHO, 2009; Reading, 2009; Tarlier et al., 2007). Maternal and infant health is, again, largely influenced by social inequities such as poverty, lack

of access to adequate nutrition, and inadequate housing. Thus, this is a clinical practice area that demands access to well-qualified primary care providers who can offer essential prenatal, postpartum, and infant primary care, as well as respond to the complex health and social needs in these communities.

The CRNBC (2011c) states that DSTs “provide direction for registered nurses who have been certified by CRNBC to carry out specific certified practices. They assist these registered nurses in making clinical decisions, but are not a substitute for clinical judgment.” Similarly, NPs rely on clinical judgement to implement practice guidelines appropriately and safely. Thus, “clinical judgement” is key to the safe enactment of both the NP and the RNCP role.

We would argue that a comprehensive, substantive knowledge base is prerequisite to sound clinical judgement — and this, in fact, was recognized throughout the process of developing the competencies and scope of practice for NPs in British Columbia. We appreciate that CRNBC’s goal in limiting the scope of practice and requiring RNCP RNs to adhere to DSTs is to ensure safe practice, in keeping with the College’s mandate to protect the public. However, Vukic and Keddy (2002), in their study exploring outpost nursing practice in northern Canada, suggested that a substantive knowledge base is a prerequisite for practitioners to implement practice guidelines safely and effectively:

These guidelines can be significantly problematic as the assumption, when referring to these guidelines, is that the nurse has identified the appropriate “medical” diagnosis when treating patients. These guidelines can be the major source for prescribed practice if nurses are not adequately prepared. (p. 546)

Thus, while safe, equity-oriented practice is unequivocally paramount, we suggest that enabling nurses to practise as primary care providers within a strictly delimited scope of practice and by protocol, without ensuring that they have the requisite knowledge base to support broad-based, socially and culturally relevant primary care practice, is not a model that promotes safe practice. Considering that the recipients of care delivered by nurses working under RNCP are largely First Nations people living in rural or remote communities, we also ask whether the RNCP model represents high-quality, equitable, and socially just primary care.

Implications: Certified Practices

Recognizing that the stated goal of RNCP is to ensure public safety through regulation, the implementation of certified practices for RNs practising in a broad primary care role in remote First Nations commu-

nities has created a situation of two different standards of preparation and licensure for nurses practising in substantively similar roles:

1. NPs working with primarily non-First Nations people in urban and suburban settings
2. RNs working under RNCP in remote First Nations communities

While we have concerns, as described above, about the fit between the level and scope of primary care offered by RNs working under RNCP and the primary care health needs of people living in rural and remote First Nations communities, RNCP raises several additional ethical questions from a critical social justice perspective.

What are the implications of providing primary care through the mechanisms of RNCP to populations whose health is influenced by systemic inequities? At a community and population health level, the complexity of health issues in many remote First Nations communities demands nurses who are equipped not only to provide comprehensive primary care services but also to engage in the full range of advanced nursing practice — as are NPs — to work with communities in ways that both take into account and address the root causes of poor health, and thereby begin to shift the picture of health in remote communities. Disparities in access to the social determinants of health, such as adequate housing, secure supplies of safe food and water, education, and employment, are now universally recognized as the “causes of the causes” of poor health, in First Nations as well as indigenous populations globally (Reading, 2010). Nurses working in First Nations communities must practise in ways that take into account the social, political, and historical contexts of health — and must find ways of fostering greater equity in the provision of primary care while fulfilling the broader ideals of PHC.

Inadequate access to the resources needed for health not only directly influences the health of individuals but also complicates the provision of primary care. For example, the primary care of an individual with diabetes, which may be relatively straightforward in an urban, more affluent setting, can be complicated in a remote First Nations community, due to lack of access to affordable healthy food choices or lack of access to socially and culturally relevant diabetes-education programs. The often more complex nature of primary care calls for practitioners who are attuned to the complexities of practice in such settings and who are equipped for the challenges of offering primary care in the context of health and social disparities. As we continue to argue, both nurses and NPs working in First Nations communities need knowledge of primary care, and knowledge that can support critical analyses of the social pathways that sustain health inequities, so that they can work towards mitigating those inequities, and address people’s biomedical needs in the

everyday contexts of their lives (Browne & Tarlier, 2008). We are not suggesting that effecting improved access to the determinants of good health is the responsibility of any one health-care provider; we are referring to community engagement and development work that is most effectively addressed by health practitioners working in partnership with communities to address community-defined priorities in ways that support self-determination. This level of community engagement is what Orchard and Karmaliani (1999) identify as complex nursing work requiring advanced practice knowledge and skills — as provided by NPs.

Have the potential implications of the RNCP model at a disciplinary and professional level been fully considered? We speculate that RNCP — particularly in such a broad and complex role in terms of providing primary care — could represent a slippery slope for nursing practice. From a professional stance, we question whether it is sound ethical policy to place nurses in a role where practice is directed by protocol rather than guided by a comprehensive base of substantive advanced practice nursing theory and knowledge and by an advanced level of knowledge of how health practitioners can mitigate the impact of systemic inequities on people's health. Moreover, what might be the legal and ethical implications for RNs practising by protocol and from a less than comprehensive knowledge base, yet “independently and with sole accountability” (CRNBC, 2011c)? We ask: Is this a safe and ethical position in which to place nurses?

As we have established, nursing practice in remote communities is considered to be the predecessor of present-day NP roles, and NP education has historically been identified as necessary for filling these roles. The question is whether RNCP will enable RNs (including those with only basic experience and education) to practise in what is essentially, and historically recognized to be, an NP role, without gaining the broad base of substantive knowledge that is considered necessary to support NP practice. From a temporal perspective, the level of such NP education has consistently been viewed as above and beyond what was considered “basic” nursing education for the time. For instance, NP education was offered at a post-diploma level when the majority of nurses were diploma-prepared and at a post-BSN level when, increasingly, nurses were prepared at the BSN level. Now that the BSN is the standard for entry to practice in the majority of Canadian jurisdictions, the standard for NP education is widely recognized as a master's degree in nursing (CNA, 2008). Creating a new role, such as RNCP, that enables nurses without the requisite education to practise in remote First Nations communities in a role that is substantively similar to the NP role seems to run counter to this longstanding philosophy underlying our understanding of appropriately preparing nurses for safe and efficient practice. This obser-

vation raises the question of what factors may be driving the RNCP model in British Columbia, if not nursing's own longstanding beliefs about appropriate nursing preparation. While many factors influence inequity in health and access to health care, "it is the political and policy aspects that require most attention, both because of their inherent importance as a fundamental antecedent and their high relevance to policy decisions and because of the historical absence of attention to them in research" (Starfield, 2001, p. 553).

We, as observers external to the decision-making process, cannot be certain of the precise nature of the political and policy aspects that are driving the uptake of the RNCP role in preference to the NP role in remote First Nations communities in British Columbia. However, we speculate that in the current climate of health reforms, efficiency discourses, and incentives to streamline human resources, the creation of RNCPs may represent an initiative that, although founded on good intentions, is representative of the axiom underpinning many health-care decisions — to do more with less (Varcoe & Rodney, 2009). RNs are less costly to hire than NPs, at least over the short term. We argue that this may prove a false economy over the longer term. For example, a high rate of nursing turnover in remote communities has long been acknowledged as one of the most significant and recalcitrant health-service delivery issues in remote First Nations communities. But, notably, studies have long suggested that the main reason given by nurses for leaving their jobs in remote communities is lack of adequate preparation for the role (e.g., Morewood-Northrop, 1994). Chaytor (1994) found that nurses with adequate preparation (i.e., the Dalhousie Outpost and Community Health Nursing program) remained in outpost nursing longer than nurses with less preparation. As highly qualified primary care providers with the advanced practice knowledge and skills to work in ways that are consistent with and that support community development, contemporary NPs embody the level of preparation that has long been acknowledged as necessary to decrease nursing turnover and increase continuity in remote First Nations communities. Despite the advantages that NPs could clearly bring to health care in these settings, employers in British Columbia have created few NP positions in remote First Nations communities. We speculate that one argument driving the RNCP model in British Columbia is the belief that it will be challenging to recruit and retain NPs in remote First Nations communities, just as it has traditionally been challenging to recruit and retain nurses. However, the few NP positions that have been created have been successfully filled, suggesting that more NPs could be recruited if more NP positions were made available. Also, NPs are recruited for positions in remote First Nations and Inuit communities in other jurisdictions, so why not in British Columbia?

What are the implications of RNCP for the newly emerging role of NPs in British Columbia and other jurisdictions? As has been the case in other jurisdictions, implementation of the NP role in British Columbia is not progressing without setbacks; currently there is a dearth of funding for new NP positions in the province, leaving many new graduates unemployed or underemployed. At a time when the evolution of the role in British Columbia and elsewhere may still be vulnerable, will RNCP inadvertently serve to detract from the potential of the NP role to contribute to the health of First Nations people in British Columbia? How might the RNCP model shape future expectations around meeting health human resource needs — and needs for equitable access to high-quality primary care services — in remote First Nations communities? As stated above, RNs are less costly to hire than NPs. Will this, plus the fact that RNs are now “certified” as being adequate to function in the role (albeit in a limited scope, as we have described), institutionalize a lower standard of preparation, and in consequence will the vision of nursing practice in remote settings as the quintessential Canadian NP role be diluted and lost from view? For example, will employment opportunities for NPs in remote community practice be limited in favour of employing less costly RNs?

We also speculate that there may be a risk for RNs working under certified practices being placed in an NP-replacement role, analogous to NPs being placed in a physician-replacement role (Browne & Tarlier, 2008). Just as placing NPs in a physician-replacement role might erode the “value added” aspects of the NP role (Browne & Tarlier, 2008), placing RNs in a NP-replacement role might erode the unique aspects — and, we would argue, the unique strengths — of the RN role. Could this lead to denigration of RN practice, creating further tensions and perceived injustices or inequities between nurses? We propose the creation of practice models that support RNs and NPs working together collaboratively in roles that complement one another. Moreover, where is the incentive for a nurse working in or interested in working in a remote community to do so as an NP, when the investment is considerably less, in terms of both time and finances, for nurses to become certified, especially in times of economic uncertainty as well as uncertainty around the future role of NPs in remote community practice?

What are the implications of RNCP from the “big picture” perspective of the health-care system? We do believe that there will continue to be a role for RNs working under RNCP in remote communities, as well as RNs working within the scope of RN practice. We also recognize that it is unrealistic to think that NPs alone will be able to meet all of the health human resource needs in remote First Nations communities. Nor would we advocate for this as an appropriate model of health-care deliv-

ery, particularly given the evidence suggesting that health outcomes are improved with interprofessional collaborative team approaches (Barrett, Curran, Glynn, & Godwin, 2007; Health Council of Canada, 2008). But by the same token, these are valid reasons why a model that relies on RNCP RNs as sole primary care providers in remote First Nations communities is flawed. From an ethical and social justice perspective, we believe that the aim must be to develop models of health-service delivery that move us beyond the traditional model of nurses, RNCP or otherwise, as the sole primary care providers in remote First Nations communities. As long experience tells us, this has not been a successful model in terms of either addressing health disparities or working with communities to foster greater health and health-care equity through improved access to high-quality, socially relevant care. Our aim must be to develop a model that more closely reflects the collaborative, interdisciplinary PHC team approaches that research suggests are integral to redressing the longstanding health and health-care inequities within communities (Starfield, 2006; WHO, 2008a, 2008b).

Shifting the Status Quo

In putting forward these discussion points, we emphasize that there are roles for RNs working in an expanded role in collaboration with NPs to ensure more equitable access to high-quality primary care. This could represent an ideal model of health-service delivery in remote communities — that is, if RNCP practice were presented as part of a strategic vision of an expanded, innovative model of health care, one that could start to shift the status quo of health in remote communities. However, propagation of the traditional model wherein RNs, regardless of certification status, are used to fill the gap in health services in remote First Nations communities seems to be short-sighted and will, we argue, do little to redress the complex health and social inequities that shape health and illness, and primary care needs, in remote communities. In our view, it is equally short-sighted to not create space for NPs to practise in remote First Nations communities at a time when British Columbia has finally recognized the NP role and has clearly committed to implementing it as an advanced practice role in PHC settings, in particular with a mandate to fill gaps in primary care needs in underserved and marginalized populations.

In considering the health needs of remote First Nations communities and the implications of RNs working under RNCP in these settings from a critical social justice perspective, we are left with several important questions. We believe it would be timely to engage First Nations community leaders, the health-care community, and those in decision-

making positions related to the deployment of nurses in addressing these questions.

- Is there evidence to support the supposition that RNs working under RNCP will provide safe and efficient primary care, particularly when working in a more broad-based community health role?
- Is it possible that implementation of RNCP, while well-intentioned, risks the perpetuation of historic inequities in access to health services for residents of remote First Nations communities?
- Is it possible to reconcile the RNCP model with nursing's philosophical, social, and ethical commitment to enacting the principles of social justice in relation to fostering greater equity in health care?
- Are there ways of thinking beyond the ostensible efficiencies of RNCP, and if so, what alternatives are there to foster greater equity in the provision of nurse-led primary care in remote and rural First Nations communities?

Canadian nurses have a remarkable history in providing health care within the unique contexts of remote First Nations communities. Nurses have ensured that the residents of these communities have been able to access essential PHC. While there have been some significant gains in the health status of First Nations people in British Columbia, health continues to deteriorate on several key health indicators (BCPHO, 2009), suggesting that traditional models of primary care delivery are insufficient to shift the status quo of health disparities. In closing, we therefore ask: Can nursing demonstrate the leadership needed now to explore new models of health-care delivery and new models of partnering with communities in ways that have the potential to shift the status quo, and, ultimately, contribute to creating more equitable health with First Nations people living in remote communities?

References

- Adelson, N. (2005). The embodiment of inequity: Health disparities in Aboriginal Canada. *Canadian Journal of Public Health, 96*, S45–S61.
- Anderson, J. M., Rodney, P., Reimer Kirkham, S., Browne, A. J., Khan, K. B., & Lynam, J. (2009). Inequities in health and healthcare viewed through the ethical lens of critical social justice: Contextual knowledge for the global priorities ahead. *Advances in Nursing Science, 32*(4), 282–294.
- Barrett, J., Curran, V., Glynn, L., & Godwin, M. (2007). *Canadian Health Services Research Foundation synthesis: Interprofessional collaboration and quality primary healthcare*. Ottawa: Canadian Health Services Research Foundation. Retrieved June 2, 2011, from http://www.chsrf.ca/Migrated/PDF/ResearchReports/CommissionedResearch/SynthesisReport_E_rev4_FINAL.pdf.
- Benner, P. (1984). *From novice to expert: Excellence and power in clinical nursing practice*. Menlo Park, CA: Addison-Wesley.

- Bourassa, C., McKay-McNabb, K., & Hampton M. (2004). Racism, sexism, and colonialism: The impact on the health of Aboriginal women in Canada. *Canadian Woman Studies*, 24(1), 23–29. Retrieved June 2, 2011, from <http://www.yorku.ca/cwscf/>.
- British Columbia Provincial Health Officer. (2009). *Pathways to health and healing – 2nd report on the health and wellbeing of Aboriginal people in British Columbia. Provincial Health Officer's Annual Report 2007*. Victoria: Ministry of Healthy Living and Sport. Retrieved June 2, 2011, from <http://www.health.gov.bc.ca/pho/>.
- Browne, A. J., & Tarlier, D. S. (2008). Examining the potential of nurse practitioners from a critical social justice perspective. *Nursing Inquiry*, 15(2), 83–93.
- Brumwell, A., & Janes, C. (1994). Primary health care in Rae-Edzo. *Canadian Nurse*, 90(3), 37–38.
- Brykczynski, K. A. (1989). An interpretive study describing the clinical judgment of nurse practitioners. *Scholarly Inquiry for Nursing Practice*, 3(2), 75–104.
- Canadian Institute for Health Information. (2010). *Regulated nurses: Canadian trends 2005–2010*. Ottawa: Author. Retrieved June 2, 2011, from http://secure.cihi.ca/cihiweb/products/regulated_nurses_2004_2008_en.pdf.
- Canadian Nurse Practitioner Initiative. (2006). *Nurse practitioners: The time is now. A solution to improving access and reducing wait times in Canada*. Ottawa: Author. Retrieved November 5, 2010, from http://www.cna-aiic.ca/CNA/documents/pdf/publications/cnpi/tech-report/section1/01_Integrated_Report.pdf.
- Canadian Nurses Association. (2008). *Advanced nursing practice: A national framework*. Ottawa: Author. Retrieved June 2, 2011, from http://www.cna-nurses.ca/cna/documents/pdf/publications/anp_national_framework_e.pdf.
- Canadian Nurses Association. (2009). *Position statement: The nurse practitioner*. Ottawa: Author. Retrieved June 2, 2011, from http://www.cna-aiic.ca/CNA/documents/pdf/publications/PS_Nurse_Practitioner_e.pdf.
- Chaytor, K. (1994). *Preparing for outpost practice: An evaluation of the Outpost and Community Health Nursing Program at Dalhousie University*. Halifax: Chaytor Educational Services.
- College of Registered Nurses of British Columbia. (2009). *Competencies for Remote Area Certified Practice*. Retrieved May 14, 2011, from <https://www.crnbc.ca/Standards/CertifiedPractice/Documents/RemotePractice/472CoreCompetenciesRemoteNursingPractice.pdf>.
- College of Registered Nurses of British Columbia. (2010a). *Competencies required for nurse practitioners in British Columbia*. Vancouver: Author. Retrieved May 11, 2011, from <https://www.crnbc.ca/Registration/Lists/RegistrationResources/416CompetenciesNPs.pdf>.
- College of Registered Nurses of British Columbia. (2010b). *CRNBC – certified practices overview*. Vancouver: Author. Retrieved May 11, 2011, from <https://www.crnbc.ca/Standards/Lists/StandardResources/485CertifiedPracticesOverview.pdf>.
- College of Registered Nurses of British Columbia. (2011a). *Glossary*. Retrieved May 11, 2011, from <https://www.crnbc.ca/glossary/Pages/Default.aspx>.

- College of Registered Nurses of British Columbia. (2011b). *Nurse practitioner application: Eligibility*. Retrieved May 11, 2011, from <https://www.crnbc.ca/Registration/NPApp/NPRRegistration/Pages/Step1.aspx>.
- College of Registered Nurses of British Columbia. (2011c). *Remote Area Certified Practice. Decision support tools*. Retrieved May 14, 2011, from <https://www.crnbc.ca/Standards/CertifiedPractice/Pages/Remote.aspx>.
- College of Registered Nurses of British Columbia. (2011d). *Scope of practice for nurse practitioners: Standards, limits, and conditions*. Vancouver: Author. Retrieved May 11, 2011, from <https://www.crnbc.ca/Standards/Lists/StandardResources/688ScopeforNPs.pdf>.
- College of Registered Nurses of British Columbia. (2011e). *Scope of practice for registered nurses: Standards, limits, and conditions*. Retrieved May 5, 2011, from <https://www.crnbc.ca/Standards/Lists/StandardResources/433ScopeforRegisteredNurses.pdf>.
- College of Registered Nurses of British Columbia. (2011f). *Statistics*. Retrieved May 11, 2011, from <https://www.crnbc.ca/CRNBC/Statistics/Pages/Default.aspx>.
- De Witt, L., & Ploeg, J. (2005). Critical analysis of the evolution of a Canadian nurse practitioner role. *Canadian Journal of Nursing Research*, 37(4), 116–137.
- Doucette, S. (1989). The changing role of nurses: The perspective of Medical Services Branch. *Canadian Journal of Public Health*, 80(2), 92–94.
- Health Canada. (2010). *First Nations, Inuit and Aboriginal health: Nursing profiles*. Retrieved May 14, 2010, from <http://www.hc-sc.gc.ca/fniah-spnia/services/nurs-infirm/empl/profil-eng.php>.
- Health Council of Canada. (2008). *Rekindling reform: Health care renewal in Canada, 2003–2008*. Toronto: Author. Retrieved May 11, 2011, from [http://www.healthcouncilcanada.ca/docs/rpts/2008/HCC%205YRPLAN%20\(WEB\)_FA.pdf](http://www.healthcouncilcanada.ca/docs/rpts/2008/HCC%205YRPLAN%20(WEB)_FA.pdf).
- Health Professions Council of British Columbia. (2001). *Health Professions Council reports. Post hearing update of preliminary report: Registered nurses*. Victoria: British Columbia Ministry of Health. Retrieved May 5, 2011, from <http://www.health.gov.bc.ca/professional-regulation/hpc/review/part-i/update-regnurse.html>.
- Kubik, W., Bourassa, C., & Hampton, M. (2009). Stolen sisters, second class citizens, poor health: The legacy of colonization in Canada. *Humanity and Society*, 33, 18–34.
- Luo, Z. C., Kierans, W., Wilkins, R., Liston, R., Uh, S. Z., & Kramer, M.S. (2004). Infant mortality among First Nations versus non-First Nations in British Columbia: Temporal trends in rural versus urban areas, 1981–2000. *International Journal of Epidemiology*, 33(6), 1252–1259.
- Luo, Z. C., Wilkins, R., Heaman, M., Martens, P., Smylie, J., Hart, L., et al. (2010). Birth outcomes and infant mortality by the degree of rural isolation among First Nations and non-First Nations in Manitoba, Canada. *Journal of Rural Health*, 26(2), 175–181.
- Morewood-Northrop, M. (1994). Nursing in the Northwest Territories. *Canadian Nurse*, 90(3), 26–31.

- Nurse Practitioner Association of Ontario. (2010). *History of NP role development in Ontario*. Retrieved May 11, 2011, from <http://www.npao.org/history.aspx>.
- Orchard, C. A., & Karmaliani, R. (1999). Community development specialists in nursing for developing countries. *Journal of Nursing Scholarship*, 31(3), 295-299.
- Reading, J. (2009). *The crisis of chronic disease among Aboriginal peoples: A challenge for public health, population health, and social policy*. Victoria: Centre for Aboriginal Health Research. Retrieved May 11, 2011, from <http://www.cahr.uvic.ca/docs/ChronicDisease%20Final.pdf>.
- Reading, J. (2010, October 14). *An introduction to Aboriginal health: What determines Aboriginal health in Canada and around the world*. Centre for Aboriginal Health Research, University of Victoria Speaker Series Presentation #1. Retrieved May 11, 2011, from <http://cahr.uvic.ca/speaker-series/>.
- Reading, J., Marsden, N., Kurbanova, D., & Link, R. (2009). *Global Indigenous Health Research Symposium report. Papers and presentations: Directions and themes in international indigenous health research 2008*. Victoria: Centre for Aboriginal Health Research. Retrieved May 11, 2011, from http://www.cahr.uvic.ca/docs/CAHR_Book1_OUT_rev.pdf.
- Reimer Kirkham, S., & Browne, A. (2006). Toward a critical theoretical interpretation of social justice discourses in nursing. *Advances in Nursing Science*, 29(4), 324-339.
- Sherwin, S. (2002). The importance of ontology for feminist policy-making in the realm of reproductive technology. *Canadian Journal of Philosophy*, 28, 273-295.
- Starfield, B. (2001). Improving equity in health: A research agenda. *International Journal of Health Services*, 31(3), 545-566.
- Starfield, B. (2006). State of the art in research on equity in health. *Journal of Health Politics, Policy and Law*, 31(1), 11-32.
- Tarlier, D. S. (2001). *Voices from the wilderness: An interpretive study describing the role and practice of outpost nurses*. Unpublished master's thesis, University of British Columbia.
- Tarlier, D. S., Browne, A. J., & Johnson, J. L. (2007). The influence of geographical and social distance on nursing practice and continuity of care in a remote First Nations community. *Canadian Journal of Nursing Research*, 39(3), 126-148.
- Tarlier, D. S., Johnson, J. L., & Whyte, N. B. (2003). Voices from the wilderness: An interpretive study describing the role and practice of outpost nurses. *Canadian Journal of Public Health*, 94(3), 180-184.
- University of Alberta Faculty of Nursing and Faculty of Medicine. (1980). *Education objectives for the Nurse Practitioner Program*. [Description of Nurse Practitioner Program and the Clinical Training of Nurses, Medical Services Branch, Health and Welfare Canada.] Copy in possession of D. Tarlier.
- University of Northern British Columbia. (2010). *Remote Nursing Certified Practice*. Retrieved May 11, 2011, from http://www.unbc.ca/nursing/remote_nursing.html.

- Varcoe, C., & Rodney, P. (2009). Constrained agency: The social structure of nurses' work. In B. S. Bolaria & H. D. Dickinson (Eds.), *Health, illness and health care in Canada* (4th ed.) (pp. 122–150). Toronto: Nelson Education.
- Vukic, A., & Keddy, B. (2002). Northern nursing practice in a primary health care setting. *Journal of Advanced Nursing*, 40(5), 542–548.
- Watts, R. (2010). Part nurse, part doctor, no job. *Victoria Times Colonist*, March 11. Retrieved May 11, 2011, from http://www2.canada.com/victoriatimes-colonist/news/capital_van_isl/story.html?id=0ee01466-887c-4e9d-bf86-e750bcdce3be.
- World Health Organization. (2008a). *Closing the gap in a generation: Health equity through action on the social determinants of health. Commission on Social Determinants of Health final report*. Geneva: Author.
- World Health Organization. (2008b). *The World Health Report 2008 – Primary health care (now more than ever)*. Geneva: Author.
- Yukon Registered Nurses Association. (2009). *Legislation opens door for nurse practitioners*. [Media release.] Retrieved May 14, 2011, from <http://www.yrna.ca/assets/NPLegrelease.pdf>.

Conflict of Interest Statement

There are no conflicts of interest or financial disclosures.

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Recherche concertée internationale comme relation sociale : un exemple canado-éthiopien

**Amy Bender, Sepali Guruge, Fekadu Aga,
Damen Hailemariam, Ilene Hyman, Melesse Tamiru**

Une collaboration internationale en soins infirmiers et dans les autres disciplines de la santé s'avère indispensable pour remédier aux problèmes de santé mondiaux. Alors que les résultats et les processus produits par de telles collaborations font l'objet de rapports, peu de publications se sont intéressées à leurs fondements philosophiques ou théoriques, particulièrement en ce qui concerne la collaboration entre les pays pauvres et riches. La notion de Piaget qui concerne les relations sociales régies par la coopération et la contrainte, et la notion du « monde de la vie » de Habermas ont permis de jeter un regard théorique sur la collaboration internationale en vue d'en faire l'étude en tant que construction de la connaissance. Cet article analyse ces idées comme en témoigne l'expérience collective de Canadiens et d'Éthiopiens lors de l'organisation d'un forum interdisciplinaire portant sur la violence exercée par un partenaire intime en Éthiopie. Le projet est présenté comme une étude de cas en vue de réfléchir sur la collaboration internationale en tant que manifestation des relations sociales. Une nouvelle vision de la collaboration internationale pourrait s'avérer utile à l'amélioration des processus concertés et de leurs résultats.

International Research Collaboration as Social Relation: An Ethiopian–Canadian Example

**Amy Bender, Sepali Guruge, Fekadu Aga,
Damen Hailemariam, Ilene Hyman, Melesse Tamiru**

International collaboration in nursing and other health disciplines is vital for addressing global health issues. While the results and processes of such collaborations have been reported, few publications have addressed their philosophical or theoretical underpinnings, particularly with respect to collaboration between those in low- and high-income countries. Piaget's notion of social relations of cooperation and constraint and Habermas's notion of "lifeworld" provide a theoretical lens through which to examine international collaboration as a construction of knowledge. This article is an exploration of these ideas as seen in the collective experience of Canadians and Ethiopians organizing an interdisciplinary forum on intimate partner violence in Ethiopia. The project is presented as a case study for reflecting on international collaboration as a manifestation of social relations. Such re-visioning of international collaboration may be useful for improving collaborative processes and their outcomes.

Keywords: collaborative research methods, domestic violence and women's health, international nursing, philosophy/theory

Introduction

In our current globalized world, international collaboration is vital for research on global health. According to Jairath (2007), nursing research involving interdisciplinary teams across countries holds potential for advancing the global health–care agenda. There is a growing body of literature on international collaboration in nursing and other disciplines such as public health, and, specifically, between low- and high-income countries, spanning a range of research topics and projects. However, few publications explicate the philosophical or theoretical underpinnings of such collaborations. It is imperative that we pay attention to the collaborative process itself, because working across geographical distances, cultures, and academic and health–care systems involves complexities that are often not present in projects within the same country. These complexities are magnified in international work that crosses under-resourced and resource-rich settings around the world. As global health research initiatives between low- and high-income countries continue to evolve, a

deeper awareness of the collaborative process serves to ensure that practice is reflective and ethical and that international collaborations are in fact collaborative.

This article is an exploration of the authors' shared experiences of international collaboration in organizing an interdisciplinary forum on intimate partner violence (IPV) in Ethiopia in November 2009. Our purpose is to present the project, with its rewards and challenges, as a case study for reflecting on international collaboration at its roots, as a manifestation of social relations. Theoretically, the article draws on the work of Psaltis (2007), which brings together Piaget's notion of social relations of cooperation and constraint and Habermas's notion of "lifeworld" in seeing collaboration as a construction of knowledge.

To begin, we provide background on international research collaborations and an outline of the theoretical perspective taken. After a brief description of the IPV-Ethiopia project, examples from its planning, implementation, and outcomes are discussed through the lens of social relations of cooperation (the lifeworld of team members) and social relations of constraint (the system's external influences on that lifeworld). We hope that thinking about international collaboration in this way will inform similar collaborations across countries.

The Benefits and Challenges of International Collaboration

The recent increase in international collaborations in nursing and other health-related research, education, and practice is considered to be an inherently positive development. Suhonen, Saarikoski, and Leino-Kilpi (2009) argue that international cross-cultural comparative research is a useful tool for advancing nursing knowledge and furthering nursing interventions in global terms. They suggest that international collaboration benefits both the practice of science and social processes. The concepts identified as most relevant for understanding the context of international collaboration are globalization, internationalization, and cultural diversity (see Allen & Ogilvie, 2004; Bagshaw, Lepp, & Zorn, 2007; Callister, 2006; Freshwater, Sherwood, & Drury, 2006; McAuliffe & Cohen, 2005; Ogden & Porter, 2000).

The challenges of international research collaborations in general and how to manage them are well described in the literature. For nursing research these challenges include geographical distance (involving time zones, travel, communication); cultural and linguistic differences; and assumptions about day-to-day functioning (infrastructure issues, communication, Internet access, workloads) (Freshwater et al., 2006). Foremost among these challenges are differences in available resources and access to funding (funding source, requirements/protocols).

In addition to the challenges, the literature addressing international research collaboration has focused on the underlying social forces and the strategies or ingredients necessary for successful collaboration. For example, Bammer (2008) details a framework to address four key management challenges in research collaborations: deciding on what the collaboration includes, managing the differences that can destroy partnerships, accommodating the forces that may distort the collaboration's outcomes, and engaging supports while preserving autonomy. In describing the process of their collaboration, Bagshaw et al. (2007) call attention to the notion of team and teamwork as a solution to the practical concern of managing conflicts. In their description of the four "effective strategies" of team-building in international collaborative work, Bagshaw et al. emphasize explicit acknowledgement of diversities in the team, a reflexive stance on the part of individuals, and the development of trust.

The literature also describes benefits of collaborations outside of research. For example, Garner, Metcalfe, and Hallyburton (2009) cite the development of leadership skills and transcultural learning for students in international collaborations, leading to a concept model for international nursing education that emphasizes advocacy and ethical accountability extending to the global community. Similarly, Ogilvie, Allen, Lareya, and Opare (2003), using their Ghanian-Canadian master's program in nursing as an example, present a theoretical perspective on one of the central aims of partnership, namely capacity-building. Specifically, they describe capacity-building in terms of capital — physical, human, organizational, social, and cultural. In highlighting human, social, and cultural capital, they point to the significance of establishing relationships, without minimizing the importance of physical and organizational capital — those material and structural conditions that make the project possible.

The literature alludes to the intrapersonal, interpersonal, and social dimensions of international collaborations as well as the centrality of good communication in establishing trust. Notably, while any collaborative project entails challenges, international work presents unique dilemmas and obstacles that can be avoided or minimized when reflexively examined both individually and as a team of collaborators. In the next sections, we describe and draw from a theoretical perspective offered by Psaltis (2007) and our own experience to highlight a way of understanding such reflexivity.

Social Relations and the Lifeworld

Psaltis (2007) draws on the work of Piaget (1965) and Habermas (1987) to suggest a relation of cooperation — or the more personal, relational aspects of collaboration — as the underpinning for tending to the struc-

tural-organizational realities of collaborating so that a relation of constraint does not become the dominant dynamic of the process. Well known for his theory of child development, Piaget believed that society is first “the sum of social relations between people” (Psaltis, 2007, p. 188). More specifically, as part of his interest in social psychology and morality, Piaget (1965) distinguishes social relations of cooperation and of constraint as aspects of moral development. In relations of cooperation, there is a “levelling up” of power (Piaget, 1965, p. 336). The power is evenly distributed among people so that a more symmetrical relationship results, and each person is free to express ideas, to defend those ideas, and to consider others’ points of view. By contrast, in social relations of constraint one person/group holds more power than the others, and the relationship tends to be asymmetrical (Psaltis, 2007). With the person who holds more power exercising a dominating influence in terms of beliefs, assumptions, and patterns of behaviour, the knowledge that is acquired by those in the less powerful positions tends to be fixed and inflexible. In contrast, the knowledge derived from relations of cooperation comes through more open forms of exchange and therefore can be more constructive, generative, and novel (Psaltis, 2007).

The philosopher Jürgen Habermas (1987) theorizes two distinct realms of social life or social action situations: those of the lifeworld and of the system. The lifeworld is that aspect of social life that is mediated by communicative action, while the system is orientated towards success, efficiency, and outcome and is mediated by strategic or instrumental action. “The lifeworld” is an adapted term representing the everyday world that people inhabit and share with others in immediate lived ways, “the informal unmarketized domains of social life” in which people experience and learn (Psaltis, 2007, p. 189). It is the space where everyday interactions are infused with cultural understandings and assumptions (Habermas, 1987). These ordinary, everyday interactions are constituted by such relations as family, friends, and close, familiar colleagues. Open dialogue is emphasized as the foundation of ideal social interaction, which parallels the notion of social relations of cooperation.

The notion of system, on the other hand, rests on the established patterns of instrumental action brought about by sedimented social structures, with money and power being the two critical subsystems (Habermas, 1987; Psaltis, 2007). The system represents a level of differentiation in the lifeworld that drives a “social intercourse that has largely been disconnected from norms and values,” institutionalized in society as “purposive, rational, economic and administrative action” (Habermas, 1987, p. 154). A kind of separate reality unto itself, the system imposes external constraints on people and on their communications and actions. Throughout his work, Habermas refers to this as “the colonization of the

lifeworld,” and herein we find the parallel with Piaget’s relations of constraint.

Communicative interactions are diminished by colonization, as they are mediated by money and power; “colonization, then, leads to an erosion of ‘lifeworld resources’ relating to society, personality, and culture” (Edwards, 2008, p. 304). These effects on social relations may manifest in terms of a lack of shared meanings between people, erosion of social bonds, feelings of helplessness, reduced willingness to assume responsibility, or the destabilization of social order (Psaltis, 2007). However, colonization of the lifeworld can be prevented through social movements that are value-oriented (Habermas, 1987). This is possibly accomplished by questioning power structures and examining through open dialogue the constraining influences of money (or lack of it) as part of the system’s colonizing control over knowledge.

Psaltis (2007) argues that an international collaboration, given its particular structural issues of power and money, may appear to be promoting relations of constraint more than relations of cooperation, “thus colonizing the ideal of an unconstrained lifeworld of academic research” (p. 195). He identifies three considerations for assessing the quality of a collaboration as a process of knowledge construction. First, there is transdisciplinarity, or working across disciplines and theories, to create room for communicative action and coordination of various perspectives. Second, an emphasis on the heterogeneity of cultures, or the need to guard against the homogenization of culture, helps to prevent asymmetries of power and status; for example, team members may operate within a seemingly common culture of scientific method or the structure of professional meetings, but the notion of a common culture is a myth. Third, the funder-researcher relationship may be constrained by funding arrangements, and this manifestation of the system (in terms of money) could influence the project’s potential contribution to knowledge construction. Assessing these three points may indicate that international collaboration is a kind of social relation of cooperation in which constraints are accounted for and critically examined. In other words, when international collaboration begins in the lifeworld, the colonizing effects of the system are diminished from the start.

The IPV-Ethiopia Project

This Ethiopian-Canadian collaboration was formed out of mutual and complementary interests in Ethiopia and Canada regarding IPV as a global health research issue and as an education and practice issue for health professionals. The project was funded by the Canadian Institutes of Health Research (CIHR) and the team consisted of three Canadians

(including one Sri Lankan-Canadian) and three Ethiopians. The purposes of the collaboration were as follows: to better understand the current situation of IPV in Ethiopia; to deepen the collective understanding of IPV in global health terms; to explore how Ethiopian health professionals incorporate such understandings into their practice as researchers, educators, and care providers; and to explore how a comprehensive program of research might be furthered in Ethiopia and internationally. The main components of the project were a literature review and two forums with Ethiopians working in the area of IPV. The literature review was vital for situating the forum discussions in terms of providing an account of existing knowledge on IPV in Ethiopia. The first forum was a 1-day interdisciplinary meeting and the second, held the following day, was a nursing-specific meeting. The meetings served to examine the issues associated with providing care to women experiencing IPV and generate ideas regarding key research priorities.

IPV has been defined as coercion; arbitrary deprivation of liberty; or threatened and/or actual physical, sexual, psychological, or verbal abuse by a spouse or non-marital partner (United Nations, 1993). It occurs in epidemic proportions comparable on a global scale to rates for cancer, cardiovascular diseases, and HIV/AIDS (Heise, Pitanguy, & Germain, 1994). There have been two landmark research contributions to our understanding of IPV in the Ethiopian context: a study of seven sub-Saharan African countries, including Ethiopia (ManjuRani & Diop-Sidibé, 2004); and the Multi-country Study on Women's Health and Domestic Violence Against Women conducted by the World Health Organization (WHO) (2006). In the Ethiopian location of the WHO study, the percentages of women reporting IPV (either sexual or physical or both) were approximately 71% for lifetime and 54% for the preceding year. In this regard, Ethiopia ranked as having the highest prevalence among the 10 countries included in the study, and for lifetime physical violence alone it ranked second (Gizaw, 2002). Manjurani and Diop-Sidibé (2004) found that societal norms regarding gender roles and wife-beating tend to change with socio-economic development, increasing urbanization, and higher levels of education. They observe that the inter-generational perpetuation of patriarchal norms partially explains gender-based violence across the life cycle. A traditional patriarchal understanding of women's roles as wives and mothers in particular also underlies the WHO findings identifying women's most common reasons for not seeking help: violence seen as "normal," fear of further violence or losing children, and bringing shame to family. For Ethiopian practitioners and scholars (including co-authors) engaged in health and social services for women, a collaborative effort is vital for addressing this complicated

picture of IPV and its far-reaching consequences for individuals, families, and society. Specific to research collaborations, changes in IPV rates need to be carefully examined in line with changes in sociocultural and economic patterns of populations in the country, to ensure that the issue is understood contextually.

Our collaboration began when the team came together in writing the proposal for CIHR funding. After receiving the funding, we set the agenda for our 10 months of work, hired two project assistants (PAs) (one Ethiopian and one Iranian immigrant living in Canada), agreed on our means of regular communication, and set timelines for the literature review and the forum planning and delivery. The literature review was primarily done by distance and was completed in Addis Ababa prior to the first forum. Forum planning was primarily accomplished across distance and involved a number of tasks, including the travel arrangements for Canadian members of the team. Carrying out the forums was a central part of working together, with Ethiopian team members assuming the leadership role. The forum evaluations and feedback followed, as did team debriefings. Lastly, we needed to decide about publications and future projects and write the final report to the funder. All the while, we got to know each other and grappled with challenges that tested our communication and cooperation skills.

The IPV-Ethiopia Project: Social Relations of Cooperation and Constraint

Psaltis (2007) states that researchers should aim “to promote relations of co-operation, mutual respect, and reciprocity” (p. 195) without fear of exploring conflicts as they arise interpersonally or ideologically in order to diminish the colonizing of the ideal of the academic research lifeworld. This description fits our intentions for the IPV-Ethiopia project, beginning with the fact that the power of the Canadians in the project could not be ignored and was acknowledged openly at the first teleconference meeting of the whole team. The most obvious evidence of this imbalance of power is that two Canadians (Guruge and Bender) were in the co-principal investigator positions, with one (Guruge) holding the funding and both being responsible for submitting the final report to the CIHR. Moreover, the project serves as a case example for exploring Psaltis’s three points regarding international collaborations: the transdisciplinary nature of the team and the project, continual recognition of the heterogeneity of cultures at work in the process, and acknowledgement of our relationship with the funder and the money and power issues that this engendered.

Transdisciplinarity

Our common interest was in IPV as a global health issue, yet this interest was informed by our collective disciplines of public health, nursing, sociology, medicine, and health economics. Furthermore, in the transdisciplinary sense, we assumed that violence against women needed to be understood across a range of theories and perspectives. This assumption carried through in the literature review, as we deliberately sought documents outside of “health” and published academic research. Transdisciplinarity was also reflected in our selection of whom to invite to the forums. One of our explicit objectives was to bring together several disciplines, and this was met, with representation at the forums from nursing, psychiatry, public health, sociology, law, gender studies, and grass-roots women’s social service agencies. Comments made throughout the first forum indicated that those disciplines addressing IPV in Ethiopia were quite disconnected from one another, and notably that, as a health-care issue, IPV could be adequately addressed only with clear strategic direction involving work across sectors — the health, justice, and education systems being specifically identified.

The forum agenda was planned explicitly to cultivate transdisciplinary connections by building in time for participants to network with each other informally and through small-group work. By the end of the day, many had exchanged contact information so they could continue meeting with regard to identified research priorities. To support this networking, after the forum the Ethiopian PA compiled all presentations at the forum as well as notes from small-group discussions of research priorities and distributed these to participants.

A related point regarding the transdisciplinary nature of our project is that there were pre-existing relationships among team members that served to cultivate relations of cooperation. Professional connections, imbued with personal familiarity, were already well established between individuals in Canada and individuals in Ethiopia as well as among those within each country. Notably, trust and respect for one another in these pre-existing relationships formed a foundation for cooperation in the new relationships built around the project. As a group, we worked towards open forms of exchange, such as by having everyone provide input in e-mails and teleconferences that were part of the planning process. And with the trust and respect established within the team, new relationships formed outside of the team. For example, as a nursing professor the second author made new IPV research connections with Ethiopian researchers who attended the forum and agreed to provide thesis advice for PhD students. Our transdisciplinarity in this sense was an expression of social relations of cooperation between people and was

vital to the quality and outcomes of the project in terms of new learning about IPV, the synergistic development of ideas regarding key research priorities, and future work between those in Canada and those in Ethiopia. This implies that these relationships crossed not only disciplines but also cultures.

Heterogeneity of Cultures

The heterogeneity of cultures (Psaltis, 2007) was evident in several collaborative processes of the IPV-Ethiopia project. Even within our shared understandings of research, moments of learning sprang from our various communications across distance. For example, several months after receiving the funding, and with planning underway, the Ethiopian team members submitted the project proposal to the Addis Ababa University research board for approval, which surprised Canadian team members, who assumed that this would have already been addressed when CIHR funding was first granted. The forum planning was suspended until the research board informed us that holding a forum did not require its approval and the proposal was withdrawn. The forums, originally scheduled for September, were held in November as a result. Another example concerns the literature review. Canadian expectations regarding the timeline for writing the review clashed with the practical challenges of accessing documents from several Ethiopian organizations. It was only when the team met face-to-face in Addis Ababa that these difficulties were fully appreciated by the Canadians, since such barriers to accessing information are not typically experienced in Canada. Similarly, the dissemination of forum results, in the form of conference presentations and manuscripts, was discussed in Addis Ababa; though Canadians assumed that the Ethiopian PA who conducted the majority of the literature search would be invited as an author of a poster presentation, for the Ethiopian team members it was not common practice to include assistants as authors, and this required negotiation. In these examples, assumptions about the mythical homogeneity of academic research culture may have been operating. Each situation involved moments of ideological conflict with regard to conducting and disseminating research, and, as Psaltis points out, such conflicts need to be respectfully explored. Our collective acknowledgement of these assumptions was vital for recognizing that asymmetries of power and status may have been at work and that these could be corrected through open dialogue about our cultural differences.

Relationship With Funder

At various points in our collaboration we had to navigate the system with its realities of money and power that were part of the project.

Specifically, asymmetries of power had to be acknowledged in terms of the relationship of the project team and the funder. In short, we were implementing an Ethiopian-based project in Canadian funds from a funder that, understandably, expected the project to be relevant and beneficial for Canadians. For example, early in the timeline a money issue arose with respect to ensuring timely payment of our Ethiopian PA within the usual protocols of administering funds — a structural condition that, notably, did not affect payment of the Canadian PA. First, given our short timeline, an Addis Ababa University account for the PA was not arranged for direct university–university payment. Also, the Canadian university could not issue paycheques in Ethiopian currency. Then, during an attempt to send paycheques directly via courier, it was learned that courier companies cannot deliver to a post box address, the usual means of receiving mail in Ethiopia. In the deliberations about these challenges via Internet and telephone, the PA, understandably, grew concerned about ever being paid. In the end, after several months, it was decided that the cheques would be delivered in person when the Canadians arrived in Ethiopia for the forums, and the PA was able to cash them at a central bank in Addis Ababa that accepted Canadian currency. While we questioned the power structure of the Canadian university administering funds, we had to find a way to work within it. Grounded in a relation of cooperation, the team communicated regularly over time about this structural constraint in order to overcome it.

Finally, as Psaltis (2007) explains, the funder–researcher relationship may influence a project’s unique contribution to knowledge construction. Dissemination of our project’s outcomes, a form of knowledge construction, exemplifies the challenge of overcoming this structural constraint. While a condition of funding was to disseminate the outcomes of the forums in terms of implications for immigrant women in Canada, it was also important to share knowledge in Ethiopia and internationally. The project team met after the forums in Addis Ababa to discuss preparation of the manuscripts for publication. In an effort to equalize opportunities for authorship, it was agreed that the Canadian co-principal investigators would assume leadership for one manuscript each and the Ethiopian team members for two other manuscripts. It was further collectively decided to target journals, such as the *Canadian Journal of Nursing Research*, that provide space for Canadian and international nurse researchers to contribute knowledge from interdisciplinary cross-cultural perspectives. Publication itself can be fraught with challenges of access and equity, especially for authors in low-income countries whose first language is not English. Recognition of such challenges is the starting point for critical reflection and dialogue regarding one of the “colonizing” implications of international collaboration in general.

Conclusion

Countering the colonization of the lifeworld — striving to minimize the social relations of constraint — is possible only when attention has been duly paid to the lifeworld, where social relations of cooperation begin and flourish. This implicitly involves valuing diversity, recognizing that the development of trust takes time, and communicating openly and respectfully so that reciprocity and equitable distribution of workload and outcomes are ensured. When international collaboration is seen as a social relation of cooperation, critical ethical questions must be asked. For example, how do researchers in low-income countries safely name the asymmetries of power they experience in international collaborations without fear of reprisal or cuts to foreign funding? Where, how, and by whom are such situations discussed so as to resist the colonizing of the lifeworld of research and practice? These questions are particularly important for nurses, who tend to endure lower professional, social, and economic status the world over. The cross-country structural arrangements described here represent the relations of constraint that were undoubtedly part of our experience in this project. However, relationships between nursing colleagues in Canada and Ethiopia continue as a result of the project and we will carry on the search for funding and publication opportunities in areas of collective research interest. This experience has shown us that social relations of constraint are unavoidable in our globalized world. We also understand that social relations of cooperation are not only possible but necessary in nursing research collaborations, particularly when relatively few nurses in many parts of the world have access to the academic research arena. Social relations of cooperation is a perspective that shifts research away from exclusively outcome-driven initiatives and towards research that is also explicitly value-driven and reflexive. In this project we learned that the best international collaborations may be those that are understood within system realities but are approached *first* as social relations between people who respect and trust one another and openly question each other's disciplinary and cultural perspectives and power, regardless of where the collaboration takes place.

References

- Allen, M., & Oglivie, L. (2004). Internationalization of higher education: Potentials and pitfalls for nursing education. *International Nursing Review*, 51, 73–80.
- Bagshaw, D., Lepp, M., & Zorn, C. R. (2007). International research collaboration: Building teams and managing conflicts. *Conflict Resolution Quarterly*, 24(4), 433–446.

- Bammer, G. (2008). Enhancing research collaborations: Three key management challenges. *Research Policy*, 37, 875–887.
- Callister, L. C. (2006). Collaborative international research. *Journal of Continuing Education in Nursing*, 37(1), 39–45.
- Edwards, G. (2008). The “lifeworld” as a resource for social movement participation and the consequences of its colonization. *Sociology*, 42(2), 299–316.
- Freshwater, D., Sherwood, G., & Drury, V. (2006). International research collaboration: Issues, benefits and challenges of the global network. *Journal of Research in Nursing*, 11(4), 295–303.
- Garner, B. L., Metcalfe, S. E., & Hallyburton, A. (2009). International collaboration: A concept model to engage nursing leaders and promote global nursing education partnerships. *Nurse Education in Practice*, 9, 102–108.
- Gizaw, B. (2002). *Some reflection on criminalizing domestic violence against women with emphasis in Ethiopia*. CERTWID. Addis Ababa: Addis Ababa University.
- Habermas, J. (1987). *The theory of communicative action*. (Trans. T. McCarthy.) Cambridge: Polity Press.
- Heise, L. L., Pitanguy, J., & Germain, A. (1994). *Violence against women: The hidden health burden*. World Bank discussion paper. Washington: International Bank for Reconstruction and Development/World Bank.
- Jairath, N. (2007). Global health: The role of nursing research. *Nursing Research*, 56(6), 367–368.
- ManjuRani, B. S., & Diop-Sidibé, N. (2004). An empirical investigation of attitudes towards wife-beating among men and women in seven sub-Saharan African countries. *African Journal of Reproductive Health*, 8(3), 116–136.
- McAuliffe, M. S., & Cohen, M. Z. (2005). International nursing research and educational exchanges: A review of the literature. *Nursing Outlook*, 53, 21–25.
- Ogden, J. A., & Porter, J. D. H. (2000). The politics of partnership in tropical public health: Researching tuberculosis control in India. *Social Policy and Administration*, 34(4), 377–391.
- Ogilvie, L., Allen, M. A., Lareya, J., & Opare, M. (2003). Building capacity through a collaborative international nursing project. *Journal of Nursing Scholarship*, 35(2), 113–118.
- Piaget, J. 1965. *The moral judgment of the child*. (Trans. M. Gabain.) New York: Free Press.
- Psaltis, C. (2007). International collaboration as construction of knowledge and its constraints. *Integrative Psychological and Behavioral Science*, 41, 187–197.
- Suhonen, R., Saarikoski, M., & Leino-Kilpi, H. (2009). Cross-cultural nursing research. *International Journal of Nursing Studies*, 46(4), 593–602.
- United Nations. (1993). Declaration on the elimination of violence against women. In *Canada-USA Women's Health Forum*, 6. New York: Author.
- World Health Organization. (2006). *Multi-country study on women's health and domestic violence against women. Summary report: Initial results on prevalence, health outcomes and women's responses*. Geneva: Author.

Acknowledgements

This project was made possible by a Meetings, Planning, and Dissemination Grant from the Canadian Institutes of Health Research.

We gratefully acknowledge the valuable contributions and all the hard work of our project assistants, Andargachew Kassa and Khosro Refaie-Shirpak.

There are no known conflicts of interest.

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Happenings

Philosophizing Social Justice in Nursing: 14th International Philosophy of Nursing Conference Held in Vancouver

Patricia Rodney

We at the University of British Columbia School of Nursing were most pleased to co-host the 14th International Philosophy of Nursing Conference, held September 20–22, 2010, in Vancouver. We were especially happy to welcome our international colleagues who travelled to Vancouver to take part in this first IPONS conference to be held in Canada.

A Brief History of IPONS¹

IPONS was launched in September 2003 at the 7th international conference, held at the University of Stirling in Scotland. The broad purpose of the Society is to bring together individuals from different countries in an international network to promote and support the growing discipline of philosophy of nursing. The specific aims of IPONS are to

- promote and establish philosophy of nursing, and health care in general, as a credible and important field of philosophical and critical inquiry
- establish a growing international network for this purpose
- conduct and support philosophical inquiry in a manner that informs and engages with health-care practice, theory, research, education, and policy from national and international perspectives
- support philosophical inquiry into nursing and health care across cultures and countries, including those who may have difficulty making their voices heard

The Society, in association with Wiley-Blackwell, has its own scholarly journal, *Nursing Philosophy*, published quarterly. IPONS also hosts an

¹ Adapted from <http://www.ipons.dundee.ac.uk/index.html>.

annual conference. In an e-mail discussion list provided by JISCMail, members can initiate and contribute to debate on various issues.

The Vancouver event was only the second annual IPONS conference to be held outside of the British Isles. Some of the faculty at the UBC School of Nursing are IPONS members and had attended the Society's conferences in the past. We were therefore delighted to be able to host a prestigious gathering of nurses, philosophers, and other colleagues who have staked a claim in the value of philosophizing on behalf of our discipline. Nursing ideas play a key role in envisaging and operationalizing a more just and equitable world. The UBC School of Nursing is academic home to a significant investment in social justice theorizing, philosophizing, and action, and we therefore welcomed the opportunity to meet a wide variety of national and international colleagues for continuing dialogue and collaboration during the conference and beyond.

Conference Details

The keynote speakers for the Vancouver conference, and their topics, were as follows:

Trevor Hussey, Professor Emeritus of Philosophy, Buckinghamshire New University, and Part-Time Tutor in Philosophy, University of Oxford: *Just Caring*

Joy Johnson, Scientific Director, Institute for Gender and Health, Canadian Institutes of Health Research, and Professor, UBC School of Nursing: *Whose Voices Count?*

Sioban Nelson, Professor and Dean, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto: *Competency's Reflex Arc: An Approach to a Genealogy of Reflective Practice*

Fifty concurrent papers were presented by nurses, philosophers, and others on a diverse array of topics related to social justice and nursing philosophy. Special featured papers were given by Annette Browne and Sheryl Reimer Kirkham: *Problematizing Social Justice Discourses in Nursing*; Barbara Pesut: *A Moral Stone? Philosophizing Social Justice in Rural Palliative Care*; Mark Risjord: *Nursing and Human Freedom*; and Joan Anderson: *The Evolution of Critical Theorizing and Postcolonial Scholarship in Nursing: Toward a Critical Humanism*. The conference closed with a panel discussion and audience engagement on *Using Nursing Philosophizing to Solve Social Justice Issues*.

The dialogue throughout the plenary and concurrent sessions was energetic and inspiring. There were 86 registered participants (including a number of graduate students) from a variety of countries: 56 from Canada; 13 from the United States; 9 from the United Kingdom; 3 from

Hong Kong; and 1 each from Ireland, Japan, New Zealand, Norway, and Sweden. The evaluations from the conference indicate that participants greatly appreciated the opportunity to learn from the expert presenters and from each other. Overall, the conference affirmed the importance of IPONS in promoting international nursing inquiry into philosophy and ethics.

The Planning Committee consisted of the following faculty members from the UBC School of Nursing:

Conference Chair: Sally Thorne, Professor and Director of the School

Scientific Review Chair: Colleen Varcoe, Professor

Program Chair: Patricia Rodney, Associate Professor

Site Coordination Chair: Angela Henderson, Associate Professor

Forthcoming Nursing Philosophy Issue

Reflecting the theme of the 14th IPONS conference, the journal *Nursing Philosophy* is compiling a special issue on Philosophizing Social Justice in Nursing, scheduled for publication in Volume 13 Issue 1 (January 2012). The Guest Editor will be Colleen Varcoe from the UBC School of Nursing.

The Next Conference

The next IPONS conference is to be held August 26–28, 2011, at West Park Centre, Dundee, Scotland. The theme is Healthcare and the Politics of Austerity and the call for abstracts is open until July 21, 2011 (see <http://www.ipons.dundee.ac.uk/events.html>).

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Les perceptions des patients concernant les soins individualisés : une évaluation des propriétés et des résultats psychométriques de l'échelle de soins individualisés

**Ursula Petroz, Deborah Kennedy,
Fiona Webster, Agnes Nowak**

Les organisations de services de santé désirent offrir des soins centrés sur le patient. Toutefois, il reste difficile de mesurer cet aspect de la qualité des soins. Cette étude transversale a examiné la fiabilité et la validité de l'échelle bipartite de mesure des soins individualisés (ESI-A, ESI-B) (*bipartite Individualized Care Scale [ICS-A, ICS-B]*) dans une population canadienne ayant subi une arthroplastie genou-hanche. La cohérence interne des ESI-A et ESI-B était élevée; cependant, la validité factorielle n'était pas entièrement étayée. Vingt-cinq pour cent des participantes et des participants ont fourni des commentaires additionnels ouverts afin de décrire leurs perceptions, leurs besoins et leurs suggestions, et noté que l'échelle de Likert les obligeait à regrouper leurs commentaires et ne leur permettait pas de communiquer leur perception de chaque membre du personnel infirmier. Les conclusions de l'étude indiquent que lorsqu'ils évaluent les soins infirmiers, les patientes et les patients trouvent important de pouvoir partager leur histoire personnelle. Les études qualitatives qui seront effectuées dans l'avenir devraient examiner ce que pense le personnel infirmier des soins centrés sur le patient, ainsi que comporter une investigation sur les systèmes et les aspects liés au processus qui favorisent ou gênent la prestation de soins plus individualisés.

Mots clés : soins centrés sur le patient

Patients' Perceptions of Individualized Care: Evaluating Psychometric Properties and Results of the Individualized Care Scale

Ursula Petroz, Deborah Kennedy, Fiona Webster, Agnes Nowak

Health-care organizations aim to provide patient-centred care, yet measurement of this aspect of care quality remains a challenge. This cross-sectional study investigated the reliability and validity of the bipartite Individualized Care Scale (ICS-A, ICS-B) in a Canadian hip and knee arthroplasty population. Internal consistency of the ICS-A and ICS-B was high; however, factorial validity was not fully supported. Twenty-five percent of participants provided additional open-ended comments to describe individual perceptions, needs, and suggestions, noting that the Likert-scale approach required them to aggregate their feedback about rather than share their perceptions of individual nurses. The findings indicate that it is important to patients to be able to share their individual stories when evaluating nursing care. Future qualitative studies should examine the nurse perspective on the provision of patient-centred care, including investigation of systems and process-related features that foster or hinder more individualized care.

Keywords: patient-centred care, patient-focused care, client-centred care, nursing-care quality, patient satisfaction, care maps

Patient-care delivery in clinical specialty areas is driven by two objectives: the provision of efficient, standardized care; and the delivery of patient-centred care. The increasing use of care maps has led to more consistency in care, improved quality, better health outcomes, reduced risks, decreased length of stay, and increased patient education (De Bleser et al., 2006; Woolf, Grol, Hutchinson, Eccles, & Grimshaw, 1999). However, following such care pathways may result in lower care flexibility and decreased thinking by staff (Atwal & Caldwell, 2002; Ilott, Rick, Patterson, Turgoose, & Lacey, 2006) and might not sufficiently meet individual patient expectations (Dozier, Kitzman, Ingersoll, Holmberg, & Schultz, 2001). Patient-centred care is a phenomenon that has been defined as a “way of providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patients’ values guide all clinical decisions” (Institute of Medicine, 2001, p. 3). A recent dimensional analysis of patient-centred care by Hobbs (2009) established that the concept includes a “complex series of nurse-patient interactions that go beyond the collection of information about patient preferences”

(p. 59). According to the author, the goal of patient-centred care is “the alleviation of vulnerabilities as experienced by the patient” (p. 55), which consist of compromised physiological states and threats to individual identity such as feeling alienated or lacking control.

Looking at definitions of patient-centred care, it is clear that the provision of more individualized care is a central element of patient-centredness that appears frequently in the nursing literature. Radwin and Alster (2002) generate the following empirical definition of individualized care: “Individualized care results when the nurse knows the patient as a unique individual, and tailors nursing care to a patient’s experiences, behaviors, feelings, and perceptions” (p. 62). The importance of individualized care is well established and has been found to be highly valued by nurses, patients, families, and health-care administrators (Davis, Byers, & Walsh, 2008; Radwin & Alster, 2002). It is correlated with high levels of patient satisfaction (Dana & Wambach, 2003) and health-related quality of life (Suhonen, Valimaki, Katajisto, & Leino-Kilpi, 2007).

Increasingly, health-care organizations are attempting to assess patient perspectives and to evaluate performance and quality of care (Jenkinson, Coulter, Reeves, Bruster, & Richards, 2003). However, there is limited research on the types of patient needs that remain unmet during hospitalization and an evident lack of sufficient attention to specific patient needs and expectations (Muntlin, Gunningberg, & Carlsson, 2006). In North America the NRC Picker Survey is commonly used to assess patient satisfaction with care. A clear picture of patient perceptions of individualized care, an important element of patient-centred care, cannot be obtained using standard patient satisfaction surveys alone (Davis et al., 2008).

Little is known about patients’ perceptions of individualized nursing care (Land & Suhonen, 2009) and patients’ views regarding the importance of specific individualized nursing interventions. Studies designed to incorporate patient perspectives can help to clarify dimensions of patient-centred care (Hobbs, 2009). The search for an instrument to measure the quality of individualized and patient-centred aspects of care has turned up a significant body of research in relation to an instrument called the Individualized Care Scale (ICS) developed by Suhonen, Valimaki, and Katajisto (2000). This instrument was developed through a process of deductive reasoning based on an extensive review of the literature on individualized care (Suhonen et al., 2000; Suhonen, Valimaki, & Leino-Kilpi, 2002). Content analysis was used to explore the definitions and to conceptualize relevant dimensions of the construct (Suhonen, Leino-Kilpi, & Valimaki, 2005). Individualized care was conceptualized as a phenomenon that recognizes that individual patients experience and perceive the same care in a variety of ways according to their different values

(Suhonen et al., 2005). Dimensions include consideration of patients' views on how individuality is supported through nursing interventions and, for example, how their personal situation is being considered, how their individual feelings and reactions are taken into account, and how their decisional control over care is realized. Instrument questions and subscale foci match some of the dimensions of patient-centred care as described recently by Hobbs (2009). In Hobbs's work, dimension components include the patient's perceptions of events, abilities, resources, and choices and describe the patient as an individual with needs, preferences, values, and beliefs that must be integrated into the care experience. The questions examine nurse-patient interactions as perceived by patients and include areas such as patients' vulnerabilities related to the clinical situation, patients' personal life situation, and patients' decisional control over care. Suhonen et al. (Sukonen, Valimaki, Leino-Kilpi, & Katajisto, 2004; Sukonen et al., 2005) conceptualize individualized care in two ways: in terms of the patient's perspective on the degree to which nursing interventions have been tailored to his or her individual needs, situation, characteristics, and preferences; and in terms of how well the patient's individuality has been taken into account in his or her care.

The ICS has demonstrated good psychometric properties in European studies and was used in a recent international comparative survey with an orthopedic patient population (Suhonen et al., 2008). Available results have demonstrated that there are differences between countries in the way that patients' perceive the nursing care they receive (Suhonen et al., 2008). After consulting with the ICS developer, we designed this study to test the instrument in a Canadian health-care setting, recognizing the multiculturalism and diversity of Canadian residents.

Aim of the Study

The purpose of this study was primarily to explore the psychometric properties of the ICS in a Canadian Centre of Excellence for Hip and Knee Replacement and secondarily to examine whether participants perceived their care to be individualized. The specific research questions were as follows: 1. *To what extent is there evidence to support the factorial validity of ICS scores when applied to patients receiving hip or knee replacement?* 2. *To what extent is there evidence to support the internal consistency of ICS scores when applied to patients receiving hip or knee replacement?* 3. *To what extent is there evidence to support the convergent construct validity of the ICS when applied to patients receiving hip or knee replacement?* 4. *Is there a difference in either ICS-A or ICS-B total scores based on (1) age (≥ 65 vs. < 65 years), (2) discharge unit (acute vs. short-term), and (3) gender?* 5. *To what extent is there*

an association between (1) total Schmidt scores and ICS-A and ICS-B total scores, and (2) length of stay and ICS-A and ICS-B total scores? 6. What are patients' views on individualized nursing interventions and individualized care received?

Methods

Design

Consistent with the original methodology used by Suhonen et al. (2005), a cross-sectional design was applied to explore the psychometric properties of the ICS at point of discharge with patients undergoing total hip replacement (THR) or total knee replacement (TKR). Owing to the subscales and multi-item nature of the ICS, internal consistency and factorial validity were examined. A convergent construct validation approach was used to examine the validity of the ICS by comparing its scores to those of the Schmidt Perception of Nursing Care Survey (SPNCS), a measure to assess similar information (Schmidt, 2003, 2004).

Sample and Setting

Patients were recruited at a Canadian tertiary-care facility specializing in joint-replacement surgery. Consecutive patients undergoing primary THR or TKR from April to December 2009 were approached prior to discharge from either of two acute-care units or the short-term rehabilitation (STR) unit. Our projected sample size was 400, based on the requirements for the factor analysis of five to ten respondents per variable (Streiner, 1994). Inclusion criteria were as follows: (1) able to read and understand the questionnaire, (2) primary replacement procedure, (3) discharge home from acute-care or STR unit, and (4) able to complete the questionnaire independently. Approval was granted by the institution's research ethics board and informed written consent was provided by all participating patients.

Measures

The ICS is a 38-item self-administered questionnaire divided into two parts. Developed in Finnish, the ICS has been translated into English, Greek, and Swedish. An adapted English version reduced to 34 items, with 17 items in each part, has been used in the United Kingdom as part of an international comparative study (Suhonen et al., 2008). Part A asks about how nurses provided care, with items such as (2a) *nurses talked with me about my needs that require care and attention* (ICS-A, 19 items). Part B asks about the degree to which the patient experienced individualized care, with items such as (2b) *my needs that require care and attention have been taken into account in my care* (ICS-B, 19 items) (Suhonen et al., 2000,

2004, 2005). The instrument is intended for use in acute-care hospitals at the point when patients are being discharged home. Both the ICS-A and the ICS-B consist of three subscales: clinical situation, personal life situation, and decisional control over care. A scale from 1 (*fully disagree*) to 5 (*fully agree*) is used for patients to rate their level of agreement with each statement. Scores are then added up for all subscales and for the total score each of Part A and Part B.

Several expert analyses have established the content validity of the ICS (Suhonen et al., 2000). In terms of internal consistency, Suhonen et al. (2005) report Cronbach's alpha as 0.94 for the ICS-A and 0.93 for the ICS-B. Principal component analysis supports factorial validity by generating a three-factor solution, which accounts for 65% of the variance in the ICS-A and 61% in the ICS-B (Suhonen et al., 2005). Structural equation modelling has also provided support for the hypothesized dimensions and domains in the ICS (Suhonen et al., 2008). Evidence for the convergent validity of the tool was observed in a study examining the ICS with components of the SPNCS and the Oncology Patients' Perceptions of the Quality of Nursing Care Scale (Suhonen, Schmidt, & Radwin, 2007).

For the purposes of establishing the convergent construct validity of the ICS, the SPNCS was administered together with the ICS. The SPNCS is an empirically constructed scale based on a grounded theory study of patients' experiences of nursing care received during their hospital stay (Schmidt, 2003). The measure consists of four subscales: seeing the individual patient, explaining, responding, and watching over. Each subscale includes three to five items, a total of 15 items to be rated on a Likert scale from 1 to 5. The total scale had a Cronbach's alpha reliability of 0.96 in a 2004 study sample (Schmidt, 2004). Evidence of its validity has been demonstrated in several studies (Schmidt, 2004; Suhonen, Schmidt, et al., 2007).

Data Collection

In order to meet ethics board regulations concerning patient privacy, a physiotherapist or occupational therapist who were part of the patient's circle of care approached the patients for verbal consent to have a research assistant (RA) visit them on the day prior to discharge or the day of discharge. For those patients who agreed, the RA provided written and oral information about the nature and purpose of the study, and later, after written consent had been obtained, distributed the ICS and SPNCS questionnaires. Information on the following variables was obtained from the patients' charts: age, gender, type of surgery, length of stay, hospitalization (acute care only or acute care plus STR), and discharge destination. In terms of hospitalization, most patients in the facility are dis-

charged from the acute-care unit after 4 to 5 days; the STR unit is used for those who require up to 7 additional days of care due to their home-support situation, their preoperative function, or the presence of co-morbidities.

It is important to mention that the RA reported that many patients expressed disappointment when they realized that their participation in the study would not consist of providing individual feedback in the form of an interview. It became apparent that many patients wanted to give additional feedback and suggestions related to nursing care and that they wished to share their personal experiences. Given that the questionnaires did not include open-ended questions, patients were encouraged to write any additional comments on the back of their questionnaires.

Data Analysis

All quantitative analyses were conducted using SPSS version 16.0 statistical software. The factorial structure of the ICS-A and ICS-B scales was explored by performing principal component analysis followed by an oblique Promax rotation. An oblique Promax rotation was applied because we believed a correlation would exist between factors. Following interpretation of the results from the factor analyses, we calculated Cronbach's alpha for each subscale. We also examined the distributions of ICS-A and ICS-B scores and, based on the findings, calculated summary statistics for the total scores. *T* tests for independent sample means were applied to test for differences between (1) persons aged ≥ 65 and those aged < 65 , (2) acute-care and STR units, and (3) males and females. We applied Spearman's correlation coefficient to examine the associations between (1) total Schmidt, ICS-A, and ICS-B scores; and (2) length of stay and ICS-A and ICS-B total scores. Spearman's coefficient was chosen based on a scatterplot of the data, which suggested a curvilinear relationship between the Schmidt, ICS-A, and ICS-B scores.

Our research design did not include a qualitative component. However, many patients provided open-ended responses on the back of the questionnaires. Our team made the decision to conduct a secondary data analysis (Van Den Berg, 2005) of the handwritten notes, which were transcribed verbatim, excluding any confidential information such as name, unit designation, or date. Using standard descriptive qualitative methodology (Sandelowski, 1995), two researchers, one an expert in qualitative research methodology, independently coded the transcripts. Theory was peripheral rather than central to this work (Sandelowski, 1993) and was based on our understanding and application of some aspects of narrative theory — that is, the assumption that patients' voices can and should prevail over the theoretical voice of the researchers.

Therefore, we looked for repetitive patterns in the open-ended questions and organized these into themes.

Results

The response rate of eligible patients approached by the RA was 89.8% for completion of both questionnaires administered; 10.2% declined participation mainly for the reason of “not having the time” or “being tired when approached”; in a few cases the reason was “not being interested.” Overall, 10.2% of those approached by the RA did not meet the inclusion criteria; the most common reason was “language barrier” or “not being able to read or understand the questions.” The characteristics of the 412 participants are summarized in Table 1.

Variable	Characteristics
Gender	Female <i>n</i> = 266 (65%)
Age: <i>mean (SD)</i>	64.8 years (11.06) (<i>range</i> = 35–89)
Surgery type	TKR <i>n</i> = 259 (63%);THR <i>n</i> = 153 (37%)
Unit of discharge	Acute care <i>n</i> = 291 (71%) STR <i>n</i> = 121
Length of stay: <i>mean (SD)</i>	Acute care: 5.1 days (<i>range</i> = 3–15) STR: 8.8 days (<i>range</i> = 5–19)

Table 2 summarizes the mean scores by item in the ICS-A and ICS-B. Missing data are also captured by item, the lowest being 0.7% and the highest 5.3%. Several ICS-B items describing patients' care experiences ranked higher than the related ICS-A items, which describe specific nursing interventions; for example in item 13a, *nurses asked me what I want to know about my condition*, 60.3% of respondents agreed or strongly agreed, versus 86.2% in item 13b, *I have received sufficient information about my condition*. Items with the highest percentage of respondents disagreeing or strongly disagreeing included mainly ICS-A items and only a few ICS-B items.

Table 3 displays the pattern matrix factor loadings for the ICS-A. The unrotated variance components were 53.5, 8.8, 6.7 for the three factors, compared to 23.6, 22.6, 23.0 for the rotated factors. With the exception of two items, the loading patterns support the three-factor structure proposed by the measure's developer. Table 3 also reports the pattern matrix

Table 2 Item Means, SDs, Missing Data, Strongly Agree / Agree With Statement

ICS-A Abbreviated Items	n	Mean (SD)	Missing Data %	Agree %
<i>The nurses:</i>				
1a talked with me about feelings I have	408	3.93 (1.23)	1.2	70.8
2a talked with me about my care needs	410	4.35 (1.03)	0.7	83.7
3a gave me the chance to assume responsibility for my care	407	4.51 (0.90)	1.5	88.7
4a identified changes in how I have felt	403	3.99 (1.09)	2.4	72.0
5a talked with me about fears and anxieties	395	3.57 (1.34)	4.4	59.3
6a made an effort to find out how the condition has affected me	401	3.57 (1.28)	2.9	60.6
7a talked with me about what my condition means to me	397	3.36 (1.33)	3.9	49.8
8a asked me what kind of things I do in my everyday life	404	3.30 (1.44)	2.2	48.8
9a asked me about my previous experiences of hospitalization	405	2.93 (1.44)	1.9	36.5
10a asked me about my everyday habits	404	2.89 (1.45)	2.2	35.2
11a asked me whether I want my family to take part in my care	409	3.31 (1.53)	1.0	51.8
12a made sure I understood instructions received	406	4.25 (1.07)	1.7	82.3
13a asked me what I want to know about my condition	403	3.67 (1.30)	2.4	60.3
14a listened to my personal wishes with regard to my care	405	4.01 (1.13)	1.9	70.7
15a helped me take part in decisions concerning my care	403	3.95 (1.21)	2.4	68.3
16a helped me express my views on my care	401	3.69 (1.23)	2.9	58.4
17a asked me what time I would prefer to wash	406	3.51 (1.47)	1.7	57.9

ICS-B Abbreviated Items					
1b	Feelings about condition taken into account	389	3.85 (1.17)	3.6	66.3
2b	Care needs taken into account	402	4.18 (1.06)	2.7	79.6
3b	I assumed responsibility for my care	406	4.58 (0.73)	1.7	94.1
4b	Changes in how I felt taken into account	398	4.12 (0.98)	3.6	75.5
5b	Fears and anxieties taken into account	399	3.93 (1.14)	3.4	56.4
6b	Effects of condition taken into account	404	3.98 (1.10)	2.2	70.3
7b	Meaning of condition taken into account	401	3.86 (1.16)	2.9	65.4
8b	Activities in everyday life taken into account	402	3.58 (1.31)	2.7	52.8
9b	Previous hospital experiences taken into account	391	3.58 (1.35)	5.3	44.7
10b	Everyday habits taken into account	403	3.58 (1.32)	2.4	56.4
11b	Family involved in care	403	4.20 (1.12)	2.4	77.4
12b	I followed instructions I have received	400	4.68 (0.74)	3.1	94.5
13b	I have received sufficient information about my condition	406	4.36 (1.03)	1.7	86.2
14b	My hopes/wishes have been taken into account in my care	403	4.02 (1.09)	2.4	70.3
15b	I have taken part in decision-making concerning my care	404	4.23 (0.99)	2.2	80.4
16b	Opinions I expressed have been taken into account in my care	400	4.18 (0.99)	3.1	77.3
17b	I made my own decision on when to wash	407	4.14 (1.25)	1.5	77.9

Table 3 Pattern Matrix Factor Loadings for the ICS			
ICS-A	Component		
	1	2	3
ICS10a	.877		
ICS9a	.877		
ICS8a	.740		
ICS11a	.572		
ICS17a	.563		
ICS14a		.816	
ICS15a		.807	
ICS3a	-.406	.738	
ICS16a		.638	
ICS12a		.609	
ICS13a		.489	
ICS1a			.813
ICS5a			.753
ICS4a			.716
ICS6a			.687
ICS7a	.491		.604
ICS2a		.495	.546
Subscales as conceived by developer:			
Clinical Situation: ICS1a, ICS2a, ICS3a, ICS4a, ICS5a, ICS6a, ICS7a			
Personal Life Situation: ICS8a, ICS9a, ICS10a, ICS11a			
Decisional Control Over Care: ICS12a, ICS13a, ICS14a, ICS15a, ICS16a, ICS17a			
ICS-B	Component		
	1	2	
ICS8b	.972		
ICS7b	.919		
ICS9b	.912		
ICS10b	.881		
ICS6b	.811		
ICS5b	.755		
ICS1b	.638		
ICS14b	.580		
ICS4b	.562		
ICS2b	.520		
ICS12b		1.0	
ICS3b		.902	
ICS15b		.619	
ICS16b		.557	
ICS13b		.531	
ICS11b		.512	
ICS17b		.339	
Subscales as conceived by developer:			
Clinical Situation: ICS1b, ICS2b, ICS3b, ICS4b, ICS5b, ICS6b, ICS7b			
Personal Life Situation: ICS8b, ICS9b, ICS10b, ICS11b			
Decisional Control Over Care: ICS12b, ICS13b, ICS14b, ICS15b, ICS16b, ICS17b			
<i>Note:</i> See Table 2 for details of specific items.			

factor loadings for the ICS-B. A two-factor structure rather than the three-factor structure proposed by the measure's developer was supported. The unrotated variance components were 54.0, 9.6 for the two factors, compared to 35.6, 28.0 for the rotated factors. Examination of the initial component matrices for the ICS-A and ICS-B revealed that all items loaded > 0.54 for ICS-A and > 0.49 for ICS-B. Cronbach's alpha was 0.94 for both scales. Given the magnitude of these factor loadings and internal consistency coefficients, all ICS-A items were summed to form a single score and all ICS-B items were summed to form a second single score. The distributions of the ICS-A and ICS-B scores were not consistent with a normal distribution. Accordingly, median and percentile values are reported as measures of central tendency and dispersion in Table 4. Spearman's rank order correlations between the Schmidt total and the ICS-A and ICS-B totals were 0.76 (95% CI: 0.72, 0.80) and 0.80 (95% CI: 0.77, 0.83), respectively.

Measure	Median (25th, 75th percentiles)	Cronbach's α
ICS-A (17 items)	64 (52, 76)	0.94
ICS-B (17 items)	70 (60, 81)	0.94
Schmidt (15 items)	65 (56, 73)	0.96

The total scores of neither the ICS-A ($\bar{d} = 0.60, t_{346} = -0.35, p = 0.73$) nor the ICS-B ($\bar{d} = 1.05, t_{347} = 0.73, p = 0.47$) differed between patients aged ≥ 65 and patients aged < 65 . The SPNCS scale did detect differences in these age groups ($\bar{d} = 3.04, t_{377} = 2.60, p = 0.010$). Length of stay was not associated with the ICS-A ($r = -0.06, p = 0.25$) or the ICS-B ($r = -.03, p = 0.55$). Also, discharge unit (acute-care vs. STR) was not associated with the ICS-A ($\bar{d} = 0.13, t_{347} = 0.07, p = 0.95$) or the ICS-B ($\bar{d} = 0.92, t_{348} = 0.57, p = 0.57$).

For almost all items, males' agreement with the statements of both scales was slightly higher than females'. However, there was a non-significant difference between females and males for the total score means of the ICS-A ($\bar{d} = 2.95, t_{347} = 1.67, p = 0.10$) and the ICSB ($\bar{d} = 2.58, t_{348} = 1.70, p = 0.09$).

Qualitative Feedback

The themes we identified related to positive experiences of nursing care, negative experiences of nursing care, nurses as overworked, and a sense

that patients encounter many nurses during a hospital stay and therefore cannot respond to questions about “nursing care” that merge this multiplicity of experiences into one category. Finally, some patients indicated that they did not want nurses to ask about their feelings, which suggests that this item on a questionnaire should be contextualized, perhaps by asking patients if such care is desired before asking if it was provided.

For the most part, the nurses were described positively, with adjectives such as “professional,” “caring,” and “excellent” used frequently to describe their work. Following are some of the comments written: “everyone on staff is so pleasant to interact with,” “this has been a very positive experience,” “the nursing care has been excellent,” “my preferences and concerns have been recognized,” “my progress has been carefully monitored and assessed.”

However, respondents also indicated that questions about nurses’ interventions were difficult to answer, as the survey asks about nurses as a single, homogeneous group. One participant wrote: “nursing staff is not a single entity — they are individuals: on a scale of 1 to 10, I had several 10s, several 5s and at least one -1.” When patients described a negative encounter they often stressed that it was not representative of the overall care they had received and that this confounded their ability to rate their nursing care overall. One patient wrote: “I found nurse x hostile, sarcastic and somewhat uninterested — I would not have mentioned it, but it was so much in contrast to what was provided by all the remaining staff.”

Of those respondents who reported problems with their nursing care, most attributed this to the nurses being “overworked” and “rushed.” Several people believed that poor nursing was related to lack of funding and low staff-to-patient ratios. One patient commented, “Lack of funds is the number one reason why the nursing staff are unable to be more one on one, or attentive with me as a patient.” Many commented that the nurses’ workload was too large, preventing them from spending more time with patients individually.

Specific instances of poor nursing care were cited. These included the following: family members being asked to leave the bedside for the night, patients being left in a wet bed due to leaking ice bags for over 2 hours, patients being left on the bedpan for over an hour, patients not being properly hooked up to the call button, and patients not having their beds properly anchored. However, in general, participants indicated that such poor nursing care was an exception. One respondent summed up her opinion this way: “I wish this questionnaire had dealt with isolated incidences; 99% of the staff was very good but I had one really bad experience.”

Finally, participants commented on the overall survey design. Some felt that the focus on “feelings” was not appropriate or useful. One

respondent wrote: "I was not asked all the 'touchy feely' questions noted in this survey; I felt the questions were cliché-riddled and not relevant."

Discussion

In this Canadian sample of patients hospitalized for THR and TKR, the factorial validity of the adapted English version of the 34-item ICS was not fully supported. The three subscales in ICS-A — the patient's clinical situation, personal life situation, and decisional control over care — were supported with the exception of two items: 3a (*gave me the chance to assume responsibility for my care*) and 17a (*having a choice when to wash*). The subscales in ICS-B were not supported, with the items making up personal life situation not loading as a separate factor. It is possible that these findings are related to the sample. In prior research, general orthopedic and trauma patients were studied. Also, the mean age of the sample was 8 years older in this Canadian study than in Suhonen, Valimäki, et al.'s (2009) international comparative study. Between-country differences have also been reported and may have influenced the findings (Suhonen, Berg, et al., 2009). As described by Suhonen et al., it is not known whether these differences result from differences between cultures, nursing-care practices, health-professional roles, or patient-related factors (Suhonen, Berg, et al., 2009). It should be noted, however, that the sample is considered representative of the Canadian THR and TKR population, as the gender distribution and age of the sample are reflective of current trends reported in the 2008–09 annual report of the Canadian Joint Replacement Registry (Canadian Institute for Health Information, 2009).

Due to the results of the factor analyses, reliability and other descriptive estimates were not reported for the subscales. The Cronbach's alpha estimates of 0.94 for the ICS-A and ICS-B in this sample compare favourably with estimates in the literature. Consistent with prior findings, there was also evidence of convergent construct validity in that the sum of the ICS-A and the ICS-B displayed good correlation with the sum of the SPNCS (Suhonen et al., 2005). Interestingly, neither the ICS-A nor the ICS-B discriminated between patients under and over 65, whereas the SPNCS scale did discriminate between the two age groups. In the study by Suhonen, Valimäki, Katejisto, and Leino-Kilpi (2006), age was found to be predictive of positive perceptions of individual care. The findings of that study were similar to ours in terms of length of stay and gender.

Comparing this study's item means with the item means in the Suhonen et al. (2005) study, patient perceptions in the European sample were comparable to those in the Canadian sample. For example, lower

means were obtained for more personal questions related to everyday life activities and habits. The present study confirmed previous findings (Land & Suhonen, 2009; Suhonen et al., 2008) that not all nurses ask patients about their personal habits, everyday life activities, and previous experiences with hospitalization, but added the insight that not all patients desire this type of exchange. Our results do not provide a clear picture of the importance to patients of nurses getting to know them as a person. One patient commented that she had already provided information about her personal life on the preoperative questionnaire and that this would give nurses what they required in order to care for her. At this hospital, all patients provide comprehensive information about their personal life situation preoperatively and the information is accessible to all health-care providers, which might have influenced the way respondents answered this survey question. Another patient stated that nurses have many responsibilities and that the inclusion in care of more personal aspects is not needed. These statements could be consistent with the view of many patients. Interestingly, Lynn and McMillen (1999) found that when patients were asked to rank elements of nursing care, they did not value the need for nurses to *know who they are as a person*. Of 90 items, this item ranked 83rd. In the same study, nurses also ranked this item low (72nd). This large study conducted in the southeastern United States comprised 448 patients and 350 nurses from seven hospitals and a total of more than 40 medical/surgical units. In a similar study by Larrabee and Bolten (2001), in the category “caring about me” the item *getting to know you* was important to only 34% of the 199 medical/surgical patients surveyed prior to discharge. More qualitative studies should be conducted to investigate how nurses experience patients’ wishes with respect to sharing more personal aspects of their lives. Studies could also further explore how important it is for nurses to “get to know” their patients. In addition, in order to conceptualize close-ended questions, patients should first be asked if questions on specific nursing interventions are desired. This means that researchers should explore what is really important to patients in specific health-care settings before asking if an intervention has been completed by staff, as it may not even be of concern to the patients.

In this Canadian sample, the patients apparently experienced greater family involvement than those in the European sample (Suhonen et al., 2008) (ICS-A, 3.31 vs. 2.67; ICS-B, 4.20 vs. 3.58). This finding cannot be generalized to other Canadian hospitals but might confirm this joint replacement centre’s particular focus on family involvement. Family members at the hospital are encouraged to become “coaches” and to accompany the patient through the whole experience, from pre-admission to post-discharge.

Many patients commented that this survey was difficult to answer because it aggregated all nurses who provided care for the patient together and it was hard to think in terms of an average. It seems likely that some respondents who had one or few negative experiences amongst many positive ones chose to give a neutral response (neither *agree* nor *disagree*) whereas others selected *disagree to some extent* or *disagree*. In addition, patients expressed clearly that they wanted to comment on their individual stories and that the design of the study did not include the option of exploring their individual perceptions of interactions with specific nurses. It now seems somewhat paradoxical to use a standardized survey approach to assess patient perceptions of individuality in the care they received. It is interesting that no publications on the results of the ICS include a discussion of such conflict experienced by respondents. There are no reports that respondents in the European studies chose to provide handwritten comments to supplement their perceptions. Future qualitative studies might enhance our understanding of this phenomenon from a patient perspective.

Some patients perceived nurses as busy, overworked, and rushed, with little time to listen, talk, and provide more individualized care. The increase in patient admission rates and the significant decrease in length of hospital stay associated with Ontario's strategy to decrease THR and TKR wait lists has indeed affected this hospital's nursing units and might have influenced patient perceptions of nurses' workload. Although health-care delivery models and resources available to support care are under constant scrutiny and budgetary evaluation, little seems to be done to educate patients on current realities in health-care delivery, such as nurse-to-patient ratios. Recent work by Suhonen et al. (Suhonen, Gustafsson, Katajisto, Valimaki, & Leino-Kilpi, 2010a, 2010b; Suhonen, Valimaki, & Leino-Kilpi, 2009) describes driving and restraining forces for the provision of individualized nursing care, including staffing, organization of work, and nurses' personal characteristics. The qualitative findings of our study indicate that nurses' personal characteristics might play an important role in how patients perceive the care they receive. While all nurses at this centre have a comparable workload, apparently some are able to respond to individual patient needs better than others. Personal characteristics might include a nurse's individual values, work organization, approach, and attitude. It is not uncommon to observe nurses telling patients how busy they are, that they do not have time, and that they have to care for a number of other patients. Such remarks contribute to patients' perceptions that nurses are overworked or that the facility is understaffed. Nurse leaders should provide education and support by discussing the impact of nurses' comments on patients' perceptions.

The generally higher ratings for the ICS-B might be a result of these items being perceived as not specific to nursing care but as relating to the care provided by the interprofessional team. For example, patients might have received information about their condition from professionals in a variety of health-care disciplines, which then resulted in a higher rating for item 13 in the ICS-B compared to the ICS-A. However, it can only be speculated that the higher means are a result of patients evaluating the care experience in general and not nursing care in particular. Respondents also reported that they could not answer some of the questions as they found them to be irrelevant to their particular situation. For example, both the ICS-A and the ICS-B include an item about previous experiences with hospitalization. It is not clear if those respondents who had never been hospitalized before chose not to answer, selected the neutral response, or disagreed with the statement. Some respondents also suggested that some questions were ambiguous. However, the number of missing item responses was not high (Table 2) and in fact was lower than that reported by Suhonen et al. (2005).

Our study had several strengths, including the representativeness of the sample of the Canadian arthroplasty population and the rigour with which data were collected. Ongoing communication with the RA allowed for early identification of respondents' wish to provide additional information and hence the suggestion that they write their comments on the back of the questionnaire. These additional data deepened our understanding of the patient perspective on not only the care received but also the survey instrument. A limitation of the study was the exclusion from the questionnaire of two statements used in the recent European international ICS study: *It is important that nurses care for me as an individual* and *During hospitalization the nurses cared for me as an individual*. In that study, the majority of patients in Finland (89%), Sweden (97%), and the United Kingdom (80%) agreed strongly or to some extent that it was important for them to be cared for as an individual, whereas in Greece only 71% considered this important (Suhonen et al., 2008). The agreement was somewhat lower when patients were asked if nurses cared for them as an individual, with only 55% of the UK sample strongly agreeing (Land & Suhonen, 2009). However, our study's additional qualitative data provide insight into what seems to be important to the Canadian patient population. A strong message emerged from the many pages of handwritten notes: that it is most important that all basic care needs be met, such as toileting, and that patients not have to endure any "unpleasant" encounter with a nurse.

Implications and Future Directions

Further research is needed to determine the best methods for evaluating dimensions of patient-centred care. As expressed by one quarter of the participants, many patients might prefer to share their individual stories by commenting on the care provided by specific nurses than to complete a survey that tends to aggregate all nurses into one category. Patient experiences also need to be contextualized in order to provide a better understanding of how their evaluation of particular aspects of care aligns with their preferences, such as being asked about their personal feelings. The findings also highlight the importance of continuous evaluation of the quality of nursing care and the need for future research to examine organizational culture and the characteristics of nursing care delivery as well as unit structures and processes. The findings demonstrate the need for ongoing nursing management investigation of isolated incidences of poor nursing care, as reported by some patients. Unit leaders are responsible for obtaining ongoing individual patient feedback and following up on any concerns identified.

Finally, nurse leaders must assume responsibility for implementing strategies that improve care dimensions such as emotional support, an area that commonly does not score well. Nurses need to be adequately prepared to incorporate patient-centred approaches into their routine practice. Targeted interventions could include the use by all staff of standard open-ended questions (such as What is on your mind today?) that promote communication between patients and health-care providers. Aside from asking such specific questions, nurses must be encouraged to become more attentive and comfortable with whatever information their patients choose to share with them.

References

- Atwal, A., & Caldwell, K. (2002). Do multidisciplinary integrated care pathways improve interprofessional collaboration? *Scandinavian Journal of Caring Sciences*, 16(4), 364–367.
- Canadian Institute for Health Information. (2009). *Hip and knee replacements in Canada — Canadian Joint Replacement Registry (CJRR) 2008–2009 annual report*. Ottawa: Author.
- Dana, S. N., & Wambach, K. A. (2003). Patient satisfaction with an early discharge home visit program. *Journal of Obstetric and Gynecological Neonatal Nursing*, 32(2), 190–198.
- Davis, S., Byers, S., & Walsh, F. (2008). Measuring person-centred care in a sub-acute health care setting. *Australian Health Review*, 32(3), 496–504.
- De Bleser, L., Depreitere, R., De Waele, K., Vanhaecht, K., Vlayen, J., & Sermeus, W. (2006). Defining pathways. *Journal of Nursing Management*, 14(7), 553–563.

- Dozier, A. M., Kitzman, H. J., Ingersoll, G. L., Holmberg, S., & Schultz, A. W. (2001). Development of an instrument to measure patient perception of the quality of nursing care. *Research in Nursing and Health, 24*(6), 506–517.
- Hobbs, J. L. (2009). A dimensional analysis of patient-centered care. *Nursing Research, 58*(1), 52–62.
- Ilott, I., Rick, J., Patterson, M., Turgoose, C., & Lacey, A. (2006). What is protocol-based care? A concept analysis. *Journal of Nursing Management, 14*(7), 544–552.
- Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Retrieved October 10, 2010, from http://www.nap.edu/html/quality_chasm/reportbrief.pdf.
- Jenkinson, C., Coulter, A., Reeves, R., Bruster, S., & Richards, N. (2003). Properties of the Picker Patient Experience Questionnaire in a randomized controlled trial of long versus short form survey instruments. *Journal of Public Health Medicine, 25*(3), 197–201.
- Land, L., & Suhonen, R. (2009). Orthopaedic and trauma patients' perceptions of individualized care. *International Nursing Review, 56*(1), 131–137.
- Larrabee, J. H., & Bolden, L. V. (2001). Defining patient-perceived quality of nursing care. *Journal of Nursing Care Quality, 16*(1), 34–60, quiz 74–35.
- Lynn, M. R., & McMillen, B. J. (1999). Do nurses know what patients think is important in nursing care? *Journal of Nursing Care Quality, 13*(5), 65–74.
- Muntlin, A., Gunningberg, L., & Carlsson, M. (2006). Patients' perceptions of quality of care at an emergency department and identification of areas for quality improvement. *Journal of Clinical Nursing, 15*(8), 1045–1056.
- Radwin, L. E., & Alster, K. (2002). Individualized nursing care: An empirically generated definition. *International Nursing Review, 49*(1), 54–63.
- Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science, 16*(2), 1–8.
- Sandelowski, M. (1995). Qualitative analysis: What it is and how to begin. *Research in Nursing and Health, 18*(4), 371–375.
- Schmidt, L. A. (2003). Patients' perceptions of nursing care in the hospital setting. *Journal of Advanced Nursing, 44*(4), 393–399.
- Schmidt, L. A. (2004). Patients' perceptions of nurse staffing, nursing care, adverse events, and overall satisfaction with the hospital experience. *Nursing Economics, 22*(6), 295–306, 291.
- Streiner, D. L. (1994). Figuring out factors: The use and misuse of factor analysis. *Canadian Journal of Psychiatry, 39*(3), 135–140.
- Suhonen, R., Berg, A., Idvall, E., Kalafati, M., Katajisto, J., Land, L., et al. (2008). Individualised care from the orthopaedic and trauma patient's perspective: An international comparative survey. *International Journal of Nursing Studies, 45*(11), 1586–1497.
- Suhonen, R., Berg, A., Idvall, E., Kalafati, M., Katajisto, J., Land, L., et al. (2009). European orthopaedic and trauma patients' perceptions of nursing care: A comparative study. *Journal of Clinical Nursing, 18*(20), 2818–2829.
- Suhonen, R., Gustafsson, M. L., Katajisto, J., Valimaki, M., & Leino-Kilpi, H. (2010a). Individualized care scale – nurse version: A Finnish validation study. *Journal of Evaluation in Clinical Practice, 16*(1), 145–154.

- Suhonen, R., Gustafsson, M. L., Katajisto, J., Valimaki, M., & Leino-Kilpi, H. (2010b). Nurses' perceptions of individualized care. *Journal of Advanced Nursing*, 66(5), 1035–1046.
- Suhonen, R., Leino-Kilpi, H., & Valimaki, M. (2005). Development and psychometric properties of the Individualized Care Scale. *Journal of Evaluation in Clinical Practice*, 11(1), 7–20.
- Suhonen, R., Schmidt, L. A., & Radwin, L. (2007). Measuring individualized nursing care: Assessment of reliability and validity of three scales. *Journal of Advanced Nursing*, 59(1), 77–85.
- Suhonen, R., Valimaki, M., & Katajisto, J. (2000). Developing and testing an instrument for the measurement of individual care. *Journal of Advanced Nursing*, 32(5), 1253–1263.
- Suhonen, R., Valimaki, M., Katajisto, J., & Leino-Kilpi, H. (2006). Patient characteristics in relation to perceptions of how individualized care is delivered – research into the sensitivity of the Individualized Care Scale. *Journal of Professional Nursing*, 22(4), 253–261.
- Suhonen, R., Valimaki, M., Katajisto, J., & Leino-Kilpi, H. (2007). Provision of individualised care improves hospital patient outcomes: An explanatory model using LISREL. *International Journal of Nursing Studies*, 44(2), 197–207.
- Suhonen, R., Valimaki, M., & Leino-Kilpi, H. (2002). “Individualised care” from patients', nurses' and relatives' perspective – a review of the literature. *International Journal of Nursing Studies*, 39(6), 645–654.
- Suhonen, R., Valimaki, M., & Leino-Kilpi, H. (2009). The driving and restraining forces that promote and impede the implementation of individualised nursing care: A literature review. *International Journal of Nursing Studies*, 46(12), 1637–1649.
- Suhonen, R., Valimaki, M., Leino-Kilpi, H., & Katajisto, J. (2004). Testing the Individualized Care Model. *Scandinavian Journal of Caring Sciences*, 18(1), 27–36.
- Van Den Berg, H. (2005). Reanalyzing qualitative interviews from different angles: The risk of decontextualization and other problems of sharing qualitative data. *Forum: Qualitative Social Research*, 6(1), art. 30.
- Woolf, S. H., Grol, R., Hutchinson, A., Eccles, M., & Grimshaw, J. (1999). Clinical guidelines: Potential benefits, limitations, and harms of clinical guidelines. *British Medical Journal*, 318(7182), 527–530.

Acknowledgements

This project was funded through one of the organization's annual Practice Based Research Awards.

We are grateful for the tremendous support received from the following: Alvin Ho-Ting Li, Research Assistant; Margaret Blastorah, Director of Nursing Research and Knowledge Translation; Anne Marie MacLeod, Operations Director at the Holland Centre; and Professor Paul Stratford at McMaster University for his expert methodological and statistical support. We would like to thank Dr. Riitta Suhonen and Dr. Lee

A. Schmidt for allowing us to use their scales for the purposes of this study. We are also grateful for the support received from Dr. Suhonen when approached with questions.

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Book Review

***Staying Alive: Critical Perspectives on Health, Illness and Health Care* (2nd ed.)**

Edited by Toba Bryant, Dennis Raphael, and Marcia Rioux
Toronto: Canadian Scholars' Press, 2010, 450 pp.
ISBN 13-978-1-55130-370-3

Reviewed by Helen Vandenberg

Critical theoretical approaches are becoming increasingly popular in health-care scholarship. Many nursing researchers now utilize critical theoretical approaches to understand and critique political, economic, and social injustices related to health and health care.

This accessible and well-organized book is divided into four sections. In the first section, the authors describe common conceptual perspectives used to develop knowledge about health and health care, including epidemiological, sociological, political economy, and human rights perspectives. The authors briefly discuss how health studies are shaped by various knowledge paradigms, including positivism, idealism, and realism. Particular attention is paid to various critical analyses, including how researchers employ critical theoretical perspectives to uncover power structures, critique social injustices, and strive towards eliminating inequities.

In the second section, the authors describe how broader social structures such as class, gender, race, and public policy influence the health of societies. The authors critique the influence of neoliberalism and individualism and explain how these ideologies help to depoliticize health care by drawing attention away from broader political, social, and economic determinants of health. They argue that health-care providers must begin to question the dominance of the medical model and the narrow focus of health care at the level of individual behavioural choices, lifestyle, and biology.

In the third section Bryant, Raphael, and Rioux provide a historical overview of the health-care system in Canada. Comparisons are made with the American health-care systems to raise questions about the movement towards privatization. The authors discuss how current financial, jurisdictional, and organizational features of the Canadian health-care system contribute to health inequities. They reveal how key features of the Canadian system, such as private practice-public payment

and federal payment–provincial delivery, are maintained by key players seeking to protect their interests and maintain the status quo.

In the final section of the book, critical perspectives are used to draw attention to several important issues in health care. The authors analyze how health care shapes and is shaped by constructions of gender and disability. They examine how pharmaceutical use and public health have been influenced by political and economic factors. In the final chapter the authors provide an eloquent summary of the key themes of *Staying Alive*. One of the highlights of this section concerns the growing evidence for the impact of social determinants on health worldwide. The authors argue that governments address this evidence according to their political commitment to equitable resource allocation. For example, in Canada and the United States there tends to be less support for resource sharing, while in the United Kingdom, Sweden, and Norway there tends to be more support. There is now compelling evidence showing that those countries that tend to share resources and wealth have healthier populations.

Bryant, Raphael, and Rioux provide an excellent selection of evidence for the strengths of critical perspectives in health and health care. With looming shortages of health-care providers, increasing burnout, monetary inefficiency, and growing demands, the critiques provided in this book are timely and essential. Nevertheless, the volume leaves the reader wanting more. Little is suggested about how the broader social, political, and economic determinants of health might be addressed. Emphasis is placed on helping health-care providers understand and develop more equitable public policies, but is this enough? Further analysis and debate are needed regarding approaches to change. Health-care providers will not be able to change the status quo without resistance from powerful players, nor without losses from attempts to critique dominant structures. Action strategies must be debated before we can have a clearer picture of potential possibilities and pitfalls. Thinking through these solutions and challenges will help to prepare health-care providers for the struggle ahead.

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