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**CJNR**

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EDITORIAL

## **A Salute to Our Reviewers: Partners in the Scientific Endeavour**

It has become a tradition at *CJNR*, in the final issue of each volume, to publish the names of those who have served as reviewers during the preceding year, as a way of publicly acknowledging their vital contribution to the Journal. We think of our reviewers as partners. As editors we rely heavily on their assessments and evaluations in our deliberations on what will be published in the pages of *CJNR*. This means that we share responsibility with our reviewers for what appears in print. We draw on their expertise to assess the conceptual basis and scientific merit of a research study and to ensure the integrity of what we publish. The feedback and direction that their critiques provide us and our authors lead to improved manuscripts. As we have stated in *CJNR*'s editorial pages over the years, through their comments to editors and authors, reviewers make essential contributions to the development of science, particularly nursing science.

In recent years there has been much debate about the strengths and weaknesses of the peer-review system, including examination of the costs and benefits to the individuals concerned and a search for alternative methods of assessment. This is a subject that has been reviewed and revisited continually (e.g., British Academy, 2007). While members of a number of disciplines have critiqued peer review and pointed out its flaws, no one has been able to come up with a better model for assessing quality. Warts and all, peer review remains the “gold” standard for judging the quality of scholarly work and a fundamental characteristic of scholarly journals, distinguishing them from other means of publishing research. But this standard can be upheld only if reviewers possess the knowledge and experience needed to expertly and fairly critique and judge the quality of a research study.

The peer-review system fulfils the same function for the scientific community and its consumers that Health Canada does for the food industry: When it works, it is one of the best ways to safeguard the research consumer and the public against insufficiently documented or even fraudulent results and against research practices that can endanger public health and undermine the public trust.

Thus a well-functioning peer-review process ranks at the top of the list of components that are critical to a journal's success. When Dr. Gottlieb assumed the editorship of *CJNR* 15 years ago, the Journal had but a handful of reviewers on its roster. Few of these were doctorally prepared and the quality of their reviews tended to be uneven, reflecting the state of the Canadian nursing research community at the beginning of the 1990s. Very early on, the editorial staff realized that the future of *CJNR* and its quality were directly related to the quality of the reviews. With the assistance of leaders in nursing academia and practice across the country and around the world, we extended our reviewer base. As submissions to *CJNR* have grown more specialized and more sophisticated, we have also come to draw, when appropriate, on the expertise of methodology and content specialists outside of nursing. Systems have been put in place, at the initiative of former Associate Editor Dr. Anita Gagnon, to ensure continued improvement in the quality of reviews. These have included orientation packages for new reviewers and feedback to reviewers, most recently in the form of sharing each reviewer's comments with the other reviewers. Currently we have an army of more than 350 reviewers upon whom we can call, and each year we extend invitations to many additional ones.

### **Caveat Lector**

In recent years there has been growing concern within the scientific community about published studies that purport to be scientific but have not been peer reviewed. This situation has come about with the exponential increase in online publishing and in the number of journals that purport to be peer reviewed but in reality are not. In October 2007 the watchdog of biomedical publishing, the Worldwide Association of Medical Editors (WAME), issued a policy statement defining what constitutes a peer-reviewed journal: "To be considered peer reviewed, a journal must obtain *external reviews* for the *majority of manuscripts* it publishes including all original research and review articles... To be considered peer review, a manuscript should have been reviewed by at least one external reviewer: it is typical to have *two reviewers* and sometimes more [whose] opinions are sought" ([www.WAME.org/resources/policies#definition](http://www.WAME.org/resources/policies#definition); italics ours). *CJNR* meets and even exceeds all of these criteria.

We are well aware of the costs to the researcher of submitting to a peer-reviewed journal: the time-consuming nature of the process and uncertainty about the outcome. The researcher may need to resubmit a paper several times, or even to submit it to several journals, before it is ultimately accepted. Both junior and senior investigators can be tempted,

for the sake of expediency or for other, less noble, reasons (arrogance, desperation, etc.), to choose non-peer-review means of disseminating their findings as final results (rather than as preliminary or speculative results). Certainly, different avenues are suitable for different types of work, or work in different phases of refinement. However, it is exceedingly rare that a serious scholarly work intended for wide consumption will leave its author's desk free of errors and omissions. Such a manuscript only stands to benefit from a second, a third, or even an eighth pair of eyes before being exposed to a broad audience. These additional pairs of eyes are what the peer-review system offers.

In nursing and in other fields, we have come to see that while all interesting ideas, well-written manuscripts, or provocative presentations are worthy of attention, those that have withstood the test of peer review occupy a special place. Sophisticated consumers of scholarship (whether or not they conduct research or write papers themselves) consider the source of any research or scholarly work — ignoring only the poorest and most flimsily documented work — basing their confidence in a particular study or paper partially on whether it appears in a publication that uses rigorous peer review. While most will agree that peer review is important, serious difficulties arise when a journal (or one of its authors) uses the label “peer reviewed” when the selection process does not meet the WAME criteria outlined above. When the term is misused, readers attempting to place the findings in context, or to assess the productivity of the researcher and the heft of his or her research program, are at a marked disadvantage — one could even say that they are at risk of being gravely misled.

There is a flip side to the problem of misinformation about just what kind of review a manuscript has undergone. It is unwise to assume that an article is free of shortcomings and mistakes in research design or in the reporting or interpretation of findings merely because it appears in a journal with a stringent peer-review process such as *CJNR*. At *CJNR* we aim to publish any manuscript that advances nursing or the health sciences, particularly if it has important implications for the Canadian context (this is becoming more of a challenge as the quantity and quality of submissions increase). We also make every attempt to ensure that the peer-review process is completed in a timely manner. We believe that, while no study is perfect, some value can be found in any manuscript as long as it is driven by an understanding of the basics of the research process and honest reporting and has stood the test of critical external review. So, while the peer-review and editorial processes are among our best means of identifying sound findings and valid, balanced conclusions, peer review cannot substitute for readers' critical reflection and healthy

scepticism. Peer review is a complement of, not a substitute for, vigorous and fair discussion about the correct interpretation of findings, especially when controversial issues, such as patient well-being, are on the line. And peer review of individual studies is only one part of the first phase of reaching a scientific understanding of a phenomenon or a treatment approach — such an understanding occurs far into a chain of scientific effort, once a critical mass of studies has appeared and has undergone careful systematic review. Still, every journey begins with a first step, and peer review of each new piece of the puzzle is a critical part of that first step.

### **Reciprocity and the Community of Researchers**

Do we find it difficult to find reviewers? We feel blessed to have reviewers who are committed to *CJNR* and to the advancement of nursing science. They are gracious and generous with their time, willing to share their talents and expertise. Generally, our reviewers make every attempt to comply with our requests and to submit their critiques within 4 weeks. When they decline, it is usually at the start or end of a semester or when grant-submission deadlines loom and time is at a premium. They tend to do so with apologies and great regret. On the whole, our relationship with reviewers has been extremely positive. We appreciate our good fortune, particularly in light of reports that many journal editors experience difficulty securing reviewers. Some journals have had to scale back the peer-review process (making do with fewer reviewers, asking reviewers for less extensive analyses, and conducting more reviews in house). Others have resorted to paying their reviewers, a practice more prevalent in for-profit publishing houses, which factor this into the cost of producing their journals.

Our reviewers, and those who review for other scholarly journals, subscribe to an ethos of sharing: They are willing to give of their time and knowledge because they know this is the right thing to do for the community of scholars and readers. They have bought into a system whereby, in exchange for having their own work reviewed, they give in kind. Also, they intuitively accept the unwritten rule of reciprocity that enables the peer-review system to function: The review process is part of the informal mentoring that we all receive throughout our careers; when we reach a point where we can give back, we do so.

All in all, there is much evidence that the partnership among authors, reviewers, and editors, which functions in a spirit of promoting and developing excellence, is running smoothly at *CJNR*. The majority of the original research submissions we receive represent good-faith efforts to produce sound work. We receive few complaints about unfair

or biased reviews and often receive expressions of genuine gratitude towards our reviewers. Revisions are submitted on time and rarely fail to address reviewers' comments and concerns. The vast majority of reviews are insightful, specific, and diplomatic. More often than not, they are exceptionally thorough, obviously the result of much time and effort. Reviewer satisfaction with the process also appears to be high, with reviewers nearly always agreeing to repeat assignments. Most importantly, we hear from readers, and see for ourselves, that the research contributions are more sophisticated and impressive with each successive volume of the Journal. This is not only a reflection of the maturation of the Canadian nursing research community, but also a tribute to our reviewers.

Our reviewers have invested heavily in *CJNR*, and the editors, authors, consumers, and the public are enjoying the dividends. May this vital partnership continue to grow stronger with each successive volume.

**Laurie N. Gottlieb, Editor-in-Chief**  
**Sean P. Clarke, Associate Editor**

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*Guest Editorial and Discourse*

**Relating the “Is-Ought Problem”  
to Nursing Inquiry**

**Franco A. Carnevale**

**Overview of Past and Current Contributions**

The publication of this *CJNR* focus issue on Ethics, Values, and Decision-Making provides an opportunity to review past and current trends in this area of nursing inquiry. I discuss these trends with regard to an under-articulated philosophical problem in the relation between empirical and normative research: the “is-ought problem.”

*CJNR* has been publishing focus issues since 1994. In 1997 an issue was devoted to Values and Decision-Making. This included two research articles, one on the development of a scale for measuring decision-making control preferences, the other an analytical comparison of two frameworks for investigating patients’ treatment preferences.

In 2002 the focus theme was expanded to Ethics, Values, and Decision-Making. The number of excellent submissions was so great that the editors decided to extend the focus over two issues, with six comprehensive articles under Ethics and Values and six under Decision-Making. The first instalment included two qualitative research reports, three analytical discussions of specific issues (incongruities between the nurse-patient relationship and the scientific paradigm, clinician beliefs and values underlying untreated pain, and a feminist framework for understanding hope), and a grammatical/linguistic analysis of the Canadian Nurses Association’s past and current codes of ethics. The second published four qualitative research reports and two analytical discussions; the latter examined surrogate decision-making and equipoise in clinical nursing research.

To date, the authors submitting to *CJNR* and the work accepted by the Journal reveal three trends: (1) an extension of the values and decision-making theme to explicitly include ethics, (2) the publication of a larger number of papers, and (3) articles that include analytical discussions as well as empirical reports — the latter have become exclusively qualitative.

It is now 10 years since the publication of the first focus issue on Values and Decision-Making. What is on the menu this time around? This issue of the Journal presents six major contributions: three qualitative research reports, a theoretically driven integrative analysis of a body of published qualitative studies, and two analytical discussions.

Judith MacDonnell explores the relevance of power relations for nursing ethical inquiry through a case study of community nurses in Ontario. She uses a qualitative design based on a feminist bioethics framework to examine public health nursing policy regarding research with diversely situated sexual minorities. Brenda Beagan and Carolyn Ells report on their analysis of qualitative interviews with 20 nurses regarding their moral experience of everyday work. The study examines nurses' professional values and how well they are able to enact them in their work. Ignasi Clemente presents findings identified through an innovative conversation analysis of ethnographic data. The article reports on clinicians' practices of partial disclosure of information to adolescents with cancer in Barcelona.

Anne Simmonds and Elizabeth Peter examine a series of published qualitative research reports on intrapartum nursing and midwifery using Margaret Urban Walker's expressive-collaborative model of morality. Walker's model is favoured for its focus on everyday practices and knowledge, as distinguished from the "theoretical-judicial" models that dominate clinical ethical discourse.

Judy Rashotte and Louise Jensen present an analytical discussion that explores the relationship of ethics to validity in hermeneutic phenomenological inquiry. They specifically examine how to engage in ethical questioning in hermeneutics. Finally, Mary Ellen Macdonald and Mary Ann Murray conduct a historical and theoretical analysis of the clinical use of the word *appropriate*. Referencing rhetorical theory, they argue that the word is used to "smuggle" values into clinical encounters, which serves to marginalize patients and compromise relationships.

Thus the scope of this collection of work is remarkably broad, from everyday concerns to policy, from the context of cancer to intrapartum nursing to sexual diversity, from North America to Spain. A wide diversity of theoretical frameworks is used, including hermeneutics, feminist inquiry, rhetorical theory, and an expressive-collaborative model of morality, as well as diverse qualitative research methodologies. It is striking that, since the publication of an article on the measurement of decision-making control preferences in 1997, no quantitative studies have been published in *CJNR* focus issues in this domain of inquiry. This may be attributable to the growing recognition of qualitative research methodologies in nursing inquiry as well as their strong suitability for

examining phenomena that are highly experiential and/or processual, common features of questions in ethics, values, and decision-making.

### Examining the Underlying Is-Ought Problem

The examinations of ethics, values, and decision-making described above scarcely entail normative analyses (e.g., investigations of the moral norms that are required for particular domains of nursing practice), although some of the analytical discussions touch on normative considerations. This domain of inquiry involves a complex philosophical problem that requires more explicit consideration: the is-ought problem.

The Scottish philosopher David Hume (1739/1978) points out in his *Treatise of Human Nature* that prescriptive (i.e., *ought*) inferences are frequently, and mistakenly, drawn from descriptive (i.e., *is*) statements or facts. For example, one may conclude that one should use corporal punishment as a means of disciplining one’s children because one’s own parents did so and most other people do so. The person is relying on what *is* the case (i.e., most people *do* strike their children as a means of controlling their behaviour) to judge what *ought* to be the case (i.e., people *should* strike their children as a means of controlling their behaviour).

Hume points out that this is a mistaken inference because the relations or affirmations expressed by *ought* or *ought not* are different from descriptions of empirical observations. An *ought* statement implies an ethical duty or obligation, whereas an *is* statement presents an empirical fact. The two are not substantively related. An *is* relation does not logically entail an *ought* obligation. To give another example, a study of nurses’ perspectives on severely disabled survivors of critical care could demonstrate that nurses regard these lives as highly compromised, suggesting that life-sustaining therapies may be excessively harmful. This observation does not morally imply that these lives should be ended.

Whereas *is* statements attempt to truthfully convey empirical facts, *ought* statements articulate ethical prescriptions. How, then, are *ought* statements to be formulated? Philosophers predominantly hold that *ought* statements need to be rooted in a moral philosophical framework (e.g., deontology, utilitarianism) and/or moral norms. For example, a specific norm such as the doctrine of informed consent is based on the moral value of respect for individual self-determination. The fact that the exercise of informed consent is time-consuming or even upsetting for patients, families, and clinicians does not disqualify the moral basis for seeking informed consent.

Facts do not necessarily involve moral relations. We need ongoing articulation of fundamental moral values, norms, principles, and/or

frameworks to continually inform the specification of particular ethical duties. Although early moral philosophical work affirmed the importance of respect for autonomy, further work has specified conditions and limits to this autonomy while affirming other moral values such as the sanctity of life. It is therefore widely acknowledged that an expressed desire to commit suicide involves different ethical responses from a refusal by a person of “sound mind” to accept medical therapy.

The is-ought problem raises an important question in nursing inquiry: How should empirical research relate to normative ethics research in nursing? The answer to this question can help to orient future discourse between these forms of inquiry.

A diversity of is-ought relations seems plausible for nursing. First, empirical data can inform ethical norms. For example, it is widely held that the benefits of treatments should outweigh the harms. Empirical data can help to determine the benefits and harms of specific treatments, strengthening the truth value of risk/benefit assertions. On the other hand, although empirical research may show how a treatment affects people, it cannot determine which effects are most morally significant. A study can demonstrate that mechanical ventilation for persons with a degenerative neuromuscular disorder can prolong life while documenting the accompanying pleasures and displeasures. However, the relative moral importance of longevity, suffering, or pleasure cannot be established exclusively through empirical research (although eliciting the opinions of the affected persons can be helpful). A cost/benefit analysis of a treatment will have to appeal to moral norms regarding the defensible value of each good and harm associated with the treatment. If all parents of children with end-stage heart disease reported that they would readily give up their own heart to save their child’s life, this empirical fact would not render such a practice ethically permissible. Moral philosophical analyses and norms relating to the value of life as an end in itself (and not a means to an end) limit the forms of personal “sacrifice” that would be morally defensible.

Second, empirical research may challenge the premises of existing ethical norms. For example, surrogate decision-making models commonly require family members to choose the treatment that the patient would have chosen if he/she could do so (i.e., the substituted judgement standard). Empirical research may demonstrate significant problems with this norm in practice. It may be difficult for the family member to truly take the patient’s perspective, project past discussions with the patient to this specific clinical situation, and dissociate one’s own wishes for the patient (i.e., one’s child, parent, spouse, or sibling) from what the patient would have wanted. Such empirical data would demonstrate the impracticability of an ideal form of surrogate decision-making, calling for

further specification of the norm — presenting a possibility for empirical and normative research to reciprocally inform each other.

Third, some empirical data may not be relevant to the content of ethical norms yet highlight problems related to the operationalization of a norm. For example, a study can demonstrate that persons facing particularly difficult situations, such as life-threatening illness, are incapable of managing the information required for them to make an informed decision about their care. Data can indicate that a person so desperately hopes for a positive outcome that he or she amplifies the likelihood of a favourable outcome and minimizes that of unfavourable outcomes. Informed consent is premised on a calculative form of reasoning that may at times be compromised. Clinicians are faced with the ethical imperative of ensuring informed consent while also attending to the patient with compassion regarding their limitations in managing such personally dire information. Such data can highlight the need to further develop the processual (i.e., “how to”) aspects of the norms in question.

Fourth, empirical data can help to identify the need for new ethical norms, by identifying moral dilemmas that were not previously recognized. For example, as success rates continue to improve in living-related organ transplantation (e.g., parent-to-child kidney transplantation), and as the demand for organs continues to exceed the supply, some persons are seeking to donate their organs to persons they do not know (“altruistic” organ donation). Is it permissible to allow a person to donate to a “stranger” an organ that he/she or a family member may need in the future? The donor and the recipient would enter into a weakly understood relational dynamic while maintaining confidential identities, providing the recipient with an opportunity to improve his/her quality of life and the donor to derive satisfaction from an altruistic act.

### **Explicitly Addressing the Is-Ought Problem in Nursing Inquiry**

The examples of is-ought relations discussed above should not be regarded as exhaustive. Many other relations can exist. The aim of this discussion is to illustrate the diverse forms of relationships that can be drawn between empirical data and ethical norms. The complex nature of the is-ought problem calls for explicit attention to empirical-normative relations in nursing inquiry, especially in the domain of ethics, values, and decision-making. Specifically, empirical research in this domain should be designed to directly address the normative implications of the findings. Such important issues should not be relegated to brief “future considerations” statements at the end of a Discussion section.

The articles published in this issue of the Journal do address this concern at one level or another. This is most explicitly evident in the

contribution by Simmonds and Peter, who use Walker's expressive-colaborative model of morality to examine the research literature on intrapartum nursing and midwifery.

I conclude this discourse with a couple of illustrations of how my collaborators and I have addressed the problem in our own research. We recently published the findings of a qualitative study of the moral experience of families with children living at home using assisted ventilation (Carnevale, Alexander, Davis, Rennick, & Troini, 2006). As we presented early analyses of our data, reporting the extraordinary distresses associated with these families' daily lives, we noted that our clinician audiences inferred that these were clearly "wrongful lives" — that we should rethink the position we were putting these children and families in and consider earlier withdrawal of life-sustaining therapies. An *ought* was directly inferred from our early empirical findings, using our data to inform risk/benefit assessments. This struck us as problematic, as we were not drawing the same conclusions from our research. It then became apparent that we were understating the forms of enrichment that these children and their families were deriving daily from their lives together. Our own "cost/benefit analysis" was much more complex. Furthermore, it was also evident that many of the so-called costs or burdens associated with the situation were, in principle, preventable. These included systematic discrimination against the child and family by community members, schools, and health professionals, as well as social and physical barriers in everyday life.

Our analysis showed that a patient-centred cost/benefit analysis failed to address the full range of morally relevant considerations. The study revealed that this population called for the examination of other moral matters, such as justice and social responsibility towards the provision of health and social services, questions about what form of life is morally worthwhile, and how to reconcile the patient's interests with those of other family members. Anticipating these complex issues, we planned a series of normative analyses to follow our empirical investigation, incorporating these into the study budget. In one paper we specifically examine the treatment decision-making implications of our data for this population (Cranley Glass & Carnevale, 2006). In another we review the methodological ethical challenges in collecting observational data with children and families, critically examining ethical norms for participant-observation research in pediatrics (Carnevale, Macdonald, Bluebond-Langner, & McKeever, in press). In a study currently underway (Principal Investigator: Bilkis Vissandjee), we are using qualitative methods to investigate the ethical issues involved in nursing across linguistic differences. Early in the study, we conducted an analysis of nursing norms to determine how nurses *ought* to be nursing in the context of linguistic barri-

ers. This normative analysis provides a framework for interpreting nurses’ accounts (i.e., the *is* of how they construe what is ethically meaningful and how they manage these issues).

The articles presented in the pages that follow make an important contribution to our understanding of ethics, values, and decision-making in nursing and in related clinical and theoretical domains. They make significant empirical, theoretical, and analytical contributions. I call for future inquiry in this domain to more explicitly examine the relationship between empirical research and normative analysis. This will help to ensure that the ethical implications of empirical data are soundly interpreted and that normative inquiry is systematically informed, challenged, and enriched by empirical examinations of the operationalization of ethical norms.

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**Le recours systématique à la rétention  
d'information chez les cliniciens :  
comment la volonté de protéger  
nuît aux besoins en information  
des adolescents atteints de cancer**

**Ignasi Clemente**

La présente étude qualitative porte sur le recours à la communication partielle des renseignements chez les cliniciens et ses conséquences sur la capacité des adolescents à participer à la gestion de leur propre thérapie contre le cancer. L'auteur a observé pendant dix-huit mois, dans le cadre d'une étude ethnographique menée dans un hôpital de Barcelone, dix-sept jeunes patients atteints de cancer, leurs proches et les professionnels qui les traitaient. Il analyse d'un point de vue microsociologique et longitudinal les interactions observées au cours des activités médicales et sociales qui se sont déroulées pendant les 86 heures d'enregistrements vidéo qu'il a recueillis. Il constate que les cliniciens font appel à quatre stratégies pour éluder les questions directes posées par les adolescents : réponses évasives; réponses circonscrites; réponses qui n'en sont pas; et anticipation des questions. Selon lui, la rétention d'information limite grandement la capacité des adolescents de participer à leur propre thérapie; même si ses buts implicites sont de protéger le patient et de réduire l'incertitude et l'anxiété, elle ne les atteint pas. S'ils tenaient compte des besoins individuels en matière d'information, conclut l'auteur, les cliniciens sauraient mieux évaluer quels renseignements divulguer, comment s'y prendre et à quel moment intervenir.

Mots clés : jeunes patients atteints de cancer, communication, incertitude



# **Clinicians' Routine Use of Non-disclosure: Prioritizing “Protection” over the Information Needs of Adolescents with Cancer**

**Ignasi Clemente**

This is a qualitative study of clinicians' use of partial information disclosure and its consequences for adolescents' ability to participate in the management of their cancer treatment. A total of 17 pediatric cancer patients, their families, and clinicians were observed during 15 months of ethnographic fieldwork in a hospital in Barcelona, Spain. Eighty-six hours of videotaped medical and social activities were analyzed micro-interactionally and longitudinally. Clinicians used 4 strategies to evade direct answers to adolescents' questions: contingent answers, narrow answers, non-answer responses, and question forestalling. Information withholding by clinicians was shown to greatly limit adolescents' ability to participate in the management of their treatment and to be ineffective in its implicit goals of protecting the patient and containing uncertainty and anxiety. The author concludes that if clinicians were to integrate adolescents' individual information needs into their communicative practices they would be able to better assess what information to disclose as well as how and when to disclose it.

Keywords: Children and adolescents with cancer, communication, information needs, uncertainty, disclosure, truth-telling

## **Introduction**

In this article, I examine clinicians' practices of partial information disclosure to adolescents with cancer in a hospital in Barcelona, Spain. Partial disclosure, defined as the selective combination of information disclosure and evasion, is not limited to deception by means of a false diagnosis or collusion by means of a misleading prognosis. It often takes the form of smaller, seemingly more mundane practices such as minimizing the information given to the patient or delaying its delivery. Much research has focused on the role of physicians in the delivery of bad diagnostic and prognostic news. Such a focus overlooks two facts: (1) this brief information event is often just part of the clinical work of informing the patient over an extensive period; and (2) while physicians may take the lead in breaking bad news, nurses play a central role in managing information before, during, and after the initial news delivery. Within a complex temporal framework, the pediatric nurse's multifaceted role of facilitator,

supporter, counsellor, educator, teacher, and child advocate is more salient (Price, McNeilly, & Surgenor, 2006). Since nurses must deal with the management of *when*, *what*, and *how* to answer adolescents' questions, an analysis of physicians' routine use of partial disclosure and its consequences will help nurses to improve their communication skills and quality of care.

Partial disclosure may fail to reduce anxiety in adolescents with cancer as well as prevent them from taking part in treatment decisions, which has been shown to improve adherence and health outcomes in adults (Kaplan, Greenfield, & Ware, 1989; Roter et al., 1998). Patients' participation is key, because, while children are overcoming cancer more than ever before (Pizzo & Poplack, 2005), survivors have significant knowledge deficits regarding basic aspects of their diagnosis and treatment, which "could impair survivors' ability to seek and receive appropriate long-term follow-up care" (Kadan-Lottick et al., 2002, p. 1832).

Choosing the appropriate time to break bad news, and the amount of information to provide, is a difficult task (Buckman, 1984; Fallowfield & Jenkins, 2004). Moreover, what constitutes sufficient and honest information and who should decide whether to disclose it remain controversial issues (Groopman, 2005). Cultural variations in the disclosure of cancer information add to the difficulty of managing information (Fallowfield, Jenkins, & Beveridge, 2002; Holland, Gears, Marchini, & Tross, 1987; Moore & Butow, 2004; Mystakidou, Parpa, Tsilika, Katsouda, & Vlahos, 2004; Surbone, 2004). In Britain, most cancer patients, regardless of whether they are receiving curative care or palliative care, want to have all possible information, both good and bad (Fallowfield et al., 2002; Jenkins, Fallowfield, & Saul, 2001). In Spain, however, only 25 to 50% of cancer patients are informed fully and directly about their diagnosis, 61 to 73% of relatives are opposed to such disclosure, and a substantial number of cancer patients do not wish to be informed (Centeno Cortés & Núñez Olarte, 1998).

In the case of adolescents with cancer, the challenge is all the more daunting because the patient is often not the primary decision-maker. Clinicians may delay informing the adolescent in order to spare him or her additional suffering, while parents tend to monitor the information provided to their child throughout the entire cancer trajectory (Young, Dixon-Woods, Windridge, & Heney, 2003).

Despite research evidence showing that withholding information may not prevent pediatric cancer patients from learning about the gravity of their illness (Bluebond-Langner, 1978) or from experiencing distress (Allen, Newman, & Souhami, 1997; Clafin & Barbarin, 1991; Last & van Veldhuizen, 1996; Slavin, O'Malley, Koocher, & Foster, 1982), in general

parents do choose to withhold information from their children (Chesler, Paris, & Barbarin, 1986).

Families of chronically ill children may favour limited information disclosure in order to protect each other, preserve a sense of “normalcy,” and prevent the illness from becoming the focus of their lives (Bluebond-Langner, 1996). Bluebond-Langner (1978) argues that when a chronically ill child is dying, parents, clinicians, and the dying child him/herself engage in mutual pretence (i.e., the parties are aware that the child is dying but act as if s/he were not) because “interaction could take place as long as everyone acted as if they still had their social roles” (p. 232). Dying children conceal their awareness of their terminal prognosis because they are responsive to their parents’ need to preserve their social roles and identities as caregivers. Bluebond-Langner and Perkel (1990) contend that, in light of the complexity of communication in the caring of chronically ill children, “the issue is not ‘to tell or not to tell’ but rather what to tell, how to tell, and who should do the telling” (p. 337).

To investigate what children and adolescents with cancer are told, as well as what they want to be told, I analyzed the patterns of disclosure vis-à-vis the specific cancer trajectories of a group of 17 patients in Spain (Clemente, 2005). The degree of disclosure varied with the particular medical and social circumstances of each child at each point in his/her treatment. Clinicians, parents, and patients constantly negotiated the limits of disclosure: Although they agreed on the need to limit information, they did not agree on what constituted sufficient information.

Non-disclosure was associated with a desire to protect patients not only from bad news but also — and more importantly — from a pervasive sense of anxiety caused by multiple, overlapping, and variable uncertainties related to diagnostic procedures, re-adjustment of treatment schedules, and the future. Based on my finding that adolescent patients often imagine worse scenarios than suggested in the information given later on by clinicians, I conclude that non-disclosure is an ineffective communication strategy for containing uncertainty.

## **Data and Methods**

The present analysis of clinicians’ use of partial disclosure was part of a qualitative study examining the participation of pediatric cancer patients in the management of information about their treatment. In order to analyze prospectively how children negotiate what they are told, I conducted an ethnographic study of the relationship between disclosure (i.e., the social process of communication regulation) and uncertainty throughout unpredictable cancer trajectories from diagnosis to long-term remission, relapse, or imminent death. An ethnographic approach, char-

acterized by participant observation in situ (Spradley, 1980), was chosen in order to qualitatively ground pediatric cancer patients' lived experiences in the activities and interactions within which they occurred, took shape, and acquired meaning (Woodgate, 2006a, 2006b; Woodgate & Degner, 2002).

Seventeen (10 boys and 7 girls aged 3–18) Spanish- and Catalan-speaking cancer patients, their families, and a clinical team at a hospital in Barcelona participated in the study. Purposive sampling was used for maximum variation (Patton, 1990) to identify a wide range of communication patterns. Because of the hospital's field of specialization, most participants were adolescent boys with bone tumours undergoing first-line multimodal therapy. Adults completed IRB-approved consent forms. Children over 7 years of age provided written assent. Pseudonyms are used and some personal information has been modified to protect the identities of participants but no medical information has been changed.

Over a period of 15 months of ethnographic fieldwork in 2000–01, I used a range of ethnographic methodologies to observe children's cancer trajectories, including daily participant observation of medical and social activities, biographical questionnaires, unstructured and semi-structured interviews, and videorecordings by the patients and myself. In addition to extensive fieldnotes written both to document activities and to develop analytical categories inductively (Emerson, Fretz, & Shaw, 1995), this period of observation resulted in a corpus of 86 hours of recordings, including 14 hours of medical conferences.

Two complementary analyses were carried out to integrate the different data sets. The first was conducted with a subsample of 12 adolescents (aged 11–18) and the second with all 17 participating patients (aged 3–18). The first analysis examined adolescents' questions during 70 medical conferences, primarily daily ward rounds and outpatient visits. These conferences were the focal points around which treatment was organized, decisions made, and patterns of information disclosure established. They were also one of the few medical events at which parents, patients, physicians, and nurses were all present. The conferences exhibited the conventional practice of the physician playing the leading role in the delivery of information, particularly when the news is bad (May, 1993; Peel, 2003; Price et al., 2006; Ptacek & Eberhardt, 1996). In the vast majority of cases, the adolescents directed their questions at the physicians, the physicians responded, and the nurses took on a supportive role, listening and occasionally adding to the physicians' responses. As May (1993) points out, because of the emphasis placed on nurses' refraining from contradicting physicians, the manner in which physicians manage information during such medical conferences affects nurses' individual interactions with patients.

A total of 500 questions posed by adolescents were examined using the qualitative method of conversation analysis (Goodwin & Heritage, 1990). I focused on adolescents because they were the largest age group in the data set and the most active in terms of expressing their information needs and pursuing information. In conversation analysis, the sequential organization of talk makes it possible for the researcher to observe how a speaker publicly interprets what the previous speaker has said and done. The researcher primarily relies on how speakers display for “each other the meaningfulness of a prior action” instead of relying on accounts related during interviews (Goodwin, 2006, p. 6). Conversation analysis has been used extensively to study medical communication (Heritage & Maynard, 2006; Maynard, 2003).

In the second analysis, adolescents' questions were examined in conjunction with the data collected from the entire sample (aged 3–18). Two analyses were developed to contextualize the isolated micro-interactive examination of adolescents' questions. *Temporal contextualization* located the questions within individual cancer trajectories, relying on the contextual natural history mode (Briggs, 1998) and the illness trajectory approach (Bluebond-Langner, 1996, p. 13; Charmaz, 1991; Kleinman, 1980). *Communicative contextualization* analyzed the patterns of information compartmentalization, disclosure, and collusion (Bluebond-Langner, 1978, 1996; The, Hak, Koëter, & van der Wal, 2000).

## **Results**

I identify four strategies used by clinicians to avoid answering adolescents' questions: *contingent answers*, *narrow answers*, *non-answer responses*, and *question forestalling*.

### ***Contingent Answers***

A contingent answer is accurate but highly flexible and open, with a provisional statement that is dependent upon certain conditions. An answer such as *if/when X happens, then Y will happen* is both uncertain and specific. It is uncertain because it is subject to revision if the underlying condition is not met. A contingent answer does not provide a specific date or commit the clinician to a specific course of action. At the same time, it is specific to the extent that it sets a sequential ordering of future events, imposing a logical order on an unknown and uncertain future.

In extract 1, Tony, a 15-year-old boy with Hodgkin's disease, asks a question about a severe infection that he has developed. Tony has relapsed once already, and although he does not present with swelling or lump masses in the head or neck area, many of his infection symptoms closely resemble common symptoms of Hodgkin's disease (Steen & Mirro, 2000,

pp. 338–339). His pediatric oncologists know neither the cause of the infection nor how to treat it. Tony has been hospitalized for almost a week at the time of this interaction, receiving different courses of treatment. He is now on a new course of antibiotics that shows some promise. Tony has just asked how many days he has to remain in hospital for the intravenous antibiotic treatment. He has given a rationale for his question: He has told the clinicians he wants to calculate the number of days of total hospitalization. Tony was then given a contingent answer: It will depend on the presence or absence of fever.

Tony's pediatricians are identified as DR1 and DR2. Conversations were in Catalan and Spanish but only the English translation is presented here. A simplified version of the conversation analytic transcription conventions (Schegloff, 2007) is used to represent how different parts of talk are produced and related in time. Square left brackets “[” on two successive lines with utterances by different speakers indicate the beginning of simultaneous talk. Equals signs “=” connect two continuous lines by the same speaker, broken up to accommodate the placement of simultaneous talk. Parentheses enclosing certain numbers, such as (0.7) or (0.2), represent silence in tenths of a second — for example, (0.7) indicates 7/10ths of a second of silence. Colons “:” indicate sound stretching — the more colons, the greater the stretching. A hyphen after a word or part of a word indicates a cut-off or self-interruption. Punctuation marks are used not in the grammatical sense but to indicate the intonation contour of a segment of talk. A period indicates a falling intonation contour, a question mark a rising one, and a comma a continuing one. According to these conventions, an interrogative with a falling intonation contour takes a period and not a question mark. Finally, a word enclosed in parentheses indicates uncertainty on the part of the the transcriber but represents a strong likelihood.

EXTRACT 1

- 1 TONY: And if the fever goes but I still have a cou:gh, I would  
2 still have to stay here.  
3 (0.7)  
4 DR1: If you have no fever: maybe we'll let you go home. But  
5 [you'd have to go two or three days without fever=  
6 TONY: [Oh::  
7 DR1: =at least. In other words [count on, if today you=  
8 TONY: [hm,  
9 DR1: still have a fever, you can count count two or three days  
10 here. More.  
11 TONY: Hm: interesting.

In line 1, Tony asks a second question to suggest a hypothetical scenario in which he will remain in hospital for as long as he has a cough. He has already been given a contingent answer to his fever question and is now seeking confirmation of an additional condition for having to remain in hospital. Note that Tony's question is itself an *if/then* contingent statement to be confirmed or disconfirmed with *yes* or *no*. Instead of answering *yes* or *no*, Doctor 1 responds to Tony's *if/then* contingent question with a contingent answer. Doctor 1 repeats some elements of Tony's question, but she makes her answer even more contingent. She repeats the structure *if/then* without any reference to the cough, adds a "maybe," which upgrades the uncertainty of her answer, and appends a long, contrastive explanation, prefaced by "but," that includes even more conditions that must be met. Tony's fever must not recur for at least 2 days. The number of *ifs* has multiplied, and, not surprisingly, Tony utters only an ambiguous "interesting," neither accepting nor rejecting the clinician's answer.

### ***Narrow Answers***

With a narrow answer, the clinician performs the action of answering but may not answer the question fully. Pedro, a 15-year-old boy with osteosarcoma, has just learned that he has a tumour and is to start chemotherapy immediately. Pedro's parents have opposed informing him about his diagnosis, but the clinicians have argued that it is better to tell Pedro. During the delivery of the tumour diagnosis, the clinicians have focused on the positive aspects of the treatment — for instance, that chemotherapy will reduce Pedro's pain. Pedro, on the other hand, uses his questions to ask about the negative aspects of the tumour and its treatment. In extract 2, Pedro asks if his leg will remain the same after the tumour is surgically removed.

#### **EXTRACT 2**

- 1 PEDRO: And does it remain the same as it was before?  
2 (0.3)  
3 DR1: More or less.  
4 (0.2)  
5 DR1: Eh? What happens is that this is a process, (0.2) which is slow and you  
6 will also have to collaborate a lot, because you'll have to do a  
7 lot of physical therapy.

Pedro's question does not get a *yes/no* answer. Instead, the clinician provides a delayed and vague "more or less." The clinician technically answers, but her answer contains little information and no elaboration of her "more or less." She continues with what sounds like an extension of her answer, but this results in a shift in the conversation, away from spec-

ulation about the outcome of the surgery and towards the process of physical therapy. Clinicians avoid giving detailed answers not simply to withhold information relevant to the question but also because a detailed answer might provoke questions on more sensitive topics.

### ***Non-answer Responses***

In a non-answer response, the clinician may give what seems like an answer but does not address the question. Reassurances, calls to be stoic and to remain optimistic, invitations not to worry excessively, teasing dismissals, and jocular downplaying of the patient's fears routinely take the place of answers. Clinicians try to convey the impression that there is no reason to worry. They pretend to answer but without providing information. This can fuel the patient's anxiety. In extract 3, Robert, a 17-year-old with osteosarcoma, asks what drug will be administered during his final chemotherapy session.

#### **EXTRACT 3**

- 1 ROB: And which chemo is th[is].
- 2 DR1: [Buagg it's a bomb::, bufshhhh
- 3 ROB: But what is it, cisplatin.
- 4 DR1: I've told you, if I were you I'd start worrying now.

Instead of giving the name of the drug, the clinician makes a teasing remark. Robert then asks about his most feared drug, cisplatin. During the previous administration of cisplatin, Robert developed mouth sores and had to be isolated. Robert assumes that if the clinician is not telling him what drug will be administered it could well be cisplatin. In response to Robert's request that the clinician explicitly confirm whether it is cisplatin, the clinician offers reassurance, jokingly dismissing Robert's fears as unfounded. Robert's fears are not assuaged with such non-answers, and he will continue to pursue information about his chemotherapy (not reproduced here).

### ***Question Forestalling***

A fourth communication strategy is to forestall sensitive questions from the outset as a precautionary measure. Two steps are essential in this strategy. First, clinicians may avoid questions that venture into the unknown by adhering strictly to talk about the present course of treatment. Evidence of the success of this strategy is that the adolescents in the present study never asked such questions as What caused my cancer? Why me? Why now? Will I be cured? or Will I die? The range of cancer topics discussed during medical interactions is thus restricted. Second, clinicians may avoid answering non-sensitive questions that



might lead to sensitive ones. Extract 4 (below) offers strong support for my argument that a clinician may avoid answering a question not because of its specific subject matter but in order to pre-empt the discussion of sensitive matters later on.

In extract 4 we encounter Tony again, now asking questions about his autologous peripheral blood stem cell transplant, or auto-transplant, which is the last programmed therapy of his second-line treatment. Since he has already been hospitalized for more than a week because of his severe infection and sees no end in sight, Tony makes the assumption that his current infection and its treatment will delay his auto-transplant. Tony's initial question, about whether the auto-transplant has been delayed, is evaded on multiple grounds in 24 turns.

EXTRACT 4

- 1 TONY: Is the day of the auto-transplant going to be delayed,  
2 (0.9)  
3 DR2: Let's see, it's not that it's delayed or moved up.  
4 (0.2)  
5 DR2: We still don't have a date.  
6 (0.3)  
7 DR2: Because, (0.2) we have to wait first of all, for you to  
8 re[cover].  
9 DR1: [What kind of questions you[a:sk,  
10 DR2: [Then, on the [day of the=  
11 MOM: [shsss:  
12 DR2: =auto-transplant? It's when you're pe[rfect.=  
13 DR1: [Well.  
14 DR2: [It- no no it doesn't have to be [delayed, relax.  
15 DR1: [No- [No, bu- but listen, and  
16 you say it's been delayed. If we still don't know what  
17 day[:. [how can it be delayed.  
18 DR2: [Of cou[:rse,  
19 MOM: [shhh  
20 DR2: Uh it's scheduled for when [you are well..  
21 DR1: [(Of course).  
22 DR2: Imagi[ne that.  
23 DR1: [It's scheduled for whe::n (0.2) whe:n [it's=  
24 DR2: [(Look.)  
25 DR1: =the moment most suitable.

A detailed analysis of the clinicians' responses is beyond the scope of this article but I will summarize some key observations. First, the clinicians offer Tony little or no time to expand on his question or to say anything

else, since their responses continually overlap. Second, Tony's question could have been answered with a simple *yes*, *no*, or *the auto-transplant has not been scheduled yet*. Third, Tony's question is not as unfounded as the clinicians imply. The clinicians' responses indicate a high degree of uncertainty, as in "it's scheduled for when you are well" and "it's scheduled for when...the moment most suitable." These responses give Tony little information about the actual date of his auto-transplant. Fourth, the clinicians' dismissals of Tony's question implicitly reject any trace of pessimism: There is no reason to question or revise the treatment. However, their efforts to forestall sensitive questions are only partially successful, since Tony later poses another question, "But the sooner the auto-transplant, the better?" This second question (not reproduced here) is also dismissed.

### **Discussion**

This study examined clinicians' use of partial information disclosure — that is, the selective combination of information disclosure and evasion. Specifically, I have analyzed four clinician strategies for evading questions posed by adolescents with cancer: contingent answers, narrow answers, non-answer responses, and question forestalling. In line with previous research, I have shown how partial disclosure often fails to reduce patients' anxiety. Extract 3, in which Robert reacts by asking about the chemotherapy drug he most fears when the clinician evasively responds with a tease, illustrates how adolescents may imagine worst-case scenarios in the absence of adequate information (Chesler & Barbarin, 1987; Orr, Hoffmans, & Bennetts, 1984). Partial disclosure also serves to create three obstacles to adolescents' ability to obtain the information they need and, ultimately, to deal with cancer and its treatment on their own terms. First, patients' accumulated knowledge about their treatment is undermined and the validity of their subjective experiences negated. Second, unless reassurances and teasing remarks are accompanied by information, the patient's information needs remain unmet. Finally, because adolescents routinely rely on questions to tell clinicians what they want, their ability to influence the decisions that parents and clinicians make on their behalf is directly undercut.

By analyzing in detail these smaller, seemingly more mundane forms of partial disclosure, this study responds to Bluebond-Langner's call for a focus on what to tell pediatric cancer patients, how to tell them, and who should do the telling. More importantly, I extend mutually exclusive definitions of disclosure and non-disclosure (Holland et al., 1987; Mitchell, 1998) to develop a nuanced conceptualization that identifies specific practices within these two extremes. As illustrated in my moment-by-moment analysis, what constitutes sufficient disclosure is debatable — it is

in fact the cause of much disagreement among clinicians and patients. If we are to meet the information needs of pediatric patients, we must give their understandings of disclosure priority over any a priori and static definitions. Finally, by examining the actions of clinicians and children in a social context, the study advances research that analyzes chronic illness from the perspective of the child (Beresford & Sloper, 2003; Woodgate, 2006b; Young et al., 2003) rather than that of the parent (Clarke, Davies, Jenney, Glaser, & Eiser, 2005; Dixon-Woods, Findlay, Young, Cox, & Heney, 2001).

The findings have a number of implications for nursing practice. First, the expectation that nurses refrain from contradicting physicians (May, 1993) may lead them to adopt similar patterns of partial disclosure in their own interactions with patients. Second, because nurses often work within the disclosure limits set by family members and clinicians, a patient's "awkward questions" can be particularly stressful for a nurse who has developed his/her own independent relationship with the patient (May, 1990, 1993). Third, disclosure is a temporally unfolding process (Arber & Gallagher, 2003) that extends over the entire cancer trajectory (Clemente, 2005; Good, Good, Schaffer, & Lind, 1990). If nurses play a supportive role during physicians' delivery of news, they are pivotal to the long-term management of information (Price et al., 2006).

Appropriately managed disclosure of information can take place only with the collaboration of nurses. The active participation of nurses in decisions about disclosure is essential to their everyday work and to their role as patient advocates (Price et al., 2006). Nurses may be the health professionals best positioned to assess what pediatric patients know and want to know, as well as to mediate between patients, parents, and physicians. In their role as primary clinical liaison (Coyle, 2001), nurses are taking an increasingly active part in diagnostic and prognostic disclosure (Farrell, Ryan, & Langrick, 2001), which may result in better-informed cancer patients. Nurses and physicians can benefit by integrating the questions of adolescents into the difficult task of meeting their information needs, which will vary with the individual and over time. Since a generic, "one size fits all" approach is ineffective, adolescents' questions can serve to guide clinicians in determining what information they want when they are ready to be informed. In this way, clinicians and parents can decide *with* rather than *for* the patient how much more information he or she needs and is able to handle.

In order to provide comprehensive analyses of information disclosure, future studies should examine nurses' interactions with adolescents who have cancer when physicians are not present, particularly outside ward rounds and outpatient visits. Such research will elucidate how nurses develop communication practices and alliances with pediatric cancer

patients within or beyond the limits set by parents and physicians. Future studies should also analyze the relationship between patient satisfaction with information disclosure and the expanding role and responsibilities of nurses (Peel, 2003). Finally, the triangulation of qualitative research methods and analyses (Woodgate, 2000) is necessary to overcome children's and adolescents' reluctance to discuss their cancer experiences, a common research limitation (Bearison, 1991; Phipps, Steele, Hall, & Leigh, 2001). Combining participatory methods of interviewing children (James & Prout, 1997; Pufall & Unsworth, 2004) with other methods, such as conversation analysis (Hutchby & Moran-Ellis, 1998), will provide new insights into how adolescents with cancer construct and experience their social worlds.

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## **Les infirmières canadiennes face à la difficulté de mettre en pratique les valeurs qui leur sont chères**

**Brenda Beagan et Carolyn Ells**

Les chercheuses ont mené des entretiens qualitatifs auprès de 20 infirmières d'une ville canadienne dans le but d'analyser leur expérience morale au travail. Elles ont demandé à celles-ci d'indiquer ce qu'elles valorisaient dans leur vie professionnelle et de préciser en quoi leur travail leur permettait de mettre leurs propres valeurs en pratique. Les répondantes sont quasi unanimes à évoquer leur adhésion à des valeurs comme l'aide, la sollicitude, le besoin d'être utile à la société, la relation axée sur le patient, la défense des droits, l'intégrité professionnelle, les soins holistiques et la volonté de transmettre des connaissances qui permettront aux patients de se prendre en main. Elles relèvent les difficultés et les frustrations qu'elles éprouvent lorsqu'elles tentent de mettre ces valeurs en pratique. Les obstacles de nature systémique comprennent notamment les hiérarchies professionnelles, la structure organisationnelle, les problèmes que connaît le système de santé et les dynamiques de pouvoir. Les faire tomber n'est pas une tâche qui appartient aux seules infirmières. Elle nécessitera un éventail de stratégies complexes : changements systémiques; restructuration des relations de pouvoir; et création d'une culture fondée sur l'éthique et propice au respect des valeurs essentielles à la prestation de soins infirmiers de qualité.

Mots clés : éthique, soins infirmiers; vie professionnelle

# **Values That Matter, Barriers That Interfere: The Struggle of Canadian Nurses to Enact Their Values**

**Brenda Beagan and Carolyn Ells**

Qualitative interviews were conducted with 20 nurses in a Canadian city to explore the moral experience of nurses in their working lives. The participants were asked what they valued in their profession and how well their work lives enabled them act on their values. Almost uniformly, they expressed commitment to the values of helping others, caring, making a difference, patient-centredness, advocacy, professional integrity, holistic care, and sharing knowledge for patient empowerment. They identified several challenges and frustrations experienced in attempting to enact these values. System-level challenges included professional hierarchies, organizational structures, issues in the health-care system, and power dynamics. Removing these barriers cannot be left to nurses alone. It requires complex, wide-ranging strategies: system change, power restructuring, and the creation of ethical climates and cultures that support values that are essential to good patient care.

**Keywords:** Ethics, nursing; decision-making, ethical; moral distress; burnout, professional

Attention to ethical practice in health care has been dominated by medical ethics, which has meant a tendency to focus on highly charged medical situations — what Varcoe and colleagues (2004) call “big ‘E’ ethical issues” (p. 317). The ethical situations that arise in nurses’ everyday practice are often dismissed, and they are not identified as ethical concerns by researchers, theorists, or nurses themselves (Cohen & Erickson, 2006; Smith & Godfrey, 2002).

Distinctions made by Andrew Jameton (1984) regarding challenges in nurses’ ethical experiences are still apt. Nurses can experience uncertainty about the ethical aspects of a situation, experience conflict between relevant ethical values or responsibilities, and experience ethical distress when something prevents them from acting ethically. According to the Canadian Nurses Association (CNA) (2003), ethical distress occurs when “a decision is made regarding what one believes to be the right course of action, but barriers prevent the nurse from carrying out or completing the action” (p. 3). Such barriers can be individual, interpersonal, or institutional (Cohen & Erickson, 2006; Hamric, 2000; Torjuul & Sorlie, 2006).

After studying hospital nurses for more than 10 years, Chambliss (1996) concludes that ethical concerns in nursing are primarily systemic and structural, transcending the moral practices or commitments of the individual nurse. A persistent problem is interprofessional conflict as nurses try to do what they believe should be done in the face of counter-directives by others (cf. Storch, Rodney, Pauly, Brown, & Starzmoski, 2002). In a study with critical care nurses, Gutierrez (2005) found that nurses who were excluded from patient care decision-making perceived their work as devalued. Lacking a sense of autonomy, they felt powerless and constrained in ethical decision-making. Chambliss points out that ethical distress is not individual: "Remove a nurse with an ethical problem from the hospital, replace her, and her replacement will encounter the same problem" (p. 91). Confirming consistency across studies, Redman and Fry (2000), in their systematic analysis of nurses' ethical conflicts, conclude that most of these arise from institutional constraints against rather than uncertainty about the right course of action.

In Canada, Varcoe and colleagues (2004) studied the ethical experiences and needs of nurses on the west coast. They conclude that ethical practice in nursing is utterly contextual. Participants struggled to enact their personal and professional values — to do "good" — in the face of conflicting values and institutional constraints. They described being caught between physicians and patients; caught by the medical emphasis on technology and cure, at the expense of care; and caught by the need to document and account for their work, discounting those aspects of care that were not quantifiable. In the context of the dominant ideologies of scarcity and the need for efficiency, the nurses learned to ration their time and their care, which left them wondering if they were doing the right thing. Many participants were troubled by the belief that they were not practising ethically: "As one said, 'It's everything I can do, but it isn't enough.' This inability to 'do good' and 'do enough' ...gave rise to profound moral distress" (p. 320).

Unresolved ethical distress is, clearly, linked to burnout (Severinsson, 2003; Sundin-Huard & Fahy, 1999), as well as to nurses' leaving their posts or leaving the profession (Corley, 1995, 2002). When nurses undergo intensive professional training, they not only acquire skills unique to their profession and specialized knowledge, but also assimilate the attitudes, values, and beliefs of their profession (Thompson, Melia, & Boyd, 2000). This process of professional socialization continues throughout one's career, sometimes reinforcing values and attitudes, sometimes transforming them in the context of practice (Cohen & Erickson, 2006; Lindh, Severinsson, & Berg, 2007). Juthberg, Eriksson, Norberg, and Sundin (2007) suggest that nurses unwittingly "deaden" their consciences,

compromising their values in order to get along in interprofessional environments. The *Code of Ethics* for nurses in Canada identifies core values as follows: provision of safe, competent, and ethical care; promotion of health and well-being; respect for choice and autonomy; advocacy for respectful and dignified treatment of all persons; observance of confidentiality; upholding of justice; observance of accountability; and advocacy for quality practice environments (CNA, 2002, p. 8). If Canadian nurses do in fact hold these values and are prevented from enacting them in daily practice, then ethical distress is a likely outcome.

In contrast to previous studies that have asked nurses about their experiences related to ethical concerns, the current study did not predetermine the ethicality of experiences, nor did it predetermine categories of ethical uncertainty, conflict, or distress. Rather, we asked nurses about their values, and about how those values were or were not supported in their daily practice. Because of our broad focus on values, nurses had room to discuss issues they might not have identified as ethical, particularly as “big ‘E’ ethical” (Varcoe et al., 2004). This approach enabled us to unearth everyday ethical tensions, which are more subtle than ethical dilemmas (Cohen & Erickson, 2006). We took ethical tensions to include not only ethical distress (where barriers prevent one from doing the right thing) but also those routine feelings of simply being torn between conflicting values (Cohen & Erickson) or competing value sets (e.g., whether to be a “good nurse” or a “good co-worker”) or uncertainty about ethical aspects of a situation. These feelings create a tension — a mental strain — that implicates one’s values and the culpability of one’s conduct and character. What one nurse defines as an ethical issue another might not. We wanted to explore the intersections among values, practices, and ethics, regardless of whether or not an individual nurse saw the issue as ethical in nature.

This article reports on a qualitative study with 20 nurses in Halifax, Nova Scotia, Canada, addressing four questions: *How do nurses view the core values of their profession? To what extent do they find themselves able to enact those values in practice? What barriers to acting on those values do nurses identify? What ethical tensions arise when there are barriers to acting on core values?*

## **Methods**

Following university research ethics approval, we recruited nurse participants through posters, announcements in newsletters and circulars, snowball sampling, and recruitment letters sent to nurses in the Halifax metropolitan area. Those who were interested in participating contacted the research team. Several more nurses expressed interest than we were able to interview. In selecting participants, we strove for diversity in race, gender, age, and years of nursing experience. Volunteers took part in a

one-on-one semi-structured qualitative interview following a guide that was developed from the literature as well as from discussions among the research team. The interviews drew upon the ethnographic tradition (DePoy & Gitlin, 2005). They were intended to elicit rich descriptions of participants' perceptions and experiences so that their accounts could be analyzed in relation to those of other participants as well as in relation to discourses on ethical practice and nursing values. In the interviews, participants were asked about the values they believed to be inherent to the profession when they entered it, how those perceptions may have changed over time, and their experiences with trying to act on those values in their day-to-day work.

In total, 20 nurses were interviewed by a trained research assistant who was not a nurse. The demographics of the participants are listed in Table 1. Each nurse met with the interviewer at a time and location

	#
<b>Sex</b>	
Male	2
Female	18
<b>Ethnicity</b>	
Caucasian	14
Racialized minority	6
<b>Practice setting</b>	
Community	6
Hospital	14
<b>Years in practice</b>	
< 5	3
5–9	2
10–14	1
15–19	2
20+	12
<b>Age</b>	
25–35	3
36–45	6
46–55	5
56–65	3
Not provided	3

convenient for the nurse. Consent was obtained. Interviews lasted approximately 1 hour and were audiotaped with permission. The tapes were transcribed verbatim and the transcripts were coded inductively using AtlasTi qualitative data analysis software.

In accordance with standard qualitative practice, themes were generated through in-depth examination of the transcripts. In an inductive and iterative process, data were read in depth and labels (codes) were applied to words, phrases, and concepts used time after time by participants. Text segments were compared within and across transcripts to refine coding. Codes were compared, clustered, and sorted until sufficiently distinct and comprehensive themes were generated and defined (Boyatzis, 1998; Luborsky, 1994). Further analysis followed common techniques in qualitative research, including memoing and thematic interpretation (Coffey & Atkinson, 1996). The findings reported here are drawn particularly from responses to questions about professional values, but the transcripts were also searched for instances in which participants spoke implicitly about values that guided their practice or about situations in which they were or were not able to act in accordance with their values.

One research assistant coded all of the data for internal consistency. She was trained in the use of the software and developed and used a codebook. Codes were refined through weekly meetings of the primary researcher and other research assistants. Participants received a descriptive feedback report based on all the interviews and confirmed the findings of the research team.

## **Findings**

### ***Values That Matter***

Nurses expressed their values when speaking about their motivations for practising nursing, the reasons why they had initially chosen the profession, and the reasons why they had remained in the profession despite some challenges, as well as what they thought makes a “good nurse.” They were fairly consistent in the values they expressed and often conveyed a deep commitment to those values. The key values identified were helping others, caring and compassion, making a difference, patient-centredness, advocacy, professional integrity, holistic care, and sharing knowledge for patient empowerment.

The value of ***helping others*** was raised frequently during the interviews. The nurses spoke about their desire to “help,” about the importance of being in a “helping profession,” and about nursing in order to “help others.” Many identified the desire to help others as their primary reason for choosing nursing as a career and for finding it “fulfilling and satisfying.” Helping was viewed as distinct from caring and empowering.

It was seen as *doing for* the patient and as central to the provision of assistance.

**Caring and compassion**, also described as empathy, were tied closely to the value of helping others. Yet some participants drew a clear distinction between these two values, noting that helping others can take place without compassion. Compassion can be understood as an emotional connection to the suffering of others. Caring or compassionate action involves understanding the other, then choosing to act in his or her best interests. Some participants referred to a selflessness in caring that nurses expect of themselves and each other:

*A good nurse is able to be compassionate and holds someone's hand or hugs them without having to be [told]. It should come naturally. You should be intuitive enough to know what the person needs at that moment in time.*

One participant said that nurses should be willing not only to care but to care specifically for strangers.

Most participants explained that their choice of nursing as a career was closely linked to **making a difference**, a value held dear. One nurse spoke broadly of “wanting to make a difference and making it a better world.” Others spoke of going the extra mile. For instance:

*A good nurse should have the understanding that that person is at a very vulnerable place in their life and you have the ability to — in some way, shape, or form — touch that person's life, and whether they remember you or don't remember you they'll probably remember that it wasn't as bad as they had feared it would be.*

The words used to describe **patient-centredness** differed, but the description always included the right of patients to have a say in their own care. Some nurses described an evolution in patient-centred care: a gradual shift away from *doing for* the patient towards a team approach — *doing with* the patient — so as to provide the best care possible. The core of this value seemed to be respect for the individuality and knowledge of the patient: “We're giving back part of the care to the patients — what does *this* patient want? — whereas before everybody got the same thing.” Participants noted that nursing care should accommodate the distinctiveness and individual needs of each patient.

Patient **advocacy** was a strongly held value. It was identified as “one of the primary responsibilities of a nurse” and as an integral part of a nurse's standard of care. Its importance stems from nurses' intimate knowledge of their patients: “You certainly have the ability to advocate on their behalf, because you're the one who knows them the best — you're with them all the time.” This value lies in a deep-seated belief that nurses

ought to use their knowledge of a patient to act in his or her best interests. One participant described a situation in which a nurse's failure to advocate — to insist on a second opinion — led to a patient's death. The participant considered this an inexcusable abandonment of the patient. Another participant said that nurses can play a role as health advocates on a larger scale, at the level of the health-care system; she described this as an "exciting opportunity," one she clearly thought nurses ought to embrace.

Participants valued **integrity** in both personal and professional terms, describing it as doing what you are "supposed to do," "stand[ing] up for what you believe," "doing the right thing," and not going "over the line." What had drawn one participant into the nursing profession was the integrity of his preceptors, who were "meticulous about their charting or their care [to] make sure it's done as per protocol" because "they wanted to be the best nurses possible." Some participants linked integrity to a strong commitment to accountability:

*It's the code of conduct for nurses. They have a responsibility to maintain standards. Accountability is one of them. If you did something wrong, own up to it... If you've made a medication error...you'll have to suffer the consequences but at least you know in your mind that you've done the right thing.*

A willingness to provide **holistic care** was frequently named as an essential value in nursing practice. Participants described holism as a relationship with the whole patient:

*I could easily just carry out the orders that the doctor has written, [but] I have a choice within my practice to try to explore and further that relationship with the patient, explore what else I can do to help the person... You don't look at just what's in front of you. You always look at the whole picture. That's holistic care.*

Participants ascribed considerable importance to their profession-specific knowledge, naming their expertise yet also insisting on the importance of **sharing knowledge for patient empowerment**: "Knowledge is power, and you empower people by giving the knowledge to them." One nurse elaborated:

*I value knowledge because I like knowing as much as I can about what I'm doing and being able to impart that to the people that I am taking care of, so that they can further themselves or take advantage of it [my knowledge] or take responsibility for themselves.*

The value here is the manner in which knowledge is wielded — shared with patients rather than used by nurses to reinforce their own authority.



### **Challenges and Frustrations**

In describing the values that mattered most in their everyday work, the nurses revealed numerous challenges and frustrations. This section focuses on the emotional impact of the nurses' experiences while the next identifies *why* some of these challenges arose. The inability to make a difference, or sustain patient-centredness, and conflicts between the values of patients and those of colleagues were repeatedly cited as emotional frustrations and challenges. For some nurses, the emotional toll of their inability to enact deeply held values was burnout and detachment, which in turn compromised their ability to enact other values such as caring, compassion, and helping. Many of the participants became profoundly disillusioned when they found that they were unable to do what they had entered nursing to do.

**Inability to make a difference.** Participants faced significant obstacles to enacting their desire to make a difference in patients' lives, or to alter the course of their patients' care when they knew the care being provided was not what the patient wanted. Several participants came to realize that making a difference was never as easy as it seemed:

*You go in really wanting to change everything and then you can't even move forward an inch sometimes. I think maybe in my heart, not in the front of my brain, I thought everything would be wonderful. But it's not like that. It's hard work.*

**Values in conflict.** Several nurses spoke about the difficulty of enacting patient-centred care when their values came into conflict with those of the patient. This challenges the notion of empowering patients by sharing expert knowledge:

*Sometimes there's a dichotomy between what I know is best for you or what medically is best for you and what you choose to do. I'm a firm believer in giving somebody education to make the choices, but sometimes it's hard to [reconcile] their not doing the right thing. "Why can't you take your medication?" I think that's one of the biggest ethical challenges.*

Some participants spoke of nurses unintentionally and perhaps unwittingly imposing their own values, especially in the case of a nurse believing strongly that a particular course of action is in the patient's best interests. When this is not what the patient wants, the value of patient-centred care is compromised.

Challenges to professional integrity arose because of differences in values or practices among colleagues. When they worked with people who had different perceptions of what constitutes professional behaviour,

or of what constitutes an acceptable standard for fulfilling one's duties, nurses were torn between collegiality and professional integrity:

*If you don't adhere to the standards of practice, then you shouldn't be in nursing. If you start down the slippery slope, it never stops. If you make that decision not to do proper patient care...if you do it once, you're willing to do it again. I don't feel that people get to a level in their professional life where they're pulled up and reported to the College for a one-off incident. It's a pattern.*

One participant said that nurses about to begin a new job should be advised "to look at the vision and the philosophy of the nurses that you'll be working with so that you know that it's congruent with your own beliefs before you actually start the job." Her warning suggests that incongruent ethical stances may be a source of considerable day-to-day tension.

***Unenacted values take an emotional toll.*** While acknowledging that the reality of their workplaces was often different from what they had expected, participants were quick to state that their values had not changed. One participant said, "My values didn't change, but sure enough there is frustration." Some nurses cited the emotional toll taken by routinely having difficulty enacting one's professional values. Many participants spoke of a drain of energy, which some described as burnout. The constant giving in a profession that tends to give very little in return led some participants to move to a less demanding practice setting or from full-time to part-time work. Such changes allowed them to work in environments where they could provide care in ways that did not leave them drained of energy and detached from their work: "You give and you give and you give all day. We have to replenish that energy. That's human nature."

Emotional detachment from the constant giving of themselves seemed inevitable to the nurses, vital to the preservation of their own health and well-being. The participants felt that, in order to function in their work (and in their lives), they had to detach themselves emotionally and mentally from their work, the politics of their profession, and their patients. One participant stated that pediatric nurses cannot become involved with their patients beyond a superficial level, adding that to become detached one has to be more professional and less sympathetic. A coronary care nurse made a similar claim, adding that attending bereavement services for patients is a signal that the nurse has become too attached. While none of the participants was specifically asked to articulate *why* it was so important not to become "too attached" to patients, there was a suggestion that one must maintain emotional control in order "to cope" or to do one's job competently:

*I try to remain as detached as I can to get my work done, but I still want [my patient] to feel that...I'm really there for her and I'm feeling it as much as I can, helping her out. You know, I don't want to dissolve into a slobbering mess. That's not going to help anybody either.*

Ironically, while participants expressed the view that burnout and detachment can have negative consequences for patients, these responses also compromise caring, helping, and compassion — the very nursing values that many participants cherished. Detachment, while protective, becomes a barrier to experiencing compassion, a deeply held value. One participant commented that nurses who are more detached in their approach are rarely thanked by patients and are rarely acknowledged as helping or as making a difference.

Not surprisingly, several nurses reported “relentless” and profound disillusionment upon finding themselves routinely unable to enact their core values: “I found my values were being challenged all the time because I wasn’t able to give what I thought I wanted to give, and that was a daily frustration.” One nurse expressed this frustration particularly well:

*I want to care for my patients more than just in the way of giving out medications, washing them up for the day, or filling these tests out. It's just relentless, and that is where I am caught. What I want to do for my patient is always second, and I can't seem to get my head around not being able to do that all the time. I've contemplated a lot about switching professions, just for the mere fact of not being able to carry out the things that I want to do for my patients.*

### **Barriers That Interfere**

Participants identified a number of challenges to their ability to enact nursing values in their everyday work. Key barriers identified were hierarchies within health care, workplace structures and policies, and the priorities of the health-care system.

**Interprofessional hierarchies** within the health-care system were a frequently identified source of frustration and ethical tension, though for the most part those nurses who worked within a team found their colleagues and other health professionals to be very supportive. The workplace conflicts most often discussed were those with physicians, due to the subordinate status of nurses in the health-care hierarchy:

*I do butt heads with the physicians... As a nurse you can advocate, but if they really feel that [the patient] needs that medication, they're the ones with the higher credentials...so they're the ones that are going to make the decisions.*

One participant commented that the nurse “follows doctors’ orders... initiates treatment...and that’s your job.” For some participants, unquestioning compliance directly contradicted their core values of patient-centredness, helping, and professional integrity:

*I knew that I wouldn't have the ability to make all the decisions that I wanted to make. I wouldn't have the control. It's not an independent profession, no matter what the academics might say. I knew I wouldn't have the autonomy. I just didn't know, when I graduated, how much that would mean to me. What I see as important for my patient and what their doctor sees as important can be two very divergent things. And it can be frustrating, because I don't have the power to diagnose, I don't have the power to prescribe.*

At the time of the interview this participant was in the process of leaving the profession. Several other participants had seriously contemplated leaving as well. In contrast, some of the nurses expressed relief that the responsibility for medical care did not fall to them; they were, as one put it, “freed” by the scope of their practice — the physicians “are the ones ultimately responsible.”

Apart from the lack of autonomy, some participants argued that physicians are simply ignorant about the work that nurses do, the extent of nursing education, and the scope of nursing practice: “We work with some physicians who have no appreciation of nursing, don’t know that nurses have their own code of conduct, their own standards of practice... That’s very infuriating.” Furthermore, the participants reported that some physicians do not provide an opportunity for nurses to be heard and do not tolerate being questioned by nurses:

*Some physicians will not accept [questioning]. They don't like their authority to be challenged... I know a couple in particular who would not listen to any patients, and even for me to talk to them it wouldn't make any difference.*

This lack of acknowledgement was draining for some participants, who felt they had no place in patient care: “I’m just nobody.”

One of the underlying tensions between nurses and physicians apparently stemmed from a difference in professional values. Participants spoke of nurses as focused on care and of physicians as focused on cure, sometimes at the expense of the patient’s overall well-being. Related to this difference in focus, some participants identified an epistemological conflict between nurses and physicians, grounded in the valuing of very different kinds of knowledge. Some participants spoke of nurses’ ways of knowing being dismissed and evidence-based practice being favoured over “gut feelings,” “instinct,” and nurses’ experiential knowledge. Thus holistic

care requiring the experiential knowledge of nurses, gained through ongoing contact with patients, is compromised in a medically dominated system. The conflict between professions in terms of values was a struggle for the nurses; the interprofessional hierarchy constituted a barrier to their acting in accordance with their values.

***Intraprofessional hierarchies and organizational structures.*** Intra-professional hierarchies and the organization of the workplace caused tension for the nurses. Several participants described tensions surrounding differences in professional training. Diploma-trained nurses described feeling “diminished,” held back, and pressured by management to obtain a degree. One nurse stated:

*You would get these people who because they have their master's or their bachelor's...would have this holier-than-thou attitude...who maybe had only been there 2 or 3 years. What happened to [the value of] experience?*

Other reasons given for tensions related to workplace structure included an apparent disjuncture between frontline staff and management. A common complaint was that managers were sheltered from the realities of frontline work and failed to seek frontline input into decision-making. Some managers had little clinical experience, or no background in the speciality, and therefore were unfamiliar with the issues confronted by the nurses under their supervision and were distanced from the realities of trying to enact nursing values.

Workplace policies and practices were another source of ethical tension. Participants spoke of nurses sometimes needing to or choosing to circumvent the rules, which created areas of tension. Some cited the presence of “unwritten rules.” Lack of clarity about parameters caused one participant to move to an area of nursing where everything was “black and white,” with no room for guesswork. For such participants, routine policies and practices got in the way of enacting values, leaving nurses torn between obeying the rules and acting with integrity.

For some participants, in contrast, adhering to policies afforded a measure of protection, guarding them against personal responsibility and liability:

*It's sort of like a standard set of care you have to follow. It's quite regiment[ed]. If you don't follow it precisely and everything is okay, that's fine. But if you ever didn't follow it precisely and something went wrong, huge, huge litigation... The policies are very restrictive in some ways, but in other ways they're to protect the patients and... to protect us, so even though they're a bit regiment[ed], they're there for a reason.*

These participants appeared to resolve any ethical tensions between practice and values by deferring to the rules.

***Failings of the health-care system.*** The health-care system was often cited as a constant source of frustration and tension because of reduced staffing and lack of funding for quality care. Some participants suggested that, while all health-care workers feel the pressure of constraints on the system, because of nurses' direct contact with patients 24 hours a day, they feel the lack of time and resources as a distinctively *ethical* tension: They are unable to provide the kind of care that compelled them to go into nursing in the first place. One nurse described the situation in a graphic way that also reveals some personal distancing from the diminished care provided:

*In the hospital years ago we used to [give] a lot more personal care to people... They stay[ed] longer, so you [had] to give them their bedside care, physical care. But now...if they [the nurses] give you a bowl of water you're lucky!*

Most participants felt that they simply did not have the time to provide emotional support to patients. This was an increasing source of tension for them. One nurse explained that there was no time "to hold somebody's hand when they're crying and that sort of thing," which frustrated her ability to enact the value of holistic, patient-centred care. Decreased staffing was seen as a direct cause of increased workload and time constraints:

*In terms of cuts...it's across the board. Every place I've worked, you see it in nursing. It makes it harder because oftentimes you don't have the resources to always do the right thing to the extent you want to do it. My frustrations come from just so much more I want to do and I can't do it.*

Many participants felt they were unable to provide the best possible care when exhausted from working overtime. Clearly, they believed that their professional integrity was compromised.

One nurse suggested that cutbacks to cleaning, kitchen, and clerical staff had resulted in those support functions being relegated to nurses while, at the same time, their paperwork had increased. One participant was "irked" by having to account for every activity in order to justify staffing levels: "Are we actually measuring this so we can be staffed? How do you measure emotional support? ...that's ridiculous." Another participant spoke of nursing as having become a "paper profession" rather than a "people profession," with nurses having less and less time to perform the caring tasks they see as central to their profession.

Time pressures and stretching oneself too thin served to raise the discomfort level, but it was when these factors led to decreased patient care that distinctly ethical tensions arose. One nurse explained that where once patients were discharged to home-care services, they were now

discharged into the care of neighbours or family members, regardless of their caregiving abilities:

*You need them to do it. You teach them — how much can they learn in 2 hours...? Somewhere there's somebody suffering, but what can you do? There's no resources, no money — that's what they have to have to get assistance; they're saying there's no money.*

The ethical tensions arose from an inability to express compassion by providing quality care. For some participants, unmet needs seemed limitless and all they could do was focus on the task at hand. One participant described nurses as “policing” each other so that no one raised patients’ expectations by providing care beyond what was deemed feasible:

*Things were quiet one evening and I was going around rubbing people's backs, while the rest of the staff were totally appalled that I would do something like that, because “these people are going to expect that tomorrow night.” And I said, “Well, that's your problem.”*

For nurses who had entered the profession to help people, make a difference, or show compassion, the lack of resources to routinely enact these values gave rise to ethical tensions, which could in turn lead to profound disillusionment and detachment.

### **Summary**

The values that mattered most to the participants were clear: helping, caring, making a difference, patient-centredness, advocacy, professional integrity, holistic care, and sharing knowledge for patient empowerment. In attempting to enact these values in their work, the nurses met with frustration and challenges, including the inability to make a difference and conflicting values, leading to emotional detachment, disillusionment, and burnout. The participants identified a number of systemic barriers to their ability to enact their values. These included interprofessional hierarchies; different professional epistemologies, values, and approaches to caring; intraprofessional hierarchies; workplace structures and policies; and the priorities of the health-care system with their accompanying time pressures and reduced quality of care. One participant pointed out that nurses can have difficulty even recognizing the day-to-day ethical challenges:

*I think my biggest challenge with this [the interview] was trying to rediscover...how I've been ethically challenged throughout my practice. And it's very difficult, but I know in my heart of hearts that I'm ethically challenged 10 times more than I even recognize.*

## **Discussion**

The findings suggest consistency among nurses regarding the core values of their profession, as well as the enduring nature of these values despite barriers to their enactment in the workplace. Further, without prompting about the substance of their values, the nurses described the core values articulated in the CNA's *Code of Ethics for Registered Nurses* (2002). This finding confirms the relevance of the *Code of Ethics* for Canadian nurses. Yet confidence in one's fundamental values and the support of one's professional association for those values are no guarantee that one will be able to enact them in the workplace. Indeed the findings indicate that Canadian nurses face significant constraints in enacting their values, resulting in ethical distress.

Our findings echo those of previous research suggesting that system-level issues impede nurses' everyday work (Chambliss, 1996; Health Canada, 2002; Poncet et al., 2007; Tadd et al., 2006; Varcoe et al., 2004), causing or exacerbating ethical distress (Corley, 2002; Gutierrez, 2005; Hamric, 2000; Millette, 1994; Pask, 2005; Redman & Fry, 2000; Storch et al., 2002; Varcoe et al.). The priorities of the health-care system or of its institutions result in nurses having little say in the care of their patients; understaffing; severe constraints on nurses' time, such that they believe they are fulfilling only a fraction of their ethical mandate; demands that nurses fulfil auxiliary roles despite their inability to fulfil what they see as their primary role; the abandonment of holistic patient care under pressure for early discharge; and limited patient access to diagnostic and treatment interventions. Further, the participants appeared to believe that removal of system-level barriers cannot be left to nurses alone (Chambliss; Health Canada; Tadd et al.), as nurses function in a context of multiple players, realities, values, and goals. The ethical environment of Canadian nursing consists of social, political, economic, and institutional forces; regulatory bodies; and multiple health professions with different aims, values, and educational priorities. As health care becomes infused with corporate ideologies, assumptions about scarcity and the need to maximize efficiency form barriers to the enactment of core nursing values (CNA, 2002).

Collaborative, wide-ranging, multifaceted initiatives are needed to generate system change, restructure power, and build ethical climates and cultures that support values that are essential to good care. Such collaboration seems unattainable when nurses' ethical practices are hampered by inter- and intraprofessional differences in power, values, and knowledge and a mutual lack of understanding with respect to professional skills and abilities. Nonetheless, a commission appointed by Health Canada (2002) produced 51 recommendations for improving the working lives of



Canadian nurses; these address workload, leadership, education, violence and abuse, nurses' health, accreditation, human resources, research, and government. A comprehensive set of initiatives based on the recommendations has yet to be accepted and implemented.

In the meantime, there are practical steps that nurses and nursing leaders can take to alleviate ethical distress. They can create organizational environments that foster ethical reflection. Certain types of collaboration with other health professionals (Juthberg et al., 2007) and with nursing colleagues can cause nurses to compromise their values. This can mean "having to deaden one's conscience in order to uphold one's identity as a 'good' health care professional" (Juthberg et al., p. 339). This deadening can continue as long as everyday activity precludes time to reflect. Reflection results in the need to find justification for one's actions or inactions.

All of this suggests one immediate strategy for enhancing ethical practice even in untenable environments: the creation of opportunities for collegial discussion of nursing values. Such opportunities could take the form of continuing education courses, or could be as simple as a series of brown-bag lunches (Andrews, 2004; Cohen & Erickson, 2006; Lindh et al., 2007; Storch et al., 2002). The point is to provide mutual support for ethical questioning. Among nurses, discussion groups would focus on the kind of reflection that is needed to reverse deadening of conscience. The groups would have to be carefully facilitated, so as not to become mired in discussion that normalizes and therefore reinforces the compromising of ethical values. Facilitation by an outsider, such as a pastoral care specialist or an ethicist, might serve to promote the questioning of taken-for-granted practices. Discussions would need to be guided by critical questions such as What *should* happen in such situations? What would it take to make that happen? The immediate implication for bedside nurses might be to challenge ethical "slippage," supporting one another to find ways to enact one's professional values. This approach could also foster the development of a collective voice at the local level, which is critical since no individual can break down institutional and system-level barriers alone (Buchman & Porock, 2005).

Such ongoing discussion could also serve another, related purpose. Our findings indicate that being hindered from acting on compassion causes ethical distress. At the same time, acting compassionately and altruistically can lead to burnout and detachment, given the magnitude of patient need (cf. Abendroth & Flannery, 2006; Gutierrez, 2005). Safe places where nurses can meet regularly to discuss the ethical values that underpin their work may help to guide those who tend to cross the line into excessive empathy while also validating and affirming the importance of compassion for those who have come to see giving patients a back rub as violating practice norms. Detachment from caring and

compassion denies a core nursing value, a value that motivates many nurses to continue working.

Ideally such discussions of values and ethics would take place among bedside nurses and nurse managers, since different work situations can result in very different values and in ethical conflict (Carney, 2006; Guterrez, 2005). Similarly, it would be ideal for nurses to converse with other health professionals, especially physicians, to enhance understanding of each other's values and professional ethics as well as the causes of ethical distress in different professions (Torjuul & Sorlie, 2006). We believe, however, that it is too soon to initiate this step. Nurse managers and physicians are among the sources of nurses' ethical distress. Given existing power relations, it is critical that bedside nurses have safe places to talk with each other, to reinforce everyday ethical values in practice. At this point it may be more useful for nurses to converse with other allied health professions who also experience power differentials with physicians and managers.

Educational settings are the ideal site for interprofessional ethics education. Such learning should extend beyond the classroom to clinical rotations. At the same time, ethics education must be pragmatic — it is futile for nurses to learn ethical principles if they see no way to put them into action (Andrews, 2004). A pragmatic ethics education would emphasize contextual realities, including naming the power relations that affect everyday practice, such as nurse-physician relations. It would teach students to consider a range of possible responses when faced with resource limitations that hinder them from acting on their values, to talk with each other about the realities as well as the ideals of practice (Lindh et al., 2007), and to become active in professional organizations that provide a collective voice for change (Buchman & Porock, 2005). In clinical settings, nurse leaders and seasoned nurses need to demonstrate for students a willingness to speak out, to ask critical questions that lead to collective questioning of institutional barriers to ethical practice (Cohen & Erickson, 2006).

Finally, research is needed to assess the effects of interventions, such as those outlined above, for enhancing nurses' ability to act ethically. Nurse leaders and administrators may be able to persuade hospitals and other health-care facilities to fund such research by linking ethical work environments with nurse retention and the potential for improved care. At a time of nursing shortages across the country, many of the participants in this study were contemplating leaving the profession, working fewer hours, or transferring to a less demanding work environment (cf. Health Canada, 2002; Millette, 1994). Cherishing the values and ideals of nursing but unable to provide the kind of care they consider integral to nursing, some nurses cope by removing themselves from the

very workplaces and settings where they aspire to make a difference. Their departure signals a lack of moral will on the part of the health-care system, health professionals, and society.

### ***Limitations***

Although the participants represented a variety of work settings and demographics, the study explored the experiences of one sample of nurses in one eastern Canadian city. While a study of this nature seeks depth of description and analysis, rather than generalizability across sites, it would be interesting to explore the ethical experiences of nurses in other settings. It is nonetheless intriguing to note the similarities between our findings and those of two other Canadian studies, one on the east coast (Gaudine & Thorne, 2000) and one on the west coast (Varcoe et al., 2004). Moreover, Gaudine and Beaton (2002) found that nurse managers experienced similar ethical distress, feeling powerless and voiceless, torn between the needs of patients, families, and nurses and the needs of the hospital. There is much in our data to suggest that when nurses are unable to enact their professional values, patient care suffers. At the same time, there are hints that some nurses extend themselves in an attempt to cover the gaps. Future research might explore the relationship between nurses' ethical tensions and quality of patient care. Another limitation is the fact that neither the interviewer nor the primary researchers were nurses. While a nurse interviewer might have been better able to relate to the participants, some nurses might have been unwilling to critique aspects of their work to a fellow nurse. Lastly, the study design allowed for only one interview with each participant. Several of the nurses remarked that the interview had caused them to reflect deeply; a follow-up interview may have elicited valuable insights.

### **Conclusion**

The challenge of working in a nursing environment that does not recognize giving a back rub or holding someone's hand as part of the nursing profession, where personal satisfaction from making a difference or fulfilling one's role is rarely experienced, exacts a toll on nurses. The findings of this study draw attention to these concerns. The detailed reports of the participants, delivered with such emotional urgency and distress, should move us to action. It is urgent that the system-level issues that impede nursing work be addressed. One means of doing so may be to create local environments conducive to the discussion of ethical concerns.

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Résumé

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## **De la pertinence du terme *approprié* : la « contrebande » des valeurs en milieu clinique**

**Mary Ellen Macdonald et Mary Ann Murray**

Le terme *approprié*\* est devenu un élément clé du jargon employé en milieu clinique dans les échanges avec les patients et leurs familles et les discussions les concernant. Les auteures s'appliquent à décortiquer ce qualificatif en apparence anodin et ses implications pour la prestation des soins. Elles se questionnent d'abord sur le rôle du terme dans le discours clinique, d'un point de vue théorique et historique. Son origine serait de nature grammaticale et morale; il trouverait sa source à la fois dans la distinction qu'on a établie, au XIX<sup>e</sup> siècle, entre le *normal* et le *pathologique* et dans la médicalisation du comportement qui s'est ensuivi au XX<sup>e</sup> siècle. La réflexion proposée ici touche à la théorie rhétorique et à l'histoire des statistiques et de la psychologie, tout en prenant appui sur l'exemple des soins pédiatriques. Les auteures avancent que l'usage du terme *approprié* favorise une sorte de « contrebande » des valeurs dans les échanges en milieu clinique, susceptible de marginaliser les patients et de compromettre l'intégrité de la relation thérapeutique. Dévoilant les éléments discursifs (moraux) du terme, elles incitent les lecteurs et lectrices à réfléchir à leur façon de s'adresser aux patients et à leurs proches et de traiter des questions qui les concernent.

\*Note de traduction : l'analyse proposée ici par les auteures concerne plus précisément l'emploi du terme anglais *appropriate*.

Mots clés : discours, normal, pathologique

# The Appropriateness of *Appropriate*: Smuggling Values into Clinical Practice

Mary Ellen Macdonald and Mary Ann Murray

The word *appropriate* has become an institutional given, part of the clinical jargon used in discussions with and about patients and families. The authors unpack *appropriate*, arguing that this seemingly innocuous word has implications for clinical practice. They begin with the theoretical and historical question What does *appropriate* “do” in clinical discourse? The answer is both grammatical and moral, rooted in the 19th-century distinction between *normal* and *pathological* and the 20th-century medicalization of behaviour. The examination references rhetorical theory and the history of statistics and psychology, and it uses pediatric health care as an example. The authors argue that the use of the word *appropriate* facilitates the smuggling of values into clinical encounters, which can marginalize patients and compromise therapeutic relationships. In uncovering the discursive (moral) elements of *appropriate*, they challenge readers to critically reflect on how they speak to and about patients and families.

Keywords: Discourse, language, family-centred care, moral reasoning, normal vs. pathological

## Introduction

Every day, in every clinical setting, the word *appropriate* is heard. It has become a ubiquitous euphemism, a codified linguistic device with multiple meanings. One use of *appropriate* in clinical decision-making is for communicating whether the risk/cost/value trade-off of an intervention is sufficiently compelling to justify its initiation, continuation, or abandonment. Another use is for implying that an intervention is a “best fit” for the intended outcome. A common use of the word is as a comparator — for instance, to describe supportive care as an alternative to aggressive third-line chemotherapy. The word is also employed to describe strategies for reducing the use of health-care resources and to describe the shoring up of personal opinion under the guise of unbiased scientific certainty.

During the first author’s ethnographic fieldwork on family experiences of life-threatening illness in a pediatric intensive care unit, *appropriate* (and its converse, *inappropriate*) became increasingly noticeable. Macdonald noted the frequent yet varied use of the word by clinical staff. Nurses, physicians, social workers, and physical therapists used it throughout their discussions with and about patients and family members.



Simultaneously, the second author, in reflecting on her long experience in acute and palliative care, observed that the word increasingly arose in conversations among clinicians and between clinicians and patients. It served as a device for conveying normative messages within seemingly neutral sentences. Murray observed a heavy reliance on the word during family meetings around the goals of care, during interprofessional team rounds, and during teaching moments with undergraduate and graduate physicians and nurses.

Anthropology encourages the scrutinizing of language, the questioning of what a linguistic device does. While *appropriate* appears to be a simple word, upon reflection it becomes clear that something is lurking behind its frequent use in the clinical setting, that it is employed in complex and multivalent ways that extend its simple adjectival function. What is truly appropriate is often a matter of debate among clinicians and between clinicians and patients and their families. Further, the use of *appropriate* as a normative descriptor is at issue for both the health-care system and consumers of health care.

One of nursing's key social roles is to foster health, to facilitate "human betterment" (Rogers, 1987). This requires that the therapeutic relationship be grounded in respect and trust, fundamental to which are clarity and transparency. Close inspection of implicit and explicit messages conveyed in and through language is thus an important exercise for the health professions, including nursing. This article is intended to contribute to that process. The authors, an anthropologist and an Advanced Practice Nurse, unpack the word *appropriate*. Though an ostensibly simple term, it harbours myriad meanings and values, from grammatical to moral. We theorize why *appropriate* is so prevalent in clinical language and what this says about clinical practice.

### **Clinical Uses of *Appropriate*: What Does It "Do"?**

The word *appropriate* is rooted in Middle English and Latin, made up of *appropriare* (to take possession of), *ad* (to), and *proprius* (one's own).<sup>1</sup> In its adjectival form, the word describes that which is suitable for a particular person, condition, occasion, or place; that which is fitting, relevant, pertinent, or apt.<sup>2</sup> Following rhetorical theory (Segal, 1997), in clinical settings the word *appropriate* operates on two levels: grammatical and discursive.

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<sup>1</sup> Merriam-Webster Online: <http://www.m-w.com/>.

<sup>2</sup> *Appropriate* can also be used as a transitive verb — that is, a verb construction that requires a direct object. To appropriate is to take or make use of something without authority or right; to confiscate or usurp. The noun would then be appropriation. While the two forms are tangentially related, only the adjectival form is discussed in this article.

	Condition		Person	
	Physical	Behavioural	Patient	Family
The child's growth was appropriate for his age.	X		X	
The mother's tears were appropriate given the news she had just received.		X		X
The child's neurological test showed that he was "completely appropriate neurowise."	X		X	
A father's series of questions was described as "inappropriate."		X		X
A child who was calm was said to be "unremarkable" and was being "appropriate" with her parents.		X	X	

**Clinical Grammar: Appropriate as a Descriptive Technology<sup>3</sup>**

Table 1 provides examples of the clinical use of *appropriate* by health professionals in a pediatric intensive care unit.<sup>4</sup> The two columns on the right indicate the target of the adjective *appropriate*: (a) condition (physical or behavioural), and (b) person (patient or family member). As the table shows, at the level of grammar *appropriate* describes or qualifies two categories of clinical concern in two populations.

**Physical/patients.** The word is employed clinically as a descriptor for the physical condition of the patient. In the sentence "The child's growth was appropriate for his age," *appropriate* refers to a growth rate that is considered normal or average. The child's growth rate falls within the

<sup>3</sup> In using the word *technology*, we are referencing Foucault's use of the term. Foucault (1970), for example, uses *technology* to refer to both tools and devices as well as structured behaviours and practices with which humans exercise power over nature as well as themselves.

<sup>4</sup> Taken from ethnographic fieldnotes recorded in the pediatric intensive care unit of a tertiary care teaching hospital in a large Canadian city. For more on this study, see Macdonald et al. (2005) and Macdonald, Liben, and Cohen (2006).

norm and thus does not require intervention. Had it been *inappropriate*, it could have resulted in clinical investigation and intervention.

**Behavioural/patients and families.** *Appropriate* also serves as a behavioural descriptor, for both the patient and family members. In the sentence “The mother’s tears were appropriate given the news she had just received,” *appropriate* refers to what is considered clinically acceptable behaviour for a parent. Had the mother’s tears been *inappropriate*, her sadness might have warranted clinical intervention; for example, it could have ultimately been diagnosed as “pathological” or “complicated.”

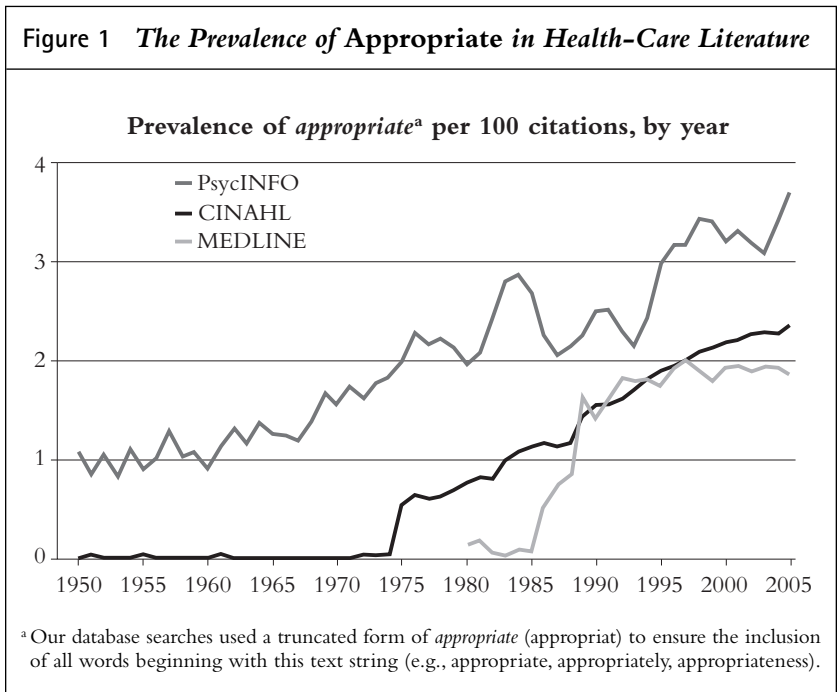
Thus, *appropriate* is a linguistic device for distinguishing that which is clinically “normal” or acceptable from that which is not. Appropriate physical or biological markers and social behaviours typically do not require intervention; inappropriate ones might. At the level of grammar, therefore, *appropriate* is a *descriptive technology* with three key functions: (1) it is a linguistic tool used by clinicians to distinguish the normal from the pathological; (2) it collapses two disparate categories, the physical and the behavioural; and (3) it describes the behaviours of family members in addition to those of patients.

### **Clinical Discourse: Appropriate as a Moral Technology**

Beyond grammar, *appropriate* can also be examined at the level of the clinical discourses in which it is embedded. Clinical discourse is a cultural product comprising many elements. As with Habermas’s (1987) description of the validity claims that underlie speech (e.g., the intention to optimize inter-subjective understanding via truth, rightness, truthfulness, comprehensibility), clinical discourse contains several elements. While clinical language may, on the surface, appear neutral, objective, drawn from value-free science, close examination reveals that myriad meanings and values surround and accompany its use. Embedded in clinical discourses are grammatical, moral, social, and political practices and agendas. The increasing prevalence of binary oppositions in nursing theory and practice is a case in point (Thorne, Henderson, McPherson, & Pesut, 2004). We argue that, at the level of discourse, *appropriate* acts as more than a mere descriptive technology; it also acts discursively as a *moral technology* — it becomes a metaphor used not simply to flag but also to *pass moral judgement* with respect to the normal and the pathological. Clinical discourses are not static entities; they should be understood as constantly evolving as jargon, definitions, values, and topics are adopted or discarded. A review of various medical and allied health databases reveals an interesting perspective on the use of *appropriate* in health texts. As seen in Figure 1, the word is a relatively recent addition to the clinical vocabulary. In this example, the truncated form of *appropriate* was entered into three fields (keyword, title, and abstract) of three health databases

(MEDLINE, CINAHL, and PsycINFO) to produce a snapshot of its prevalence over time.<sup>5</sup>

If the published reports in Figure 1 are any indication, the term *appropriate* may have entered the clinical arena via psychology and then spread to medicine and nursing; regardless, the term remains common in the literature of these disciplines today. Why it entered the clinical arena when it did, why its use steadily increased in the last quarter of the 20th century, and what all of this means for current practice requires an examination of two elements: (1) rhetorical theory, and (2) the history and values behind the introduction of the word into health care.



### **Metaphor and Rhetoric<sup>6</sup>**

English is rife with metaphoric expressions (Lakoff & Johnson, 1980). While a metaphor may appear to be a benign figure of speech, close scrutiny reveals its polyvalent and value-laden nature. For example,

<sup>5</sup> A content analysis of the term is beyond the scope of this article.

<sup>6</sup> This discussion of metaphor and rhetoric is taken partly from Macdonald (2003), where a similar argument is made about health policy as a political technology.

a metaphor may be employed to disguise or excuse: Was the death a “medical failure” or did “nature take its course”? Rhetoric, a linguistic tool of persuasion, uses metaphor as a vehicle for expressing values (Segal, 1997). Comparison of the terms *fetus* and *preborn child* makes this point clear: the term *preborn child* may rhetorically convey values such as found in right-to-life movements (be they religious or humanitarian), whereas *fetus* may be used to convey values of scientific neutrality and objectivity. “When values are explicit they may be openly debated but rhetoric uses metaphor to smuggle values into discourse that proclaims itself rational, even-handed and value-free” (Kirmayer, 1988, p. 57). Contrasting the explicit values in the phrase “withdrawal of care,” commonly heard in intensive care settings, to the more implicit values in the phrase “inappropriate approaches to care” demonstrates how subtle this smuggling can be.

Segal (1997) reminds us that the terms in which a debate is framed will constrain what can be discussed within that debate. For example, the “medicine as a business” metaphor commodifies health care, turns patients into “health-care consumers,” and frames any crises as economic, their solutions to be found in financial or managerial reconfiguration and the economic bottom line. A rights-based metaphor projects a very different image of health care. In order to critically examine a discourse, one must scrutinize the terms, phrases, and metaphors commonly employed within it. Following Kirmayer (1988) and Segal, “waking up” and interrogating metaphors in the clinical setting allows us to unpack the “institutional givens” entrenched in the disciplinary jargon (Montgomery, 1996, in Segal).

If *appropriate* is a metaphor, what is it referencing and what values is it “smuggling” into the clinical arena? Taking our cues from both Table 1 and Figure 1, we will begin the “waking up” process by looking at the history of scientific values, focusing on the 19th-century distinction between the “normal” and the “pathological.” Currently, *appropriate* appears to be serving as a politically correct proxy for *normal*, a word no longer in vogue. To make this point, we examine the rise of statistical science and the concomitant development of psychology as a science intent on defining the normal and the pathological via various measurement tools and the refining of its professional mandate. Further, we use pediatric medicine to illustrate the 20th-century medicalization of behaviours with the extending of the pediatrician’s clinical gaze onto the family.

### **The Normal and the Pathological**

The noted philosopher of science Ian Hacking (1990) draws on the seminal work of Canguilhem (1991) to show that the modern concept

of “normal” took over from where the Enlightenment concern for “human nature” left off. The word *normal* has two essential roots.

1. *Normal* entered European languages through its Latin form, *norma*, from geometry. In geometry, *norma* referred to a perpendicular T-square or right angle, a synonym for orthogonal. The root of the word *orthogonal* is *ortho-*, Greek for “straight,” “right,” or “correct.” Thus, embedded in *orthogonal* are both the descriptive (right angle) and the evaluative (right or good). Hacking explains that *ortho-* continues to have this dual meaning in English: orthodontists straighten teeth, making them right; orthopedic surgeons make broken bones right; orthodox religions are straight, ostensibly the true or correct interpretations.

Thus, as Canguilhem (1991) argues, embedded in *normal* are both the factual/descriptive and the evaluative. For example, a norm is both what is usual or typical and what is morally right (e.g., ethical norms). According to Hacking (1990), “One can, then, use the word ‘normal’ to say how things are, but also to say how they ought to be. The magic of the word is that we can use it to do both at once” (p. 163).

2. Modern usage of the word *normal* also stems historically from a medical context. The ontology of disease in the late 1700s focused on pathological organs, disease being attributed to individual organs, not the entire body. Thus, “Pathology became the study of unhealthy organs rather than sick people” (Hacking, p. 164). Originally, the normal was viewed as secondary to the pathological: That which was not pathological was seen to be in a “normal state.” In the positivist philosophy of Auguste Comte, “normal state” was transformed and placed at the centre and the pathological state was seen as deviating from the centre. The pathological state was considered not as radically different from normal but as a variation of it and defined in relation to it (Hacking, p. 166).

Through Comte’s positivist philosophy, *normal* transcended the medical sphere to enter the social and political realm. During this transformation, *normal* took on an element of “ideal” as seen in the early *norma*: “The normal ceased to be the ordinary healthy state; it became the purified state to which we should strive, and to which our energies are tending. In short, progress and the normal state became inextricably linked” (Hacking, 1990, p. 168).

A fundamental tension was created within the word *normal*: On the one hand, it represented the average; on the other, it represented the perfection for which one strives. This tension was borne out in debates between sociology and statistical science, in which the normal was cast as

either the status quo, with any deviation seen as pathological, or simply average, with excellence at one extreme of a normal distribution. Thus, contends Hacking (1990), “The normal stands indifferently for what is typical, the unenthusiastic objective average, but it also stands for what has been, good health, and for what shall be, our chosen destiny. That is why the benign and sterile sounding word ‘normal’ has become one of the most powerful ideological tools of the twentieth century” (p. 169).

### ***From Pathology to Psychology***

A related phenomenon in the 19th century was the increasingly prominent role of quantification, particularly in shaping popular and scientific epistemologies. Both the desire and the ability to enumerate populations grew throughout the 1800s as European states developed institutions to collect and publish numbers (around issues such as taxation, crime, and public health). The potential of the resultant “avalanche of printed numbers” (Hacking, 1990, p. 2) for population management and control became evident as the century progressed, adding to the sophistication of statistical science.

Psychology was particularly enamoured of the potential of quantification and statistics. While early psychology relied on the individual attribution of psychological data, social issues such as urbanization, immigration, and industrialization were increasingly being conceptualized in terms of individuals as members of statistical aggregates (Danzinger, 1990). Thus developed a new framework in psychology based on statistical norms: “Individuals were now characterized not by anything actually observed to be going on in their minds or organisms but by their deviation from the statistical norm established for the population with which they had been aggregated” (Danzinger, p. 77). This was not simply about counting heads, however; increasingly, individuals were seen as having quantifiable attributes as well. For example, social problems such as crime and deviance were increasingly attributed to the statistical distribution of individual psychological characteristics. With its growing relevance for society, psychology was to study this distribution in order to contribute to the management of these problems using administrative means (e.g., intelligence testing and personality assessment in public schools and the military). The historian of psychology Kurt Danziger writes:

Quantitative data by themselves were of course just marks on paper, but they could be transformed into a significant source of social power for those who controlled their production and interpreted their meaning to the non-expert public. Quantitative psychological knowledge was a species of esoteric knowledge that was held to have profound social implications. The keepers of that knowledge were to constitute a new

kind of priesthood, which was to replace the traditional philosopher or theologian. (1990, p. 147)

Enumerating people, their characteristics, and their behaviours using the standardization and measurement tools provided by statistics profoundly affected all areas of natural and social science, transforming the Enlightenment quest to understand “human nature” into the modern preoccupation with “normal people” (Hacking, 1990). There were far-reaching repercussions for people’s understanding of themselves and their increasingly quantified worlds. For example, the noted Disability Studies theorist Lennard Davis contends that “[t]here is probably no area of contemporary life in which some idea of a norm, mean, or average has not been calculated” (1997, p. 3). Davis goes on to demonstrate the connection between this “construction of normalcy” and what he calls the “invention” of the “disabled body” in the 19th century, a body that became so defined in opposition to what came to be considered normal.

### ***The Medicalization of Behaviour: The New Pediatrics***

In our quest to “wake up” the “appropriate” metaphor, we have thus far explored two elements. First, we looked at the complex history of the concept of normal. The ideological values that accompany the word *normal*, with its ability to be both descriptive and evaluative, are smuggled into clinical discourse under the ostensible neutrality of scientific language. Next, we revealed the connection between the rise in statistics and the desire and ability to define and measure an evolving understanding of “normal people.” In this final section we turn to a third element in the “waking up” process: the medicalization of behaviours — those of both the patient and the patient’s family. We will use the example of 20th-century pediatric medicine.

The unprecedented decline in infant and child mortality, as well as the significant decrease in childhood morbidity, in the first half of the 20th century greatly reduced the clinical workload of North American pediatricians. Through vaccinations and public health campaigns, children became healthier and had less need of medical intervention. As the need for primary care pediatricians decreased, pediatricians recreated themselves and their discipline, abandoning their focus on infection and hygiene. Pawluch (1983, 1996) argues that pediatricians began to diversify by adopting a prevention approach, which was followed shortly thereafter by a promotions approach that increased their role in the lives of healthy children (e.g., monitoring growth or attending to minor illnesses).

Following this, the pediatric speciality revitalized itself, focusing on children’s unmet needs, namely those related to behavioural problems and



other troublesome issues. Parents were encouraged to take their children to pediatricians in times of both illness and health, to book routine check-ups for such matters as growth measurement, school performance, and attention deficit disorder, bedwetting, and other behavioural problems.

The speciality of pediatrics thus broadened beyond illness and prevention and into advocacy for the “active promotion of child health in all its aspects” (Pawluch, 1983). This new understanding of health included the mental, emotional, and social development of the child and, increasingly, the adolescent as well. It was under this New Pediatrics that pediatricians extended their purview to the entire family (Halpern, 1988; Pawluch, 1983). For example, A. H. Washburn, in a 1951 speech to the Society for Pediatric Research in Atlantic City (published in the journal *Pediatrics* the same year), argued that pediatricians had a “moral obligation” to attend to children’s emotional and social development, over and above their concern for physical health, and this included “child-rearing” practices (Washburn, 1951).

It was through this medicalization of childhood (Pawluch, 2003) that the clinical gaze widened, to include not only physical diseases but also the psychosocial evaluation of children and their families. This phenomenon is still evident today. For example, an article by Barlow and Stewart-Brown (2004) outlines the pediatrician’s role in attending to “problem parenting.”

### Clinical Implications

In scrutinizing language in the clinical setting, it becomes clear that there are many hidden values behind one’s choice of words and phrases. *Appropriate* is one such value-laden word. It is used by clinicians as a linguistic and moral technology to both distinguish between and judge the normal and the pathological. In clinical jargon, *appropriate* has replaced *normal*, a word deemed politically incorrect and thus no longer in vogue. In clinical encounters, *appropriate* serves as a means of defining what is suitable for a particular person, situation, or place — a determination that requires value judgement and that references the parameters of normal. *Appropriate*, like its predecessor, *normal*, has a dual role: It describes both what is and what ought to be.

Further, as we have shown, the word *appropriate* allows for the collapse of the categories of physical health and social behaviour into one realm that is open to both clinical and moral judgement. The word can be used to describe and judge two disparate phenomena — for example, a child’s growth and a mother’s tears. While physical growth and maternal sadness are two very different entities, their description and judgement are

underlaid by the same value: measurement against the norm. To determine whether the child's growth is normal, one references a clinical average — how tall the child “ought” to be; similarly, to determine whether the mother's sadness is normal, one references normal grief reactions — how the mother “ought” to react.

A recent publication (Elliott & Olver, 2003) illustrates the hidden elements of clinical discourse. In a study of the meanings, for patients, of do-not-resuscitate orders, a version of the word *appropriate* (appropriate, inappropriate, appropriateness) is used by the authors 11 times to describe and summarize the views of patients, yet it is not found in the quoted comments of patients. For example, where the authors write, “Many mentioned the medical circumstances in which it might be appropriate to forgo attempts to maintain life” (p. 102), the patients say things like “Where everything's sort of packing up,...really, why continue?” (p. 102) or “When all systems fail, do not try to bring back to life” (p. 102). Further along, patients are quoted as saying, “If a person's going to die, why string it out any longer than is necessary...why stretch it out, why try and preserve a life with agony and pain” and “[D]on't do anything extraordinary...to prolong life” (p. 102). From this, the authors conclude: “Such terminology connotes the extension of something beyond its appropriate length, implying some form of biological or natural limit for each human life... [P]atients here invoke a biological discourse to assert the appropriateness of limiting medical authority” (p. 102). Our intention is not to criticize this study, but the authors' comments do serve as a reminder of how we may unintentionally translate patients' words into our own clinical jargon, thereby transferring our values to their words.

As demonstrated by much social analysis (e.g., Foucault, 1980, 1994), power imbalances often characterize health-care relationships, especially those between clinicians and patients. The clinicians' gaze, in assessing the normal and the pathological, objectifies the patient; and reducing the patient to a body masks the inter-subjectivity of the clinical encounter, increasing the power imbalance. The use of *appropriate* in both a descriptive and a moral sense reinforces the clinician's role as arbiter of one's health and well-being, and increasingly incorporated into this assessment is the behaviour of both the patient and the family. Therefore, the values that underlie the use of *appropriate* serve to pathologize human conduct.

Several points of reflection summarize our concerns about the use of *appropriate* in health-care settings. Non-reflexive use of the word clouds the transparency of language and values hidden within an ostensibly value-free scientific discourse. As a rhetorical device, the word serves to smuggle in judgements under the guise of neutrality. In terms of communication, we challenge readers to consider what the use of this word actually facilitates. Does it create barriers? Does it create mixed messages

and lead to false expectations? We must be continually cognizant of the role of language in maintaining hierarchies. While *appropriate* may appear neutral and scientific, our examination reveals that it has underlying values and multiple meanings; it is an imprecise word whose intentions and implications are hidden and thus not open to debate or dialogue. This would seem to be the antithesis of the patient/family-centredness and shared decision-making currently espoused in best practice guidelines and policy statements.

Clearly, more work is needed in this area. Data for this examination of *appropriate* were a secondary gain from an ethnographic project on critical care and also came from observations made in clinical practice. More focused study would be required to elicit the context-specific moral values behind the word. For example, is the term used differently by nurses, physicians, and other health professionals? Similarly, when patients and family members use the term, are they parroting medical speak or invoking their own values? There is a tendency to reduce complex moral issues to dichotomies (e.g., good/bad, normal/abnormal, inappropriate/appropriate) (Gould, 2003; Thorne et al., 2004). Use of the word *appropriate* may signal intellectual laziness: It serves as a default or comfort word, its vagueness diffusing the need for explanation. Similarly, it may be used as a time-saver — for example, a busy clinician may write “inappropriate parents” or “inappropriate grief reaction” as a device for referring a patient to another practitioner or care intervention. Qualitative exploration of the meaning of *appropriate* from a variety of perspectives — that of the clinician, the patient, the family — is an important area for future work. Furthermore, examining definitions and goodness of fit between what health-care consumers and health-care delivery systems describe as appropriate may help to inform quality improvement initiatives.

### Conclusion

We have theorized why the word *appropriate* has become common in clinical settings and what this implies for clinical practice. The word serves both as a grammatical device and as a moral technology. Distinguishing the normal from the pathological has been the modus operandi of health care for centuries. Originally reserved for physical pathologies, the word *normal* evolved to apply also to social behaviours. Taking over where *normal* left off, *appropriate* metaphorically references the historical shift that opened both psychology and medicine to the description as well as the judgement of the “health” and pathology of patients and families. Like its predecessor, *appropriate* collapses the categories of physical and psychosocial health and behaviour into one moral

realm that is open to both clinical and moral judgement. In using the word *appropriate*, one is describing both what is and what ought to be. The premises of *appropriate* facilitate an inadvertent smuggling of values, biases, and subjective judgements into clinical encounters that can disadvantage patients and compromise the therapeutic relationship.

Simply replacing one word with another is insufficient to change the attitudes and beliefs that underpin a metaphor. As Segal (1997) points out, “metaphors acquire power over time and in use, and they arise from the culture rather than being fed into it” (p. 228). It is essential that we bring an awareness to our language, to “wake up” the values so they can be discussed and debated by health professionals as well as the patients and families they serve. It is impossible to codify one explicit meaning of the word *appropriate*. Different people, different professions, different cultures, and different societies will continue to hold different views on what is appropriate. What we *can* do is reflect on what we mean and what messages we are conveying each time we use the word.

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## **L'élaboration d'une résolution de principe en matière de recherche sur la diversité sexuelle : le rôle moral des infirmières**

**Judith A. MacDonnell**

Cette étude de cas menée en Ontario, une province canadienne, examine la pertinence des relations de pouvoir en matière d'éthique de la recherche en sciences infirmières. Des infirmières de santé publique ont entrepris une réflexion critique sur le rôle qu'elles jouent pour dénoncer les inégalités sociales au moment de recueillir des données destinées à éclairer leur exercice. Ce faisant, elles ont préparé une résolution qui expose les valeurs et les principes sur lesquels devrait reposer la recherche infirmière menée auprès des différentes minorités sexuelles. L'auteure se fonde ici sur une étude de cas qualitative et un cadre féministe en matière de bioéthique pour analyser le document en question et le milieu d'exercice dans lequel il s'inscrit. Ses conclusions indiquent que les dynamiques de pouvoir, incluant celles qui relèvent du genre, influent sur la capacité des infirmières à défendre les droits des minorités sexuelles par le biais de la recherche, ce qui aura suscité l'élaboration d'une déclaration publique sur la production des connaissances. Elles comportent certaines implications pour l'éthique en matière de recherche, dont la nécessité d'explorer en quoi les discours dominants et les contre-discours, de même que les multiples dimensions du pouvoir, façonnent le rôle moral des infirmières face au besoin de remettre en cause le statu quo.

Mots clés : minorités, genre

# **Articulating a Policy Resolution for Sexual Diversity Research: Nurses as Moral Agents**

**Judith A. MacDonnell**

This case study of community nurses in the Canadian province of Ontario explores the relevance of power relations to nursing ethical inquiry. Public health nurses critically reflected on their role in challenging social inequities as they generated evidence to inform practice. In the process, they developed a policy resolution articulating values and principles for ethical nursing research with diversely situated sexual minorities. The author uses a qualitative case study design and applies a feminist bioethics framework using critical literature to analyze this document and the practice context. The findings suggest that dynamics of power, including gender, influence nurses' ability to advocate for sexual minorities through research, prompting the development of a public statement on knowledge production. There are implications for undertaking nursing ethical inquiries that explore how dominant and counter-discourses and multiple dimensions of power shape nurses' moral agency in challenging the status quo.

**Keywords:** Nursing ethics, sexual orientation, research methodology, public health nursing, feminism, minority, gender

The practice of Canadian public health nurses is shaped by the ethical and professional requirement that nurses promote the health and well-being of individuals, families, and groups as well as vulnerable populations and communities (Canadian Nurses Association [CNA], 2002; Community Health Nurses Association of Canada [CHNAC], 2003). Although the nursing profession emphasizes the diversity of individual clients and communities with whom nurses interact, there is a paucity of nursing research addressing sexual diversity, especially in the Canadian context (Giddings, 2005; Gray et al., 1996; MacDonnell, 2007; MacDonnell & Andrews, 2006; McDonald, 2006b; Stephany, 1992; Stevens, 1992; Walpin, 1997). This despite the well-documented health inequities shaping the lives of sexual minorities across age, ethnoracial status, gender, geography, and other social locations (Dean et al., 2000; Jackson et al., 2006; MacDonnell & Andrews). Sexual minorities encompass lesbians, gay men, and bisexuals for whom same-sex orientation (i.e., attraction to the same sex) is relevant and transgender people for whom gender identity (one's sense of being male or female) is a defining component of their health and well-being.



This qualitative case study employs a critical feminist lens (Peter, Sweatman, & Carlin, 2005) to explore the ethical dynamics shaping the practice of a group of public health nurses in the Canadian province of Ontario. These nurses were members of a coalition devoted to improving the health and well-being of sexual minorities. After reflecting critically on the values and methodological principles driving their practice, they developed a policy resolution, *Ethical Research and Evidence-Based Practice for Lesbians and Gay Men* (Public Health Alliance [PHA], 2002), a public and professional statement linking ethics and research.

When this policy resolution was reached in 2002, the nurses involved in the discussion were affiliated with a workgroup of the Ontario Public Health Association (OPHA) focused on challenging health inequities and enhancing care for sexual minorities — communities whose health and well-being encompass their same-sex orientation and gender identity (Dean et al., 2000). This coalition is now known as the Public Health Alliance for Lesbian, Gay, Bisexual, Transsexual, Transgender, Two-Spirit, Intersex, Queer and Questioning [LGBTTTIQQ] Equity, or PHA. In their discussion of ethical and legal issues in community nursing, Peter et al. (2005) briefly address the coalition's work to enhance social justice for sexually diverse communities, linking their contributions to the CHNAC Standard of Practice (2003) for facilitating equitable access to high-quality care. For the most part, the holistic needs of sexually diverse groups are invisible in nursing ethics research (MacDonnell, 2001, 2005). This has implications for our understanding of the relevance of ethical inquiry for this area of nursing practice.

In this article I explore the relevance of a feminist analysis and ethical dynamics for the involvement of public health nurses in the production of the knowledge that informs their practice related to sexual minority health. I apply concepts from feminist bioethics (Peter et al., 2005), a nursing framework that foregrounds ethical inquiry with a focus on gender and other relations of power, in a case study of the PHA (2002) policy resolution. The analysis is contextualized by critical literature and documentary data from other policy initiatives taken by the PHA to improve the access of sexual minorities to quality public health care.

The article begins with a description of the methodology, a critical feminist approach, the characteristics and activities of the workgroup, and the documents used. Key points in the policy resolution are noted. Through an analysis of this case focused on sexual minority health, I identify findings related to gender and other relations of power that shape nurses' ability to practise in ways that are consistent with the goals of social justice. The discussion situates these findings and the contributions of the policy resolution in the local and larger contexts of nursing practice, research, ethics, and policy. Implications for nursing are discussed.

## **Methodology**

### ***Research Design***

A qualitative case study design (Stake, 2003) focused on one workgroup, the PHA, was chosen, with the goal of a deeper understanding of the dynamics that shape nurses' involvement in the production of knowledge with sexual minorities. Nurses identified as belonging to a sexual minority or as heterosexual allies have consistently made up a high proportion of PHA members. Since the workgroup has undertaken several policy initiatives over the past 10 years to foster the access of sexual minorities to public health services, purposive sampling of this single case was used (Cresswell, 1998). In the critical feminist approach, the location of the researcher is relevant to the inquiry. I have been a member of the PHA, working as an ally on research, education, and policy initiatives, and have had insight into workgroup processes over the same 10-year period (MacDonnell & Andrews, 2006).

### ***Data Collection***

Given the retrospective nature of the study, the data include four policy documents on projects drawn up by various PHA members between 1999 and 2003. Since documents in the public domain, rather than participant interviews, were used, research ethics board approval was not required. Documents included the policy resolution *Ethical Research and Evidence-Based Practice for Lesbians and Gay Men* (PHA, 2002) and three position papers addressing access and quality of public health services for, respectively, lesbians and gay men (Duncan et al., 2000), bisexuals (Dobinson, MacDonnell, Hampson, Clipsham, & Chow, 2005), and transsexual/transgender people (Gapka et al., 2003). The latter two papers resulted from province-wide community consultations using community-based participatory action research (CBPAR). The bisexual project was completed in 2003 and published in a journal in 2005.

Literature reviews informing each PHA policy document included searches of databases such as CINAHL for health literature and contact with key informants to identify relevant policy or unpublished literature. At least two participants were involved in thematic analyses. PHA listserv members and representatives of the OPHA Board of Directors reviewed these policy submissions, which summarized existing research and gaps, implications for public health practice, resolutions, and implementation strategies for the OPHA. The submissions were approved by interdisciplinary professionals and policy analysts who make up the OPHA general membership and can be accessed online ([www.opha.on.ca/advocacy/ppres.html](http://www.opha.on.ca/advocacy/ppres.html)).

For workgroup activities, critical literature on nursing practice and research with minorities situate the analysis in the sociopolitical context. Since it is a goal of case study research to examine the particularity of the case, rather than aim for generalization, I used multiple data sources to explore the dimensions of the case, providing thick description of the workgroup and its participants (Stake, 2003). Triangulation of data over time and source enhance verification or validity (Cresswell, 1998).

### ***The Feminist Bioethics Analytic Framework***

According to Peter et al. (2005), a feminist bioethics framework offers a perspective that extends and challenges the dominant view of bioethics, which is based in biomedical tradition. As a result, nurses' understanding of what constitutes legitimate ethical concerns is affected by a prevailing discourse in health ethics equated with "highly charged medical situations... [E]veryday...ethical tensions and issues [are often overlooked]" (Varcoe et al., 2004, p. 317). In addition to a focus on ethics, defined as "values, norms, moral principles, virtues, and traditions that guide human conduct" (Peter et al., p. 39), this framework considers relations of power as both a potentially negative force (e.g., "power-over" as in oppression) and a positive force in terms of the human ability to act. As Peter et al. indicate, "power is itself ethically neutral. How it is used, is...however, ethically significant" (p. 40). An ethical inquiry focuses on processes and impacts of the structuring and exercise of power. The larger, structured dynamics of power are relevant: They are the historical, sociocultural, political, and economic contexts and the ethical challenges that nurses encounter in their everyday practice.

A focus on the relational nature of social and human relationships highlights the interconnectedness of social relationships, nurses' interpersonal connections, and nurses' relationship to the world. It also shows how relations of difference and social privilege (including gender), social disparities, and vulnerability related to social disadvantage are pertinent to ethical inquiry, as are actions that enhance care and social justice (Sherwin, 1993; Tong, 2001). A feminist bioethical analysis in this case study could reveal social structures that have an oppressive effect on nurses and their communities. Use of a lens of gender that acknowledges the intersections of gender with race, class, and sexuality offers insight into "the ways in which femininity and masculinity are reflected in lived life" (McDonald, 2006a, p. 336). Social worlds often privilege knowledges and values that are constructed from an implicit white, middle-class, heterosexual male reference point (Giddings, 2005; MacDonnell, 2007).

This analytical lens can identify complex social processes and relationships at the micro and macro levels that influence nurses' ability to practise in ways that are consistent with professional values that exhort

them to challenge health inequities and strive for social justice. The findings foreground processes in the workgroup activities and policy resolution that normalize, marginalize, or privilege certain practices and actors, in order to point out barriers to nurses' ultimate ability to provide high-quality care to sexual minorities. As Sherwin (1993) writes, "to speak meaningfully about justice, it is necessary to examine the actual forces that undermine it, as well as those that support it" (p. 21). Such an analysis can highlight nurses' concrete challenges with respect to social processes that perpetuate domination and oppression, in order to demonstrate how nurses act as moral agents in challenging the status quo in their everyday work. A critical gender analysis through this case study can reveal the transformative potential of their relationships and practices (Cresswell, 1998; Gangness & Yurkovich, 2006).

### ***Description of the Case: Public Health Alliance***

The PHA comprises both sexual minorities (i.e., those identified as LGBTTTTIQQ) and their allies. Emerging as a forum for support in the late 1990s, the coalition has, over the past decade, encompassed a diversity of age, sexual orientation, gender identity, ethnoracial, and professional status. At any given time it has approximately 10 to 35 members, mostly females of high social privilege. Since participation has shifted over time, a variety of members have been involved in activities aimed at raising awareness about sexual diversity and enhancing the ability of public health practitioners to provide equitable access to high-quality care.

In the year 2000 the PHA collectively wrote a position paper focused on two groups of sexual minorities. *Improving the Quality of and Access to Public Health Services for Lesbians and Gay Men* (Duncan et al., 2000) documents the gap in Canadian research evidence related to the health of lesbians and gay men. The authors offer resolutions with regard to making sexual minority health visible and advocating for public health education and programs, services, and other resources. In addition, they stress the diversity, such as that in socio-economic status, that exists within these communities and that influences the experiences and perceptions of sexual minorities with regard to their health. Since the issues encountered by bisexual and transsexual/transgender (trans) communities are often unique to those communities, the PHA advocated for research strategies along with education and policy strategies. Community members as well as professionals became involved in the PHA with the launching of the bisexual and trans health projects.

Over the succeeding year, as the authors of that first position paper (Duncan et al., 2000) engaged in dissemination strategies with practitioners, funding agencies, and sexually diverse communities, questions were raised about the role of professionals in enhancing the access of

sexual minorities to high-quality health care. Based on discussions with a dozen or so other nurses and colleagues and on critical reflection on their own advocacy experiences, a small group of nurses affiliated with the PHA considered implications for their practice. By engaging with the literature, as described earlier, they identified issues relevant to the content and process of sexual diversity research (e.g., health promotion discourses, partnerships with marginalized groups) and formulated a policy resolution. This resolution (PHA, 2002) set out five principles for ethical research linking specific values to the production of knowledge and policy actors involved in research. “The production of knowledge or evidence cannot be seen as separate from the socio-political structure of power in society” (PHA, 2002, p. 2). The five principles are:

1. Research on the health of lesbians and gay men must include the input and equitable participation of diverse members of the lesbian and gay communities.
2. The utilization of evidence to guide programs/services and resource allocation must include (a) members of lesbian/gay communities, and (b) published and unpublished literature and proceedings from community consultations.
3. Research funding policies and guidelines must ensure adequate input and equitable participation by stakeholders in/members of lesbian/gay communities.
4. Research capacity must be expanded beyond the academic sector and be integrated at the grassroots level, in order to ensure meaningful participation and empowerment for communities.
5. Education in cultural/diversity competency for public health practitioners, researchers, and policy-makers must address issues that are relevant to the research inquiry. (Issues around the undertaking of research on/with/about these communities must be part of higher education.)

The development of this resolution prompted the PHA to undertake two CBPAR projects with bisexual and transsexual/transgender people (Dobinson et al., 2005; Gapka et al., 2003).

### **Findings**

According to Peter et al. (2005), nurses who are involved in improving access to and equity in health care can be described in terms of their moral agency: their ability to act on values that are consistent with caring and social justice. Doane and Varcoe (2007) assert that use of a relational inquiry lens to frame nurses' development of trusting, respectful relationships with patients supports a complex view of nurses' obligation to

address suffering and injustice. In their view, such actions to enhance health and healing take place at the interpersonal, intrapersonal, and organizational levels simultaneously, since they inform each other and hence nurses' ability to care. This application of a feminist bioethics lens reveals interrelationships among the workgroup's actions to challenge the status quo at the individual, organizational, and macro levels.

By explicitly articulating principles that underpin action in relation to moral issues such as the structures that render sexual minority research invisible in health contexts, nurses as moral agents identified taken-for-granted dominant discourses shaping their practice. A key aspect of critical questioning represented through the policy resolution was an examination of social norms, ideologies, and dominant discourses framing practice (e.g., Doane & Varcoe, 2007; Peter, 2000). Having identified these often invisible dynamics of power that have oppressive or normalizing effects, the nurses could potentially question or challenge them, thus offering counter-discourses to normative assumptions (MacDonnell, 2001). Several examples of ideologies, social norms, and dominant discourses are addressed, as well as counter-discourses or strategies to challenge these norms and ideologies.

### ***Dominant and Counter-Discourses***

One example of a dominant ideology that influenced sexual minority health and nurses' practice dynamics, heterosexism, is the implicit normality and privileging of heterosexual relationships that underpin all social institutions. Heterosexism represents deeply embedded oppressive relations, and it interacts with racism, ageism, and other social relations to influence how individuals across social locations experience and understand their health (Ryan, Brotman, & Rowe, 2000). Until recently, sexual diversity was virtually invisible in Canadian health care except in the context of mental health, sexuality, and HIV/AIDS (Dean et al., 2000; Jackson et al., 2006). Over the last decade, sexual minority concerns have garnered media attention and significant progress has been made with respect to social and legal rights. However, diversely situated sexual minorities across ethnoracial status, gender, and religion have historically been pathologized and have met with exclusion, marginalization, stigmatization, and discrimination by practitioners and institutions. Well-documented negative health impacts include increased mortality, morbidity, and inaccessibility of relevant and high-quality care (e.g., Dean et al., Dobinson et al., 2005; Duncan et al., 2000; Gapka et al., 2003). Although there are benefits to identifying health risks linked to sexual diversity, given the neoliberal focus on individual responsibility for health (Browne, 2002), such dynamics can serve to limit support for the system-level

changes needed to improve the equitability of care for the historically disadvantaged (Jackson et al.).

Nurses involved with the PHA explicitly named heterosexism and its effects, and collectively strategized with communities and with their interdisciplinary colleagues to challenge heterosexism through education, policy-making, and research. The PHA (2002) policy resolution extended the conventional discussion of heterosexist effects to include barriers to the production of knowledge in academic and publication contexts. According to Kitson (2002) and Ray (1999), authoritative health bodies act as gatekeepers, controlling knowledge production through academic means. Jackson et al. (2006) point out that we need both large-scale population-based and small-scale community-based studies in order to inform high-quality care. As counter-discourses — actions that challenge the prevailing social relations — PHA strategies advocate for the altering of social structures that legitimize the production of research evidence and for consistent education of health researchers with regard to sexual minority health.

The PHA (2002) policy resolution also problematized dominant evidence-based discourses shaping the production of knowledge in health-care environments. Although the evidence-based discourse offers a research base to frame health care, experts who use positivist approaches and quantitative measures of health and health outcomes often dominate discussions of health priorities, excluding or marginalizing other approaches such as CBPAR (e.g., Browne, 2002; Bryant, 2002; Kirkham, Baumbusch, Schultz, & Anderson, 2007; Kitson, 2002). Underlying androcentric epistemological norms serve to privilege positivist research and expert knowledges (MacDonnell, 2005; McQueen & Anderson, 2001). Research used as evidence for health-care policy or practice is constructed within particular epistemological and historical, social, and political contexts and is embedded in social relations and discursive practices that shift across time and place (Browne).

The ways in which same-sex issues are taken up in research often reflect social and political dynamics that are dominated by positivism, heterosexism, and rational policy processes (Jackson et al., 2006; MacDonnell, 2005, 2007; Varcoe et al., 2004). The holistic health issues of sexual minorities are often invisible or inconsistently addressed in the education of health professionals (Dunn, Wilson, & Tarko, 2007). Therefore, researchers may have a limited understanding of the unique issues to be considered in studies with sexually diverse communities. Disclosure, identity issues, and barriers to undertaking randomized control trials influence how and whether sexual minority health is studied (Dean et al., 2000; Dobinson et al., 2005; Duncan et al., 2000). Dynamics of authority play into what research questions are addressed

and what methodologies are legitimized, how studies are funded and published, and how — or whether — this evidence is disseminated (Ray, 1999). These macro dynamics inform public health capacity and the likelihood of nurses and their organizations having the knowledge they need to care for sexual minorities at the individual or community level.

### ***Reflexivity***

According to Peter (2000), reflexivity “refers to the capacity to reveal the political nature of knowledge through the questioning of every step of the research process” (p. 109). As Doane and Varcoe (2007) stress, “reflexive inquiry moves nurses to look at both what they are doing and how they are doing it” (p. 200). The PHA’s (2002) resolution challenging the assumptions behind evidence-based discourse is consistent with the literature that critiques medicalization and advocates for the decentring of epistemic privilege (Kirkham et al., 2007; Peter et al., 2005). In a research context, the PHA advocated for participatory action approaches with their potential for meaningful community engagement in the creation and production of knowledge, especially for those who have historically been excluded (Smith & Davies, 2006; Varcoe, 2006). The PHA’s critique of knowledge production addressed the visibility of both content (e.g., research undertaken and published) and process, with a view to foregrounding which participants had voice and authority throughout the process. It advocated for engaging participants in reciprocal knowledge production through the exchange of ideas, so that the communities concerned might benefit from the process by acquiring skills, confidence, and competence (community capacity), as well as through community mobilization around particular issues (Naidoo & Willis, 2000).

Some of the nurses who contributed to the policy resolution (PHA, 2002) were not publicly affiliated with the workgroup, because of workplace constraints, concerns about stigmatization, or anticipated negative workplace dynamics related to disclosure as a member of a sexual minority (Giddings, 2005; MacDonnell, 2007). It was decided not to make visible only those participants, especially allies, who faced fewer risks in being named as author. Collective authorship served both to validate the contributions of sexual minorities and allies on the issue of knowledge production and to protect identities. As a counter-discourse, the resolution challenged notions about who controls and participates in knowledge production. Advocating for sexual minorities’ acquisition of material gains and active engagement in academic research such as CBPAR also served to challenge heterosexist and homophobic processes that render minorities invisible and docile. The actions supported the resilience of sexual minorities, which, along with a range of other strate-



gies, challenges systems to be more responsive to their needs (Duncan et al., 2000; MacDonnell & Andrews, 2006; Ryan et al., 2000; Sawicki, 1991).

A feminist bioethics approach also considers the importance of context and relationships in the research process. The implementation of PAR in professional contexts can vary considerably (e.g., Holkup, Tripp-Reimer, Salois, & Weinert, 2004; Varcoe, 2006). The PHA (2002) resolution explicitly named the goals of enhancing community capacity and building on community knowledges and strengths as consistent with ethical goals. However, Hagey (1997) cautions that communities are alert to how research is used to manage them, given their experiences of institutions “gathering data ‘on’ oppressed people...[and] phrases such as ‘hit and run’ and ‘fly in fly out’ research” (p. 1). In the case of the PHA, trusting, respectful, and inclusive relationships between the community and professionals begun with the PAR projects (Dobinson et al., 2005; Gapka et al., 2003) have since been enhanced by joint participation in education and policy initiatives. However, as Varcoe (2006) points out, “being inclusive must be seen as complex and the influence of diverse agendas and perspectives acknowledged” (p. 525).

In order to challenge health and social inequities, nurses must challenge their own knowledges, assumptions, and practices, considering that complex relations of power influence their nursing actions in ways that help to emancipate and empower their clients. The sociopolitical environment shaped by dominant neoliberal discourses is a significant force in informing the practice setting. All social institutions in this neoliberal era are marked by the use of efficiency and outcome measures of accountability and quality of care that primarily reflect economic interests (Browne, 2002; Gustafson, 2000; McQueen & Anderson, 2001). Policies and programs associated with the health professions are affected by business paradigms in which quality of care is equated with efficiency, standardization, and cost-effectiveness. Some recent health-care reforms, for instance, privilege dominant groups at the expense of those marginalized by race and gender (Gustafson). Particular conceptualizations of deservedness create exclusionary visions of care that direct health policies and organizational practices (Duncan et al., 2000; Raphael, Bryant, & Curry-Stevens, 2004). Such dynamics require an awareness of the structural underpinnings of health and solutions that may require sustained creative and collective action (Doane & Varcoe, 2007; MacDonnell & Andrews, 2006).

In the community context, practice settings are informed by demands for short-term measurable outcomes and discourses of health promotion based on behavioural and biomedical models. Nurses' coalition work with communities has been discounted or invisible in organizational

accounts of their practice (MacDonnell, 2005). Such policies and practices shape nurses' working conditions that implicitly discount the importance of continuity of care. Yet nurses require protected time to facilitate care based on in-depth understanding of the particular issues of the client base, as well as to develop trusting, sustainable partnerships between communities and institutions. There are implications for fostering nurses' ability to meet the needs of their communities, as well as to find meaning in their work (Falk Rafael, 1999; Gustafson, 2000; MacDonnell, 2007; Stevens & Hall, 1992).

Yet, along with neoliberal influences, emancipatory discourses, such as social equity, that align with health promotion initiatives consistent with social justice shape the public health environment. Such strategies can ultimately change the conditions that foster and sustain health and enhance communities' control over their living conditions (Stevens & Hall, 1992). The *Action Statement for Health Promotion in Canada* (Canadian Public Health Association, 1996) cites two key factors that support effective action: "enhancing our knowledge base and building stronger [community-institutional] alliances" (p. 9). In this vein, nurses' priorities include facilitating processes and outcomes that reflect community agency, meaningful participation, and empowerment (in ways that move beyond tokenism). Long-term organizational investment in community coalitions is consistent with this political work, as is investment in nurses' ability to create/co-create knowledge with communities (Hagey, 1997; Kirkham et al., 2007).

The PHA originated as a forum for personal support and the sharing of sexual diversity information among interdisciplinary public health practitioners, including nurses and health promoters, across regions. Although many of the practitioners worked in sexual health programs, they often felt isolated in their work related to sexual diversity. Most professional resources in their organizations and networks addressed the important but limited context of sexual health and HIV/AIDS (MacDonnell & Andrews, 2006). The PHA serves as a safe space for sexual minorities and their allies, communities, and professionals to connect across difference to address sexual diversity. Rodney, Doane, Storch, and Varcoe (2006), in a study of nursing ethics, advocate for nursing workplaces that provide a safe moral climate. Stevens and Hall (1992) demonstrate the relevance of critical and liberation theories for public health nursing practice, stressing that these incorporate reflection and action to engender empowerment, hope, and dialogue with vulnerable groups, including lesbians and gays, and that they "originate in historical contexts through oppressed groups' reflections on their own experiences" (p. 4). The PHA and the policy resolution process are examples of support systems that validate sexual minority identities and

knowledges and that foster the development of meaningful relationships (Peter et al., 2005). These spaces for identifying practice challenges and strategies for promoting self-determination are consistent with Doane and Varcoe's (2007) "active, accessible, moral-reflective spaces [for] ongoing inquiry and deliberation...on the contexts of practice" (p. 203).

### ***Gender Dynamics and Social Difference***

As members of a female-dominated profession, nurses in North America have had variable responses to their political and policy initiatives. Nurses are often well situated to advocate on behalf of vulnerable groups. However, given the gendered and historical context of nursing in professional hierarchies, their caring work can be devalued and rendered invisible, just as their knowledge frequently is in the policy and research arenas (MacDonnell & Andrews, 2006; McDonald, 2006a; Peter et al., 2005). Hierarchies within the profession, and the invisibility of sexual minority issues in nursing research, education, and the media, also contribute to the legitimacy accorded to this political work. The lack of attention to sexual diversity in nursing education, organizational training in cultural competency, and nursing research marginalizes the impact of nurses' practice with sexual minorities (MacDonnell, 2007).

Nurses can use their credentials and their association with policy bodies to garner the support necessary to challenge these deeply embedded gender dynamics. Public health nurses affiliated with the PHA use a variety of roles, such as that of educator or clinician, to press for change when working with individuals or agencies (MacDonnell, 2007). The OPHA's explicit support for the position papers and resolution on ethical research promotes knowledge translation at the macro level, given its leadership on public health issues among policy-makers, practitioners, and communities on behalf of diverse communities and public health professionals.

However, nurses are not neutral entities. They are marked by gender, race, class, sexuality, and other dimensions that influence their ability to act and to shape the legitimacy accorded to their voices (MacDonnell, 2005). Political allies work across differences in the PHA, using their heterosexuality and other locations of social privilege to draw attention to heterosexism, biphobia, and transphobia. Nevertheless, professionals — both those identified as members of sexual minorities and their political allies — who participate in same-sex activism can encounter obstacles, including discrimination or hostility based on claimed or assumed same-sex identity (Giddings, 2005; MacDonnell, 2007). Doane and Varcoe (2007) propose that such practices be seen not as negative but as a "window into meaningful relationships...and responsive care [consistent with]...health promoting ways" (p. 202).

Advocacy for sexual diversity is often construed as “special interest” and relevant for only a small number of Canadians (Jackson et al., 2006; Ryan et al., 2000). Such a discourse not only discounts the legitimacy of sexual diversity health issues (and pathologizes or otherwise invalidates the lives of those who identify as members of sexual minorities), but has particular significance in policy-making: Who is bestowed with the authority and legitimacy to participate in policy processes? Policy-makers are assumed to possess an objectivity that enables a separation of their knowledge-production activities from self-interest. Citizen activists, on the other hand, “tend to address issues that affect them personally and may be perceived by the public as self-interested” (Bryant, 2002, p. 93). This assumption is relevant for nurses who appear to have a personal and vested interest in such professional work. As Bryant states, “Citizen activists may have a genuine concern about homelessness, but not be homeless or at risk of becoming homeless” (p. 93). In fact, since addressing social oppression benefits the whole of society, professionals who — as citizen activists or in some other capacity — undertake sexual diversity work do have a “special” or vested interest. However, as Browne (2002) points out, the liberal ideologies embedded in nursing knowledges and practices can limit nurses’ awareness of the interconnectedness of social and human relationships, of how they participate in heterosexual processes, and of the role they could play in shifting heteronormative dynamics (Doane & Varcoe, 2007; MacDonnell, 2005; Peter et al., 2005).

### **Summary and Discussion**

As this analysis demonstrates, an ethical inquiry that considers the multiple power dynamics that influence nurses’ advocacy practices offers insight into the tensions that structure nurses’ ability to engage in caring that is consistent with the emancipatory goals of social justice. Although heterosexism, biphobia, and transphobia certainly shape the public health focus on sexual minority health, attention to the social and political context broadens our understanding of factors that influence nurses’ work to enhance access to relevant and high-quality care. Neoliberal, social justice, and empowerment discourses, authority relationships, evidence-building, and policy processes, as well as professional dynamics and situated privilege, are woven throughout the discussion. Reflexive and participatory action processes are described in light of professionals’ critical reflection on their research practices.

As this is a qualitative study focused on public health nurses at a particular historical time and place, its findings are not generalizable to other nursing contexts. The study offers insight, however, into concepts and relationships that inform nursing work across practice domains.

It resonates with and builds on nursing ethics research and scholarship using critical feminist and postcolonial feminist perspectives to critique nursing practice and health-care dynamics, as well as to foster transformative practices that challenge health and social inequities (e.g., Browne, 2002; Doane & Varcoe, 2007; Kirkham et al., 2007; Racine, 2003; Varcoe, 2006). By foregrounding sexual minorities, it extends the discussion of diversity and epistemic privilege in a context of CBPAR research and inclusive knowledge-translation strategies that focus on racial or ethnic difference (Holkup et al., 2004; Kirkham et al.; Varcoe). This case study extends the recent scholarship explicitly linking nursing ethics and public health practice, especially with its focus on social justice discourses (CNA, 2006; Davison, Edwards, Webber, & Robinson, 2006; Racher, 2007).

The PHA (2002) policy resolution has contributed to the development of ethical knowledge and nursing practices locally and provincially through PHA activities and OPHA policy initiatives. It provided impetus for the initiation of two PAR projects addressing the access of bisexual and transsexual/transgender communities to public health services (Dobinson et al., 2005; Gapka et al., 2003). These projects culminated in two widely disseminated position papers affirming the value of the CBPAR process in creating knowledge for their communities and advocating for its further use.

Although Canadian research bodies have developed processes for addressing research ethics with Aboriginal communities, there has been little ethics research with sexual minorities. In August 2003 a submission based on the PHA policy resolution was presented to the PRE Consultation Evolving the Tri-Council Policy Statement: Ethical Conduct Involving Research on Humans (TCPS) to Better Meet the Needs of Canada's Social Science and Humanities Communities, and was included in the report that followed. The policy resolution has also helped to shift knowledge-production processes through national research bodies.

Much work has yet to be done to challenge structures that limit nurses' understanding of sexual minority health and their supportive practices. A position statement by the Registered Nurses of Ontario (2007), *Respecting Sexual Orientation and Gender Diversity*, calls for nurses to critically reflect on the knowledge, values, and assumptions that shape their practice. It supports advocacy, education, and policy change across organizations to challenge health inequities related to sexual diversity. The three PHA position papers inform that document.

This focus on concepts relevant to a feminist bioethics framework (Peter et al., 2005) contributes to our theoretical understanding of factors that enable, constrain, or complicate nurses' ability to pursue lofty ethical goals such as social justice. It demonstrates the benefits of facilitating

critical reflection and dialogue among nurses and their communities in order to examine the complex dynamics that structure their practice and their care options. There are implications for affirming the challenges that nurses face in their everyday work. We need more nursing ethical inquiries that address the complexities of power dynamics, the positive, negative, and contradictory dimensions that shape public health and community practice, as well as those that focus on sexual minorities and other vulnerable groups.

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## **La validité de l'étude phénoménologique herméneutique : vers une éthique de l'évaluation**

**Judy Rashotte et Louise Jensen**

Cet article explore la relation de l'éthique par rapport à la validité de l'étude phénoménologique herméneutique. En premier lieu, les auteures font un bref tour d'horizon des divers discours sur la validité de la recherche qualitative appliquée de multiples façons à l'étude phénoménologique herméneutique. Elles examinent ensuite de quelle façon l'éthique relationnelle est à prendre en compte dans cette forme d'étude. Enfin, elles offrent une série de réflexions d'ordre moral pour aider les chercheurs à s'engager dans un questionnement déontologique à chaque étape du processus de recherche.

Mots-clés : étude phénoménologique herméneutique, validité

# Validity in Hermeneutic Phenomenological Inquiry: Towards an Ethics of Evaluation

Judy Rashotte and Louise Jensen

This article explores the relationship of ethics to validity in hermeneutic phenomenological inquiry. First, the authors present a brief overview of the various discourses on validity in qualitative research that have been variously applied to hermeneutic phenomenological inquiry. Next, they examine how relational ethics is a presence to bear within this form of inquiry. Finally, they offer a set of ethical reflections to help the researcher engage in a process of ethical questioning during each step of the research process.

Keywords: Hermeneutic phenomenological inquiry, validity, relational ethics, evaluation criteria

I am deeply troubled by the anonymous imperial violence that slips quietly and invisibly into our (my) best intentions and practices and, even, into our (my) transformational yearnings. ...I fear the arrogance we enact “unknowingly”; I fear my seeming lack of fear in proposing new imaginaries of validity.... Perhaps, instead, we (I) ought to be stunned into silence — literally, into silence, into a space of emptiness, into the clarity of unknowing that appropriates no one or no thing to its sameness, that “which can neither be acquired nor lost” (Minh-ha, 1989, p. 76). (Scheurich, 1997, p. 90)

Validity has always been a contentious issue in qualitative research, particularly for those conducting studies on hermeneutic phenomenology. On the one hand, some researchers are concerned with the “myriad kinds of validity” that serve simply as “masks that conceal a profound and disturbing sameness” (Scheurich, p. 80) — that is, validity within a positivist framework. *Validity*, a word derived from the Latin verb *valere*, means to be strong, and the adjective *validus* refers to the strength, firmness, and power of a thing. The Oxford English dictionary (Trumble & Stevenson, 2002) defines valid as possessing authority, such that the quality of the thing under consideration (an event, an argument, or data) can be accepted as binding given that it has been executed with all the proper formalities. Our current understanding of validity in research, which has arisen from Descartes’s dream of clarity and distinctness, finds its strength in the univocity of reality, univocal discourse, and the adherence to method. Validity becomes formalized, orienting to precision,

definition, and repeatability. From this perspective, validity is understood to have an exclusionary nature within a movement of normalization and levelling. But this understanding of validity is not in keeping with a mode of inquiry that seeks to keep the question of Being open (Heidegger, 1927/62), to engage in an un-doing (Caputo, 1987), or to show the *différance* by which things are inhabited (Derrida, 1973/2002).

On the other hand, some qualitative researchers argue that if the research report is nothing more than what might have been constructed by a good journalist, then it cannot be said to constitute original scientific research. “Validity must be distinguished from the researcher’s own sincerity and enthusiasm in presenting the findings as ‘truths,’ what has been described as ‘cardiac validity’ (i.e., how heartfelt the interpretation is) or ‘lachrymal validity’ (i.e., how much emotion it produces)” (Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004, p. 17). It appears that the issue of validity places hermeneutic phenomenological researchers “between a rock and a soft place” (Lather, 1986). However, now that reports of qualitative studies across the various methods are being systematically scrutinized for their worth and quality so that the results can be effectively applied and realistically synthesized (Sandelowski & Barroso, 2002), there is a heightened awareness of and a renewed call for intellectual rigour, coherence, and validity within the various qualitative traditions (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

We have an opportunity to keep our “understanding of validity in play, or, in motion, flexible, in flux” (Caputo, 1987, p. 263). Perhaps if we look at validity through a set of ethical reflections it will help us to “cope with the flux” (Caputo) that is demanded by hermeneutic phenomenology. It will let us stand, albeit slightly off balance, in the same world, while having extricated ourselves from the dominant scientific “method” or understanding of validity. Sobered but inspired by Scheurich’s (1997) words quoted at the beginning of this article, we are commanded to face the problem of validity, not just in terms of what we can know as a result of engaging in this form of inquiry but also in terms of what we are to do during the research process. Numerous ethical questions pervade how we are to judge the quality of hermeneutic phenomenological inquiry. How can we do justice to stories about what has happened to particular participants at a particular time and place? Whose voice should be heard in the analysis and writing when new understandings come into the clearing? How can we preserve the diversity and character of our topic without reducing them to sameness?

The purpose of this article is to explore the relationship of ethics to validity in hermeneutic phenomenological inquiry. First, we present an overview of the various discourses on validity in qualitative research that have been variously applied to hermeneutic phenomenological inquiry.

Next, we examine how relational ethics is a presence to bear within hermeneutic phenomenological inquiry. Finally, we offer a set of ethical reflections adapted from the work of Afaf I. Meleis (1996), which, when attended to, helps the researcher engage in a series of ethical questioning during each step of the research process. We do not claim to have found a high ground, nor do we seek a way out of the issue of validity; rather, we seek a meaningful way to stay and move with it, to create a new opening, not a resolution of the question of validity.

### **Validity at Play in Qualitative Research**

What, then, are the various criteria typically used to judge the validity of hermeneutic phenomenological inquiry? Throughout the 1980s and early 1990s, scholars in the qualitative domain worked hard to silence the voices of critics within the positivist paradigm by developing evaluation criteria that would meet the rigorous standards of its counterpart. This arose from the marginality of the qualitative research method in the context of academia and funding agencies (Kahn, 1993). It was assumed that if methodological trustworthiness and data truthfulness could be proven, then the findings would be considered legitimate knowledge. Original evaluation criteria included truth value, applicability, consistency, and neutrality and were an attempt to match the corresponding criteria used in the scientific paradigm — internal validity, external validity, reliability, and objectivity (Lincoln & Guba, 1985). Sparkes (2001) termed this the “replication perspective,” while Kahn referred to the criteria as “analogous language,” implying that the issue of validity is comparable in context to that of quantitative research.

Gradually, these criteria were deemed inappropriate by some and new criteria were developed. The following are examples of what have been considered criteria for evaluation: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985); credibility, fittingness, auditability, and confirmability (Sandelowski, 1986); descriptive vividness, methodological congruence, analytic preciseness, theoretical connectedness, and heuristic relevance (Burns, 1989); credibility, confirmability, meaning-in-context, recurrent patterning, saturation, and transferability (Leininger, 1994); curiosity, confirmability, comparison, changing, collaborating, critiquing, and combinations (Chenail, 2000); and interpretation of subjective meaning, description of social context, evidence of theoretical or purposeful sampling, and evidence of adequate description (Popay, Rogers, & Williams, 1998). These criteria have been labelled “foundational” (Lincoln, 1995/2002) or the “parallel perspective” (Sparkes, 2001). Despite the label change, the central motive of evaluation remained virtually the same.

In the latter part of the 20th century, critics in the qualitative domain began to challenge “issues of representation and legitimization” (Lincoln & Denzin, 2000, p. 1049) and to question the foundational standards of evaluation. Findings from cultural, feminist, and action studies brought to light the strong empiricist influence within qualitative research. Consequently, attempts were made to develop evaluation criteria “more commensurate with the philosophical underpinnings of the qualitative domain, returning the dialogue to the topics of ethics, vulnerability, and truth” (p. 1049). In fact, Sparkes (2001) identifies two evolving perspectives: “diversification of meanings,” and the “letting go of validity.” Proponents of the former perspective choose not to reject the concept of validity but to reconceptualize it in relation to particular forms of qualitative inquiry. Brink (1991) refers to this orientation as “the insider’s domain,” while Kahn (1993) calls it “metaphorical languaging.” For example, Lather (1986) initially developed her catalytic validity within her feminist, critical theory orientation but later (1993) added ironic, paralogical, rhizomic, and voluptuous validity, all of which she subsumed under the label transgressive validity. Lather (1993) addresses validity as a catalyst to discourse, “a fertile obsession,” and rewrites validity in a way that uses this postmodern difficulty to loosen the stronghold of positivism. In contrast, the champions of the “letting go of validity perspective” argue for the abandonment of the concept of validity and the seeking of alternative criteria with which to judge qualitative research. Wolcott (1994) is a proponent of this view, asking, “Should we not seek to have our work regarded as provocative rather than persuasive?” (p. 346):

And I do not accept validity as a valid criterion for guiding or judging my work. I think we have laboured far too long under the burden of this concept...that might have been better left where it began, a not-quite-so-singular-or-precise-criterion as I once believed it to be for matters related essentially to tests and measurement. (p. 369)

### **Relational Ethics in Hermeneutic Phenomenological Inquiry**

Hermeneutic phenomenological inquiry does not set out to discover fixed essences (Caputo, 1987) or essential structures that can be determined once and for all; it is not assumed “that the voicing life must be *either* the single, isolated voice of difference (such that lived-experience turns out to be idiosyncratic and subjectivistic), *or* the clear and foreclosing voice of identity” (Jardine, 1998, p. 25). Rather, it seeks to understand what it means to be human and all the possibilities for being in this world (Heidegger, 1927/62). Understanding is enabled from the outset because there is already a living connectedness with the focus of the

researcher's inquiry. In other words, a sense of kinship with the Other's lived experiences is possible because the range of human desires, feelings, emotions, and hence meaning, is bound up with the level and type of culture we share, which in turn is inseparable from the distinctions and categories marked by the language that people speak (Taylor, 1985). Language and its expressive dimension allow us to: (a) bring to fuller and clearer consciousness that which we have only an implicit sense of; (b) put things in public space, thereby constituting and shaping the kind of space in which we can share something between each other; and (c) make the discriminations that are foundational to human concerns and hence that open us to these concerns (pp. 256–263).

However, this shared public understanding seductively creates a tendency for us to understand our everydayness of being-in-the-world in a superficial and conventional manner. The task, then, of hermeneutic phenomenological inquiry is to make more meaningful what it means to *Be* as human beings. But in saying this, Heidegger (1927/62) states that we must always be on guard against arbitrary “fancies and popular conceptions” (p. 195) and be willing to revise our point of view in light of what is uncovered or released in “the clearing” (p. 171). The awareness of existence requires that the everyday perspective of existence, which can be questioned only in particular cases, be shaken and disrupted (Gadamer, 1960/89, p. 268), although this does not suggest any kind of arbitrary rejection of what is already known and understood. The everyday perspective is never abandoned; it is transcended. Gadamer further holds that we must be ready to leave things open, to even tolerate a plurality of possible interpretations, because no single interpretation can really be exhaustive (p. 363).

To do so, understanding requires engagement, to become party to the conversation in order to keep it going, “to keep it alive, to dwell in the kinships, relations, and similarities it evokes” (Jardine, 1998, p. 27). This means bringing one's preconceptions to the interpretation of a text but then deliberately risking them in the encounter. The paradox is that this view can guide us to something new that raises the possibility of achieving deeper and richer understandings. According to Gadamer (1960/89), the vehicle that facilitates this process of understanding is participative, conversational, and dialogic, for it is only in a dialogical encounter with what makes a claim upon us that we can open ourselves to risking and testing our preconceptions; new understanding is achieved through a process of moving dialectically between a background of shared meaning (the whole) and a more finite focused experience within it (the part) through the continuous process of questioning; new meaning occurs in “the art of questioning,” which “is the art of questioning even further” (p. 367).

In conversation between two people, each party is open to and accepts the other's point of view for what it is — that is, the coming to a fusion of horizons (Gadamer, 1960/89). But fusion must not be confused with consensus. When we experience Other “truly as a thou,” we do “not overlook his claim but let him really say something to us” (p. 361). This relationship to Other is based on openness. We neither objectify nor claim to speak for Other. Instead, we are open to Other as someone who has his/her own autonomous position and claims. “At work is a conversation in which we seek to understand and address the independent claims of the other and, in turn, are addressed by them” (Warnke, 2002, p. 93).

“When two people understand each other, this does not mean that one person ‘understands’ the other. ... [Rather] openness to the other... involves recognizing that I myself must accept some things that are against me, even though no one else forces me to do so” (Gadamer, 1960/89, p. 361). In other words, understanding occurs in keeping ourselves open to others' understandings, “in not thinking that something is known, for when we think we already know, we stop paying attention to what comes to meet us” (Moules, 2002, p. 23).

In hermeneutic phenomenological inquiry, Others' stories are the vehicle through which meaning is shared. Stories inhabit the textuality and difference in lived experience, which is everything each human being thinks and does and hopes for. Embedded in stories are the particular ways that Beings are granted to be and to dwell. Through exchange with Others and learning through rich modes of human expression (such as stories), we not only “become full human agents, capable of understanding ourselves” (Taylor, 1991, p. 33) but also “restore life to its original difficulty, to show that things never are what we say they are, that they do not have pure and unambiguous presence” (Caputo, 1987, p. 249). Perhaps it is this latter aspect in particular that calls for the listener to come to Others' stories with a certain compassion, a sense of togetherness, if you will, which arises precisely from the sense of this common fate of “suffering (*passio*) a common (*com*) comfortlessness” (Caputo, p. 259) of living with flux and the constraint of being unable to take hold of or show the meaning of something once and for all (Derrida, 1973/2002). Understanding what it means to be human “doesn't mean that [we] work it out in isolation, but that [we] negotiate it through dialogue, partly overt, partly internal, with others” (Taylor, 1991, p. 47). In other words, the complexity of some lived moments in life is encompassed in our minds with a story, not with theories or a system of ideas. “In one way or another, we will see these events in the light of our own principles — because stories inevitably demand ethical reasoning.... A story is always charged with meaning, otherwise it is not a story, merely



a sequence of events” (Fulford, 1999, p. 6). Therefore, the power of hermeneutic phenomenological inquiry is that it reminds us of what we know and calls us back to what we consider significant when we tell the story of our experience to another. In addition, Taylor argues that personal stories of life as actually experienced are a beginning of politics and that there is a powerful moral ideal in the search for authenticity. Therefore, exploring the meaning of a phenomenon as told through Others’ stories of their lived experiences can function in “counter-hegemonic ways, bringing into critical focus the institutions of governance, economic control, educational institutions, the media, and so on” (Gergen & Gergen, 2000, p. 1034).

Given the ambiguous and open-ended quality of experience, sharing one’s lived experience gives a measure of coherence and continuity that is not available at the original moment of experience. Consequently, there comes a sense of morality — unspoken but practical answers to how we should live. This morality is not fixed but is constantly being revised in subsequent (re)tellings, including those that put different emphases on old tellings. The purpose of (re)calling and (re)telling experiences, the meanings of which are often deeply embedded in the rich allegorical nature of our language, reflects a desire to grasp and seize the possibilities of meaning rather than to depict experience exactly as it was lived. Thus stories are ontological in nature. They are a means of fashioning experience in language (recognizing that language, like Hermes, can play tricks and is part of the flux). Therefore, the opportunity for authenticity and moral development is provided through the storytelling that occurs in the dialogical relation of hermeneutic phenomenological inquiry.

“Science is meaningless,” wrote Tolstoy, “because it gives no answer to our question, the only question important to us — what shall we do and how shall we live?” (cited in Frank, 2002). The dialogical relation that occurs in hermeneutic phenomenological inquiry provides an occasion when one can co-author responses to Tolstoy’s great question, to find meanings that go beyond the purely practical and technical (Frank). The dialogical relation that occurs within the text as told by Others becomes an occasion for Others to open the venue of ethics, the place where ethical existence occurs. Others call us into question in the dialogical relation and (re)call our responsibility to them through understanding our kinship with them, through understanding, not severing, the threads that already bind us.

Consequently, the analysis in hermeneutic phenomenological inquiry entails extensive ethical obligations. The researcher does not simply record and analyze data as text but assents to enter into a relationship with Other. The researcher becomes part of Other’s ongoing struggle

towards a moral life as well as societies' ongoing struggle to attain the ethic of authenticity, what Taylor (1991) terms "la lotta continua" (p. 71). Doing this type of research means that events and lives are affirmed as being worth telling and thus worth living and serves as a form of moral education. Asking Others to tell about their lived experiences implies value, attributes reality, and confers affirmation of choice on both the individual(s) and the communities of which they are a part (Taylor, 1991). Gergen and Gergen (2000) write that different cultures (e.g., ethnic or professional) invite different stories and therefore different expectations of those stories from audiences. Because individuals live and narrate their lives in time and place, they provide us with knowledge about much more than themselves. Individuals are products of social interchange and as a result contain elements of universality. "This is why we see ourselves and others as part of, and in or out of synchrony with, history and culture, although we may not always recognize it" (Sandelowski, 1996, p. 119). Perhaps it is here that we (re)cognize the strength, firmness, and power of the thing — that is, the validity of the research findings. Perhaps, too, it is here that we can (re)cognize the irreducibly multivalent nature of a phenomenon as lived experience. Viewed in this way, validity, like valency, is concerned with the power or capacity to both combine with and displace other meanings and understandings — in other words, to keep our understandings in play.

Yet it is of concern that, in our need to be taken seriously, the potential power of stories has been diluted by claiming quantitative notions of validity, notions that tend to silence stories rather than invite them to resonate in polyvocal ways (Burns-McCoy, 1997). Thus, our concerns relate to the (re)presentation of Other, power or dominance in the researcher-participant relationship, and the claim that the text of Other may be inaccurate, untrue, or incomplete. hooks (1990) argues that in an attempt to comply with foundational standards of validity, the hermeneutic researcher assumes a position of control or dominance:

No need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you I write myself anew. I am still author, authority. I am still colonizer, the speaking subject and you are now at the center of my talk. (p. 69)

Burns-McCoy (1997) suggests that the methodological framework of the conventional evaluation criteria drives the study forward and becomes the researcher's voice, organizing, choosing, interpreting, and

silencing (p. 9). Scheurich (1997) takes this position of dominance one step further, having found support for his view in Minh-ha's (1989) contention that the Western project is an attempt "to annihilate the Other through a false incorporation" by the Same (p. 66):

If I completely control the (O)ther, then the (O)ther ceases to exist.... In such a relationship, one side (the Same) maintains its boundaries (i.e., its validity); while the Other (the raw untheorized world) must, to gain acceptance and legitimacy, lose itself within the Same — must convert to and, thus, become the Same. The Same relentlessly seeks to capture and theorize more data in an attempt to attain and maintain power. (Scheurich, p. 86)

Olthius (2000) argues that in this period of modernity "the dominant culture in the West developed liberal stratagems of toleration of the strange and different which tended to bracket, deny, ignore, dismiss, or consume the very characteristics which constitute uniqueness or difference" (p. 1). For Scheurich (1997), converting Other into Same (thus undermining the multiple differences revealed in the unfolding particularities) is as dangerous as maintaining a concept of dualism (with the danger of Other remaining marginalized or prejudicially different and therefore lacking in power) (p. 89). As a result, he argues, by holding onto the term validity, even those who seek a radical reconstruction of what it means are fighting a lost cause due to the cultural baggage this term carries. Because validity acts as a mask for a boundary or serves a policing function across both foundational approaches and more radical alternatives, an unsettling and disturbing sameness across multiple paradigms is created.

Burns-McCoy (1997) laments that "even when our methodologies establish postpositive frameworks that acknowledge situated, constructivist readings, they still work to stabilize meaning as well as assume acceptable and expected cultural retellings" (p. 2). Accordingly, the criteria for validity are the expected trappings that set up an audience for another cultural (re)telling — "we frame the text so tightly with report-like presentation of methodology, that the polyvocality of the text is stifled, its resonance muffled" (p. 2). She posits what we believe to be the ultimate provocative question, and the one of primary importance:

Do you question the credibility and validity of my story? On the one hand, my story is incredulous. On the other hand my story is sensible and fits neatly into my world, into other's experiences, into our material realities, for when we do find avenue into purposeful self-expression, when we are no longer silenced, when our outward acts align with our internal desires, we our transformed and our worlds transform. (p. 6)

Thus there is a moral imperative within the process of establishing validity in hermeneutic phenomenological inquiry. Researchers use their subject-object position of dominance to silence Other's voice and maintain Other's marginalized position if they only change perspectives within the scholarly narration (report of findings) without changing social positions. Kahn (1993) argues that the need for the researcher to account for several relationships is at the heart of the hermeneutic research process.

A new way of discussing validity, then, might be grounded productively in a language constructed around three key relationships. The first is the relationship between the researcher and the participants. Ethical questioning starts with the influence of the researcher on the process, particularly regarding the social interactions themselves. As Shotter (2005) notes, "As soon as I begin an interchange of looks with another person, and I sense them as looking toward me in a certain way (as they see me looking toward them in the same way too), a little ethical and political world is created between us" (p. 104). Knapik (2006), for example, queries: How did elements of mutual trust or mistrust, social attractiveness, or gender differences enter into the situation? What interpretations were participants making of the researcher?

The second relationship is that of the researcher with the data, which should be moved away from the linear form of collection to coding to analysis with recognition of the actual circularity of the process. For example, how and when did aspects of the interpretation emerge, and in what forms? How were the interpretations challenged and tested over the course of the study?

The third relationship is that of the researcher with the readers. Both the researcher and the reader must *leap into* the text with a hermeneutic attitude — that is, with a sense of attentiveness, empathy, sensitivity, carefulness, respect, reflection, engagement, conscientiousness, awareness (Davies & Dodd, 2002), open-mindedness, and open-heartedness (Dahlberg & Drew, 1997). Hermeneutic phenomenological researchers must invite the reader to open the door to the experience of this otherness, while the reader must be willing to continue the engagement of dialectic, to be drawn into the implications of meaning, to pick up the thread of meaning and become part of the whole (Jardine, 1992). The reader must be open to the idea that not all interpretations will work for everyone. Indeed, the reader must engage in the same dialectical process, particularly when the findings "haunt or frustrate or resist or provoke" (Jardine, 1992, p. viii). The findings cannot simply be dismissed as untrue or untrustworthy. The reader must also come to the researcher's text with an openness of heart and mind that will allow him/herself "the luxury and the risk of getting lost in [the] huge forest of the text — and then

suddenly noticing something vaguely familiar, or glimpsing something moving out of the corner of [one's] eye, or following a rocky side trail of traces and footprints that stop at the sheer edge of a cliff" (p. vi).

### **Putting Ethics in the Evaluation of Validity in Hermeneutic Phenomenological Inquiry**

As noted by Caputo (1987), the notion of flux that underpins hermeneutic phenomenology "does not leave action behind, does not let us enter a new world, make a leap into a different sphere where there is no longer any need to act. The thought of the flux remains always and already in the same sphere, faced with the demand to act but now with a transformed relationship to action" (p. 239). Where are we to turn, whence are we to get guidance and direction, if we view validity from an ethics of evaluation? We suggest that Meleis's (1996) work on the development of criteria to ensure culturally competent scholarship, work based on a relational ethic of care, can be woven through the three key relationships of hermeneutic phenomenological inquiry. Addressing the ethical questions associated with four criteria, namely contextuality, communication styles, awareness of identity and power differential, and disclosure, is one way to evaluate the process of this form of inquiry.

#### ***Contextuality***

Meleis (1996) writes that knowledge without a context leads to marginalization of the populations under study and to stereotyping of groups. Context includes sensitivity to structural conditions that contribute to participants' responses and to the interpretations of situations informed by experiences, by validation of perceptions, and by careful review of existing knowledge. Rather than separating Others' experiences from the contexts in which they occur, the researcher recognizes Others' everyday experiences as inextricably connected to the political, social, and economic environment. In this way, the complexity of Others' reality is also emphasized and explicated. Both the researcher and the reader, engaging in the language of ethics-in-action, ask the following questions:

Has the researcher provided a thick description of events by describing them in their context? Have those thick descriptions been incorporated inside their temporal and narrative contexts? Have the concrete particulars of the particular people at particular places and times been provided? (Brinkman & Kvale, 2005, pp. 177–178)

Have the "voices" and "stories" of individuals been connected back to the set of historic, structural, and economic relations in which they are situated? (Fine, Weis, Weseen, & Wong, 2000, p. 126)

What are the traditions in which we participate that are relevant to the phenomenon under study? (Gadamer, 1960/89, pp. 3–42)

Similarly, the researcher clearly reveals and discloses his/her own context. By making these horizons explicit, the reader and participants can become aware of how the questioning is able to seek insight rather than confirm beliefs. When assumptions are unrecognized or disregarded, understanding is incomplete and Other's voice will remain hidden. Emphasizing that understanding is a dialectical process, the writing generously discloses, not only in the account of the questions asked of the Other, but in the questions the researcher asked of self, Others' experiences, and relevant texts as they unfold throughout the process. In the end, validity "lies in the ability of the researcher to be honestly open to the world" (Dahlberg, 1995, p. 190). The researcher and the reader need to ask the following questions that we believe emerge from the writings of Gadamer (1960/89), Jardine (1992), and Taylor (1991): How were the stories related to the researcher's own sociocultural context, history, and traditions? How was the researcher surprised by what the stories revealed about the phenomenon and its meaning for living in this world? Does the researcher take the measure of herself, her limitations, her confusions, ambivalence? How were the researcher and the participants changed by coming into "the clearing," and why?

### ***Communication Styles***

Another way to evaluate the process is "the extent to which the scholarly interpretations demonstrate critical understanding of preferred communication styles for the research participants and their communities, including the most congruent design for the population's communication style" (Meleis, 1996, p. 11). The evaluation would include evidence of understanding of (or attempts to understand) the subtleties and variations inherent in language, as well as symbols used. Attentiveness to communication styles demonstrates a respect for and sensitivity to language, connotation, and lifestyle. Linked to this is what Hall and Stevens (1991) call "naming." Hall and Stevens define naming as "learning to see beyond and behind what one has been socialized to believe is there" (p. 26). It is addressing Others' lives in their own terms and generating concepts through words directly expressive of their experiences. These authors contend that naming has two powers: "It defines the value of that which is named by the emphasis of selecting it and it denies reality to that which is never named" (p. 26).

Understanding of communication style is also demonstrated in the production of the research report. Richardson (1994) saw the use of a mechanistic model of writing intended for quantitative research as an abdication of our responsibility to our participants, data, and readers:

Unlike quantitative work, which can carry its meaning in its tables and summaries, qualitative work depends upon people's reading it. Just as a piece of literature is not equivalent to its "plot summary," qualitative research is not contained in its abstracts. Qualitative research has to be read, not scanned; its meaning is in the reading. (p. 517)

Hermeneutic phenomenological inquirers are ethically required to capture and preserve Others' experiences, even as they paradoxically understand that this is not possible. All they can hope for is to find a way to (re)present the experience for the reader in such a way as to cause an evocation, "to *express* meaning rather than *state* it" (Norris, 1997, p. 93). In order to highlight that which has been released, the hermeneutic researcher as writer may deliberately "disrupt, find and cultivate the familiar" (Moules, 2002, p. 31), potentially leaving the reader with the impression of exaggeration. Validity would be recognized if the reader were engaged in the phenomenon as lived by self and Other in such a way that s/he is willing to open the door to a room and take a journey to a door on the other wall (Jardine, 1992). The researcher and the reader therefore would ask the following questions that emerge from the provocative arguments of Denzin (2002), Jardine (1992), and Richardson (1994): Does the researcher seek to empower the other by writing in the distinctive styles, rhythms, and cultural dialect of the participants? Does the language make you feel the feelings of the characters, smell the smells, see the sights, hear the sounds, as though you were there? Is the language used in such a way that it brings people together in understanding? Is the language free of prejudice, repression, and discrimination? Does the researcher allow the reader to join the conversation through the use of the participants' symbolic and allegorical language?

### ***Awareness of Identity and Power Differential***

It is unrealistic to think we can eliminate the vertical power structure and rigid separation of identities. "A researcher and a participant can never possess equal power; they are differentiated by knowledge, boundaries, power, and the purpose of the encounter" (Meleis, 1996, p. 11). Consequently, validity would be recognized by evidence that the researcher is cognizant of the power differential (Meleis). There would be evidence of both a movement towards fluidity in boundaries and a process to decrease hierarchical differences. It is within the dynamics of relational ethics that one is able to see the diminishing of the boundaries and margins created by the vertical power structure. Gadamer (1960/89) even suggests:

When we try to understand a text, we do not try to transpose ourselves into the author's mind but...we try to transpose ourselves into the

perspective within which he has formed his views. But this simply means that we try to understand how what he is saying could be right. If we want to understand, we will try to make his arguments even stronger. (p. 292)

To facilitate the achievement of this goal the researcher must believe that knowledge is held to be jointly constructed by researchers and participants. For example, Knapik (2006) suggests that this would require the researcher to notice, both in the moment of the interview and during data analysis, who made what relevant and what prompted shifts in focus. For example, the researcher would provide evidence of how s/he was able to establish more horizontal relationships and develop shared authority and ownership of the data. The researcher could share his/her draft manuscripts with readers close to the setting, thus checking for “narrowness of vision, prejudices, and focus” (Moules, 2002, p. 32). This would help to ensure that the generative nature of interpretation has been honoured and kept in play. Emergent disagreements and criticisms, when viewed in relation to other data sources, would signal a need to (re)evaluate conceptualizations and/or interpret new insights, all of which would need to be reported and discussed. The researcher and the reader would therefore ask the following:

Have some constituencies or participants reviewed the material with the researcher and interpreted, dissented, challenged the interpretations?  
How did these disagreements/agreements in perspective get reported?  
(Fine et al., 2000, p. 126)

This does not mean that the participant’s reading of his/her own story is above and before all others. It must be remembered that the topic is *not* the participants, nor should the writing be a *portrait* of the participants (Moules). However, with this acknowledgement, neither does the interpretation of the generative meaning(s) of the text belong only to the researcher. “In this game [of interpretation] nobody is above and before all others; everybody is at the center” (Gadamer, 1977, p. 32). Therefore, discrepancies between accounts, whether given by one person or different persons, would not be treated as if one of the accounts were wrong, but rather would be a directive to keep the conversation alive and in flux.

Researchers as interpreters need to reveal themselves, their investments, and their position in the production of knowledge and the making of meaning, as well as the power of Others as meaning-makers (Russel y Rodriguez, 1998). The researcher, the participants, and the reader must all work at revealing their own assumptions and power to define the discourse and the authority to assert fact. We need to see in the writing when the researcher has placed his/her ideas squarely in the centre, when those of Others have been placed in the centre, and those



that are a fusion of horizons. The reader should be able to discern how the space of Others is desired, invited, and granted, while accounting for the researcher's own investment in the metaphors, values, and meanings. This is demonstrated when the researcher has resisted the temptation to reduce or distil the lives of Others to a central motivation and has instead lived with and revealed the complexity and ambiguity of their responses (Watson, 2005). If the researcher and the reader are mindful of Others' identity and power differential, they will ask:

How far did the researcher go with respect to theorizing the words of participants? Has the researcher worked to understand his/her own contribution to the materials/narrations provided and those silenced? Has the researcher worked to explain to readers the position from which participants speak? Has the researcher worked to recast the person(s) whom the participants choose to "blame" or credit for social justice or injustice? Has the researcher considered how these data could be used for progressive, conservative, repressive social policies? How might data be heard? Misread? Misappropriated? Does the researcher need to add a "warning" about potential misuse? (Fine et al., 2000, pp. 126–127)

### ***Disclosure***

Hermeneutic phenomenological inquiry seeks to open up the social world in all its dynamic dimensions, which means recognizing that lives are replete with multiple interpretations and grounded in cultural complexity. Linking this notion to disclosure, Meleis (1996) suggests that "research in a human science is predicated on authenticity of data, not on participants passing as nonmarginalized" (p. 12). She argues that marginalized groups keep their identities secret and attempt to pass as mainstream. Therefore, one of the tasks of the researcher is to uncover Others' experiences in ways that appear authentic to the participants/insiders and are understandable to the reader/outside. Authenticity, as discussed earlier, is a dialogical achievement. This requires the development of a sense of trust. "Unless relationships of trust and openness are developed, there can be no confidence that the research accurately represents what is significant to [the other] in their everyday lives" (Hall & Stevens, 1991, p. 22).

Researchers, then, would demonstrate evidence of trust-building. Hall and Stevens (1991) suggest that disclosure (and therefore the degree of trust established in the relationship) can be evaluated in a number of ways, such as by the depth and specificity of information shared, verbal and non-verbal indications of Others' comfort and openness, and Others' willingness to be involved over a period of time. Christians (2000) adds: "The research account should possess that amount of depth, detail, emotionality, nuance, and coherence that will permit a critical conscious-

ness to be formed by the reader. Such accounts should also exhibit representational adequacy, including the absence of racial, class, and gender stereotyping” (p. 145). The account, in other words, would demonstrate life as it is lived in its original difficulty (Jardine, 1998), filled with tensions and paradoxical complexities, meanings, and understandings that change over time.

Likewise, the researcher needs to build a sense of trust in the relationship with the reader, disclosing meanings and understandings of self and Other. As Kvale (1995/2002) states, “With the conversation as the ultimate context within which knowledge is to be understood, the nature of the discourse becomes essential” (p. 314). The complexities of validating hermeneutic phenomenological inquiry rest upon the researcher’s and the reader’s ability to picture and to question the complexity of the social reality investigated. As a result, ambiguity and contradictory beliefs will be inherent in the findings. If the researcher and the reader are mindful of the evidence of disclosure, they will ask the following questions that we believe emerge from the writings of Hall and Stevens (1991) and Moules (2002): Has the researcher disclosed his/her own pre-understandings and vulnerabilities? What surprised the researcher and what did the researcher do when participants brought forth something unanticipated? Does the researcher reveal the complex, ambiguous, uncertain, and chaotic nature of living the experience? At the same time, does the research attend to the ways in which there is a struggle to find coherence and a resistance to fragmentation and marginalization? Are the paradoxes inherent in being human in the lived experience revealed? Does the researcher’s account express a tale of multiple selves? Can the reader see and enter into the layering and de-layering of understanding through questioning?

[Is there] abundant, concrete detail; concern not only for the commonplace, even trivial routines of everyday life, but also for the flesh and blood emotions of people coping with life’s contingencies; not only facts but also feelings? Are the narratives structurally complex, told within a temporal framework that rotates between past and present reflecting the nonlinear process of memory work — the curve of time? (Bochner, 2002, p. 263)

### **Concluding Remarks**

There has been an ongoing struggle to answer the question, What is validity and how should it be evaluated in qualitative research? “The various proposals of evaluation criteria have made the field infinitely more complicated, but also infinitely more responsive, rich, and politically and ethically sensitive and complex” (Lincoln, 1995/2002, p. 330). An ethics

of evaluation has been purposely made prominent as another way of affirming its presence — in the sense described by Caputo (1987) — as an openness to the mystery of things and the mystery of the play of the world that hermeneutics is bent on restoring. Perhaps validity can be addressed meaningfully through a set of ethical questions that gazes towards the relational ethics inherent in hermeneutic phenomenological inquiry. We believe that by putting validity back into play in this way, we will help to ensure that Other(s) are less likely to be subsumed within the Same and also that the study is able to provide new insights into the phenomenon of interest for both self and Other(s). Equally important, engagement in ethical questioning will help to ensure that this form of inquiry does not become a means for the world to gaze voyeuristically upon Other(s). Moreover, ethical questioning is congruent with the behavioural expectations of relational ethics (Gadow, 1999), or what Olthius (2000) calls an ethics of difference, and thus offers an alternative to rational objectivity as the basis of validity. Ethical questioning expresses the willingness of the researcher to hold open an intersubjective space in which difference can unfold in its particularity. This notion of intersubjectivity, part of the postmodern turn, recognizes that “the valuing of persons requires perception of each one’s uniqueness, and perception involves engagement” (Gadow, p. 63). This difference can be achieved through dialogue and collaboration between the researcher and the Other (be it the research participants or the readers of research). Validity in hermeneutic phenomenological inquiry is “not the puppet of some method but is forced to make its own way without metaphysical, methodological assurances. Science and reason remain displaced, kept slightly off balance, robbed of their security — but liberated and put back into play” (Caputo, p. 239).

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## **Comprendre les aspects moraux des pratiques quotidiennes des sages-femmes et des infirmières de la phase intrapartum**

**Anne Simmonds et Elizabeth Peter**

Les auteures recourent au modèle de moralité « expressive-collaborative » de Margaret Urban Walker pour illustrer, sous l'éclairage de la moralité, les pratiques quotidiennes et les connaissances des sages-femmes et des infirmières du volet intrapartum. Elles donnent des exemples de ces pratiques et connaissances morales en s'inspirant d'études qualitatives sur les soins intrapartum. En se fondant sur le modèle de madame Walker pour interpréter les résultats de ces études, elles ont relevé trois thèmes, soit la création d'un espace pour l'établissement de la relation, l'affrontement de milieux moralement hostiles et la renégociation de l'ordre moral-social par la défenses des droits. Les espaces créés par les infirmières et les sages-femmes pour établir une relation avec les femmes en couches leur révèlent quelques-unes de leurs responsabilités morales. Elles doivent toutefois subir les contraintes du milieu : les rapports hiérarchiques au sein des équipes et les institutions qui entravent leur capacité à prendre leurs responsabilités morales, ce qui rend le milieu inhospitalier à certains moments. Elles ont compris que pour redéfinir ces relations, elles doivent se porter à la défense des droits des femmes qui accouchent.

Mots-clés : infirmières du volet intrapartum, sages-femmes, responsabilités morales, défense des droits



# **Understanding the Everyday Moral Practices of Midwives and Intrapartum Nurses**

**Anne Simmonds and Elizabeth Peter**

The authors use Margaret Urban Walker's expressive-collaborative model of morality to illuminate the everyday practices and knowledge of midwives and intrapartum nurses as moral practices and knowledge. They provide examples of these moral practices and knowledge by drawing on qualitative studies of intrapartum care. Using Walker's model to interpret the findings of these studies, they identify 3 themes: creating a space for relationship, encountering morally uninhabitable environments, and renegotiating the moral-social order through advocacy. The spaces that nurses and midwives create for relationship with labouring women reveal to them some of their moral responsibilities. However, nurses and midwives encounter environmental constraints: Hierarchical arrangements within teams and institutions constrain their ability to enact their moral responsibilities, rendering the environment morally uninhabitable at times. They understand that in order to renegotiate these arrangements they must advocate for women in labour.

Keywords: Perinatal nursing, midwifery, ethics, feminist

Little has been written about the ethics of intrapartum nursing and midwifery care apart from case scenarios aimed at helping practitioners to resolve dramatic issues such as obtaining consent for emergency medical interventions (Finnerty & Chisholm, 2003). While research, particularly that of a qualitative nature, has uncovered some of the everyday practices of midwives and intrapartum nurses, the ethical significance of these practices has not been articulated.

Traditional bioethical approaches in clinical settings typically entail the objective weighing of benefits and harms to determine right and wrong action and the application of principles. However, ethical practice in intrapartum nursing and midwifery is embedded in the everyday relationships that caregivers establish with childbearing women (Thompson, 2002). It is through these relationships that a plan of care is negotiated. These relationships are specific to particular individuals in a particular context and are usually well established prior to the emergence of any potential dilemma or problem. An important consideration is that, unlike most patients, who are admitted to hospital for medical reasons, childbearing women and their fetuses are generally healthy (and childbirth is not considered an illness). As these women usually do not require medical

treatment, the relationship as a vehicle for nurturing and supporting them through the birth process often becomes their main concern (Bowers, 2002).

In this article, we use Margaret Urban Walker's (1998, 2003) expressive-collaborative model of morality to identify the everyday practices and knowledge of midwives and intrapartum nurses as *moral* practices and knowledge. We first describe the model and our reasons for choosing it. We then provide examples of the moral practices and knowledge of midwives and intrapartum nurses by drawing on the results of qualitative studies. We have used exclusively qualitative studies because of their rich description of practices and have concentrated on intrapartum practices, as opposed to including all of perinatal practice, to ensure depth and focus of analysis. We identify three themes of moral practices and understandings: creating a space for relationship, encountering morally uninhabitable environments, and renegotiating the moral-social order through advocacy.

### **Walker's Expressive-Collaborative Model of Morality**

In offering an alternative to mainstream moral theorizing, Walker does not begin with hypothetical and abstract principles. She begins firmly with the everyday experiences of people engaged in meeting their moral responsibilities. Her moral epistemology rests on the assumption that the production of moral knowledge is necessarily influenced by how people are situated in terms of class, race, gender, and sexual orientation.

Walker's (1998, 2003) expressive-collaborative model of morality contains three theoretical propositions. The first is that moral knowledge is located in human social life. Here, morality exists in the context of daily practices, which, in turn, both shape ethical theory and inform one's everyday choices and perceptions. Morality, from this perspective, is "a socially embodied medium of mutual understandings and negotiation between people over their responsibility for things open to human care and response" (Walker, 1998, p. 9). The expressive-collaborative model is distinct from the traditional theoretical-judicial model, as the latter relies on the application of impersonal ethical formulas or principles to guide moral action. Walker describes a moral world that is inextricably linked with the social world, where our responsibilities to each other and to ourselves are negotiated in a climate of reciprocity and understanding. In the realm of care during childbirth, this would mean that practitioners remain open to a woman's preferences with regard to pain management during labour while also offering a clinical perspective on the progress of labour and the range of interventions that might be helpful. The end result would be a mutually negotiated understanding of how best to meet the woman's need for pain relief and to respect her other birth preferences.

In Walker's second theoretical proposition, those practices that are characteristic of morality are described as "practices of responsibility": They "implement commonly shared understandings about who gets to do what to whom and who is supposed to do what for whom" (1998, p. 16). Practices of responsibility are multifaceted; they define and express our understanding of agency. In nursing, they are often directed at people who are vulnerable, in need of health services, and therefore susceptible to the choices and actions of nurses (Peter & Liashenko, 2003). They encompass the knowledge, skills, and clinical judgement that form the basis of nursing practice. However, our practices of responsibility and moral accountability are not fixed entities; they are shaped by social roles and identities in and among the institutions and individuals that determine how responsibilities are to be shared. Nurses therefore perceive their social-moral world differently from other practitioners, by virtue of their social identities and relationships in their places of work.

Finally, Walker (1998) contends that morality is not socially modular but is a part of everyday life, and therefore that moral understandings spring from social understandings and are not abstract, isolated from social reality and context. Walker asserts that the social world is a morally differentiated one, arguing that because hierarchical power relations are the rule, diverse moral identities and positions are created as a matter of course. According to this view, one's social position and role define for what and to whom one is accountable. People understand the moral-social world differently, depending on how they are positioned, and this in turn influences the types of knowledge they use to evaluate the moral habitability of the environments in which they live and work. Walker (2003) describes a morally inhabitable environment as one that fosters cooperation and recognition and in which differently situated people experience their responsibilities as intelligible and coherent. Such an environment is possible if moral arrangements and social orders are transparent, revealing who has responsibility for what, and if criteria are identified for distributing and evaluating responsibilities.

### **Emerging Themes and Moral Practices and Understandings**

Walker (2003) proposes that moral practices can be illuminated and understood if one pays close attention to the narratives of individuals. Therefore, we searched for qualitative studies focusing on the subjective voices of nurses and midwives with regard to the ethical nature of their practice. Although studies of people's perspectives and experiences, also known as "views studies," can be difficult to locate (Harden et al., 2004), the importance of using qualitative methodologies to examine life experiences from the perspective of the person with the experience is being

increasingly recognized in health services research (Patterson, Thorne, Canam, & Jillings, 2001). The studies included in our analysis used a variety of approaches to examine nurses' and midwives' view of their practices. The commonality was how they brought the practitioner's voice to the forefront. We will briefly describe the focus and findings of each of the studies and then follow with an analysis informed by Walker's model.

In analyzing the findings of the studies, we identified three themes relating to moral practices and understandings: creating a space for relationship, encountering morally uninhabitable environments, and renegotiating the moral-social order through advocacy. We should point out that moral practices are dynamic and can be changed through a shifting of blame and responsibility, the introduction of new information, or changing social roles and normative expectations. Walker's work makes it clear that practices of morality are practices of responsibility shaped by social identities and roles in which hierarchical power relations are the rule (Walker, 1998). Consequently, these identified moral practices and understandings reflect the social and geographical positioning of the participants in the studies.

### ***Creating a Space for Relationship***

The narratives of nurses and midwives reflect a social-moral world based on their relationships with women and with other health-care providers in the perinatal hospital setting. The midwives and nurses all created a space for relationship with labouring women that allowed them to recognize some of their moral responsibilities. This space, in turn, helped the women and their partners to assume their growing responsibilities as parents of a newborn child.

Walker's (1998) view of morality is that it is interpersonal and collaborative. The relationships through which moral responsibilities are understood and enacted are constructed between people and require self-direction, responsiveness to others, and mutual accountability. The studies we examined spoke specifically to the practices of midwives and intrapartum nurses in establishing such relationships. For example, Goldberg (2005) used a "feminist-phenomenological" approach to explore ethical perinatal nursing practice from a relational perspective. Using the narratives of Canadian nurses and mothers, she identified some of the essential aspects of relational perinatal nursing practice, focusing on the importance of "introductory engagement." These initial encounters were used to create a respectful space capable of supporting and sustaining a trusting and respectful relationship. Practices described by one nurse included ensuring that women were warm and comfortable and that the initial history-taking was as much about the questions the woman wished to ask as about the information the nurse needed to collect.

The collaborative nature of moral practices also includes the relationship between the mother and her unborn child during the birth process. Thompson (2003) used personal narratives of mothers and midwives and articulates an “ethics of intimates” and engagement that includes both the relationship between midwives and labouring women and the contexts in which care takes place. Thompson concludes, based on her findings, that the midwife’s primary relationship is with the mother and the mother’s primary relationship is with her baby. By enacting her moral responsibilities to the mother by creating a space for relationship, the midwife enables the mother to maintain a connection to her unborn child.

Moral responsibilities also include practices such as paying attention, interpreting actions, and responding to situations and circumstances by means of thought, action, or feeling (Walker, 1998). Hyde and Roche-Reid (2004) describe midwives’ creation of a “lifeworld,” a Habermasian concept that represents a symbolic space for appreciating the views of women, for reflexivity and relation, and for reaching consensus through dialogue. Midwives in the study created this space by making the woman the central player in the birth and using communication strategies that enabled her to actively participate in decisions about her care. Kennedy, Shannon, Chuahorm, and Kravetz (2004) theorize that a relationship marked by mutuality, disclosure, and validation provides the foundation for a care environment in which a woman’s physical and emotional needs are met. In order to create this environment, the midwife has to be aware of the context of care, such as the nature of professional relationships, philosophies guiding practice, and system-wide policies. Like Goldberg (2005), Kennedy et al. refer to an “engaged presence” in this space, where the midwife gathers observations and combines these with the woman’s subjective knowledge to more fully understand the situation and provide appropriate care.

### ***Encountering Morally Uninhabitable Environments***

Walker (2003) notes that context can be obscured by cultural settings and social organizations that promote particular roles and ideals while leaving others invisible. As moral understandings of what is required and how one may be called to account circulate in a practice setting (Walker, 1998), one should be aware of the ways in which social context shapes relationships, practice, and decisions about the care of childbearing women. The experience of encountering environmental constraints within hierarchical moral-social arrangements among the nurses, midwives, physicians, and institutions is a common theme across the studies. These arrangements often inhibited the actions of the participants, leading them to engage in surreptitious moral practices and understand-

ings in order to meet their responsibilities to labouring women. Other elements of the moral-social order that shaped the everyday choices, perceptions, and actions of the nurses and midwives were the culture of hospitals, including their ethos of efficiency and economic profit, and the use of technology.

A central theme in Thompson's (2003) study was the use and abuse of power in relationships that often became evident through the conflicting values of the institution and the individual. While hospitals appeared to value efficiency, the personal and professional ethics of midwives focused on the individual needs and wishes of birthing women. Midwives in this study felt that power imbalances within institutions and among caregivers constrained their ability to use professional judgement in fulfilling their responsibilities to the women in their care. Similarly, Hyde and Roche-Reid (2004) found that a labouring environment that requires efficiency in order to maximize profits necessarily minimizes communication, evaluation of relationships, and mutual understanding.

Consistent with a socially critical moral epistemology, Walker (1998) argues that we do not fully understand the structures that influence the perceptions that can impede our moral recognition of those who are marginalized or different. For example, while participants in one study reported that they felt constrained by the use of routine medical interventions, they also identified mothers' lack of knowledge and preparation, inability to speak English, and "high risk" designation as barriers to the provision of effective care (Sleutal, Schultz, & Wyble, 2007). These are factors over which women may have little or no control, depending on their life circumstances. Walker (1998) notes that "diminished" participants may be accorded less respect, compassion, and reciprocity and therefore be subject to paternalistic attitudes, when they are in fact capable of making appropriate choices. Sleutal et al. raise concerns about nurses' ability to recognize moral practices that are necessary for birthing women who present special challenges.

Sleutal (2000) presents a striking and disturbing example of the misuse of power in relationships. A nurse in the study reported that she had to "try to be tactful with the doctors so they feel in control" (p. 43). At times she felt that she was a "co-conspirator," assisting with routine medical practices that were not part of the woman's plan for birth and that in the nurse's opinion were not medically indicated. At other times the nurse would perform the care tasks she deemed appropriate as long as they were hidden from the physician. According to Goldberg (2005), the experiences and narratives of women and their caregivers exist in gendered, cultural, and politicized contexts. In Sleutal's study, the oppressive structures in the nurse's environment may have precluded the negotiation and mutuality that Walker views as an essential component of moral practice.

Some midwives believed that a preoccupation with the use of technology within a “technocratic system of obstetrics” limited their ability to enable choice and promote informed decision-making, even though the latter is a culturally defined norm in midwifery (Hindley & Thomson, 2005; Hyde & Roche-Reid, 2004). They reconciled these conflicting practices by reinforcing the idealistic notion of informed choice amongst themselves and by citing the poor practice of “other” midwives. There was also a belief that the use of technology enhances professional status, but at the cost of relegating intuitive knowledge and other skills to a lower level (James, Simpson, & Know, 2003). Midwives struggled to reconcile the “ideal” of informed choice with the realities of practice, in which they sustained positions of authority over women and their choices in order to function within the medical-technological model (Hindley & Thomson). Other contextual influences on relationship included a medical “active management of labour” model, a culture of litigation, the politics and economics of competing health service agendas, busy work environments, and a generation of nurses and midwives trained and practising in technological environments such that they are unable to consider alternative models of care.

### ***Renegotiating the Moral-Social Order through Advocacy***

According to Walker (2003), a morally inhabitable environment is possible if moral arrangements and social orders are transparent, revealing who has responsibility for what, and if criteria are identified for distributing and evaluating responsibilities. At times the participants challenged the uninhabitability of the moral-social order through the use of advocacy. At other times they did not, or could not, challenge the arrangements in which they found themselves. Consequently, the arrangements did not always foster the recognition, cooperation, and shared benefits needed for nurses and midwives to meet their moral responsibilities in a way that they believed to be optimal.

The facilitation of choice and a woman’s control over her birth experience that are considered integral to client-centred care were not always a reality. Autonomous decision-making has been described as a relational process between women and nurses or midwives in which anxieties are understood and wishes respected (Goldberg, 2005; Hindley & Thomson, 2005). Some midwives avoided working with certain medical practitioners or tried to “counter the system” in order to advocate for their clients (Thompson, 2003). Some women were described as being treated like disengaged others. For example, there were reports of “ritualistic” electronic fetal monitoring, even though nurses claimed they did not favour this practice.

Both nurses and midwives recognized their professional obligation to act as advocates and to put the mother's interests above all others, although some perceived an inability to change a practice environment that was "intolerable to professional integrity" (Hindley & Thomson, 2005, p. 310). Some nurses believed that a woman's vulnerability during labour requires advocacy but described this in terms of nurses' taking control, using their intuition and judgement to make decisions — "having the guts to do what you believe to be right and in the best interests of the woman and her baby" (James et al., 2003, p. 820). Others believed that advocacy is a matter of balancing the needs of the mother within the limitations imposed by the system (Sleutal, 2000). Midwives supported their clients' autonomous choices by acting as "conduits" and providing an invisible structure and guidance, thereby enabling women to choose how to move through labour (Kennedy et al., 2004). This description suggests that while the women had the power to choose, their choices were mediated and possibly restricted by the "invisible" structure or guidance provided by the midwife.

Hyde and Roche-Reid (2004) report that while medical-technological practice, with its claim of safer childbirth, exerts professional and political power over midwifery practices, midwives have greater power relative to women: Midwives use their expert knowledge and experience to get women to agree with their plans for care. Some nurses in the James et al. (2003) study described different but equal knowledge or power with physicians; however, the practices they described were those prescribed by the physicians. The nurses in the study linked power to the control and management of labour and described themselves as "powerful" when they "ran the labour for the doctor." Although nurses' ethical practice was not specifically "named" in this study, the focus on autonomous practice, with autonomy being described as "the power to determine what needs to be done in providing patient care" (p. 815), suggests that nurses were focused on their autonomous decision-making relative to physicians rather than on advocating on behalf of childbearing women. This finding raises the question of the extent to which power was shared among the nurses and the birthing women in this study.

In her initial pilot study, Sleutal (2000) looked at techniques that one nurse used to enhance labour progress and prevent Caesarean birth. During the course of analyzing the findings of that study, Sleutal found conflicting descriptions of moral nursing practices. The nurse described practices that both allowed women to follow their body rhythms and labour at their own pace and took action to hasten and control the birth. For this nurse, advocacy entailed balancing the needs of the mother within the limitations imposed by a system dominated by a medical



model of practice. Nurses in Sleutal's subsequent study were critical of the practices of their nurse colleagues, describing them as sabotaging their own efforts to provide effective care by promoting the use of epidurals when the nurses were on their scheduled breaks. They labelled colleagues who behaved in this way as lazy, uncaring, and unmotivated. According to Walker (1998), practices of responsibility that lack clarity and transparency can give rise to a culture of blame. In a perinatal setting where team members have confidence in each other's skills and respect each other's perspectives and contributions, staff are more likely to raise issues and seek mutual support, thus promoting a trusting and calm milieu for the labouring woman and her family (Ontario Women's Health Council, 2000).

### **Discussion**

Practices of responsibility reflect the morality of everyday nursing and midwifery. They encompass the knowledge, skills, and clinical judgement that form the basis of nursing; they include paying attention, interpreting actions, and responding in thought, action, or feeling to situations and circumstances (Walker, 1998). Nurses and midwives practising in diverse hospital settings in Canada, the United States, Great Britain, and Australia share common understandings about the centrality of relationship to practice, what constitutes an engaged relationship with labouring women, and how such a relationship can be achieved. These findings support Walker's view that morality is interpersonal and collaborative, as it is constructed between people and requires self-direction, responsiveness to others, and mutual accountability (Walker, 2003).

There is also recognition that the "ideal" of promoting informed choice, usually enacted through relationship, is not always evident in practice. Thompson (2003), for example, makes a distinction between actual practice and midwives' inferred or expressed "preferred ethical response," which includes supporting and knowing the woman (p. 592).

The discrepancy between real and ideal practice is most often attributed to factors outside the control of nurses and midwives, including hierarchical power imbalances, dominating medical models of practice, system-wide pressures for efficiency and economy, and the use of technology. It is interesting to note that some of this discourse is shaped in such a way that attention is deflected away from the agency and the ability of nurses and midwives to make choices about care. For example, when agency and intention were attributed to "technology," nurses and midwives seemed to be side-stepping responsibility for how and when technology is used. There was also inconsistency between the self-

understanding of nurses and midwives as powerless and their narratives describing ways in which they exerted power over labouring women. Walker (2003) notes that our social location is critical to morality because it shapes the way in which we assign, accept, or deflect responsibilities. When practice responsibilities are unattainable or incoherent, a morally inhospitable environment is created, which has a negative impact on nursing satisfaction and care delivery (Peter, Macfarlane, & O'Brien-Pallas, 2004). If nurses and midwives believe that their values of engagement, relationship, and normality in birth are marginalized in the highly medicalized hospital birthing environment, their moral understanding and enactment of practices of responsibility may be restricted, along with their moral identity.

In their attempt to meet the particular needs of women while also conforming to institutional policies, medical practices, and the particular culture of the workplace, nurses and midwives are playing an ambiguous moral and social role. They function as “boundary workers,” called upon to navigate the values of others in order to deliver the health services for which they are accountable (Liashenko & Peter, 2006). One wonders about the degree to which nurses and midwives are truly able to foster autonomy for birthing women while straddling this line. One also wonders about the mental and moral fatigue that results from constantly seeking the middle ground while knowing, at some level, that it is not always possible to find an acceptable compromise among competing and conflicting values in situations and relationships that are mitigated by power imbalances.

According to Walker (1998), morality entails mutual understanding and negotiation. A new understanding that emerged from this interpretive review is the symbolic meaning, for nurses and midwives, of their relationship with women. While aware of when and why they were falling short of the ideal, nurses and midwives sensed that this relationship was integral to their practice and needed to be safeguarded. There was a suggestion, at times explicitly stated, that the role of nurses and midwives is to “rescue” women from a hostile environment, although no strategies beyond advocacy in a general sense were articulated, leaving the reader wanting to know more. This lack of strategizing points to the need for research that gives nurses a voice and uses their knowledge and experience to shape changes in practice and practice environments. It also highlights the need for us to question the “rescue” mentality and the belief that we are acting virtuously by making decisions independently “in the best interests” of women, when in fact this paternalistic attitude might be compromising a core value of perinatal care: placing the woman, and her choices, at the centre of practice.

## **Conclusion**

The studies analyzed in this review were based almost exclusively on the narratives of perinatal nurses, midwives, and mothers. While these narratives form the basis of our professional self-understanding, they do not necessarily reflect the real world of practice. They can, in fact, reflect “preferred” accounts of nursing (Nelson & McGillion, 2004). This potential limitation was evident in personal accounts that tended to focus on the expert or exemplary actions of the participant while suggesting that the actions of “others” were less than ideal. This approach can serve to spotlight the actions of an individual while obscuring the contexts and power differentials that influence moral practices. Further research in this area would benefit from a critical ethnographic approach that involves interviews with practitioners and childbearing women, as well as participant-observation to capture the contexts in which these interactions occur.

While the emergence of relationship as a central value in the practices of perinatal nurses and midwives underscores the need for a relational view of autonomy and decision-making, this appears to be only one element in understanding what intrapartum care “should” be. Clearly, we need to examine both the local (hospital) context and the sociopolitical environment of childbirth, including the position of women in society, biotechnology, and the power of traditional medicine. Margaret Urban Walker’s expressive-collaborative model contributes to our understanding of moral practices in the perinatal setting and highlights the need for a political and ethical approach in order to improve the care of women during childbirth.

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## *Happenings*

# **Questions in Contemporary Medicine and the Philosophy of Charles Taylor October 27–28, 2007**

**Franco A. Carnevale**

On October 27–28, 2007, a symposium titled Questions in Contemporary Medicine and the Philosophy of Charles Taylor was held in Montreal. It was convened by Franco A. Carnevale, RN, PhD (School of Nursing, McGill University), and Daniel Weinstock, PhD (Department of Philosophy, Université de Montréal). (“Medicine” is used in the generic sense, referring broadly to the health sciences and health care.)

Many scholars and practitioners in medicine and health care have become increasingly dissatisfied with the dominant philosophical conceptions available to them. A rather narrow form of discourse is prevalent, leaving a great many concerns unarticulated. These relate to a broader view of the challenges faced in health care as a practice and as a social institution. Many have turned to the ideas of the eminent Canadian philosopher Charles Taylor to help address some of these concerns. Taylor’s work has had an extraordinary impact in the humanities and social sciences, and more recently in the health sciences. Taylor is recognized for his critique of cognitivist psychology and mechanistic conceptions of human agency, his analysis of the self in modernity, and the advancement of a hermeneutical framework for the human sciences. Patricia Benner has drawn heavily on Taylor’s philosophy in her own work.

This symposium brought together scholars from a variety of disciplines to critically examine how the philosophy of Charles Taylor can contribute to current discourses on questions in contemporary medicine. Medicine here is conceived broadly in terms of its epistemological, moral, political, and ontological dimensions. The symposium was aimed at advancing our thinking in the philosophy of medicine as well as the philosophy of Charles Taylor.

Invited scholars presented papers addressing one of the symposium’s four thematic domains (two scholars per domain), while discussants

presented their critical reflections on the papers. Professor Taylor was present to actively participate in and contribute to the discussions. The papers were as follows:

### **I. Epistemology and the (Human) Medical Sciences**

*Formation in Professional Education: An Examination of the Relationship between Theories of Meaning and Theories of the Self*, by Patricia Benner  
*The Geistes/Naturwissenschaften Distinction Revisited*, by Hubert L. Dreyfus  
Discussant: Ian Gold

### **II. Ontological Conceptions of the Human Agent as Medical Subject/Object**

*Is Medical Hermeneutics Located beyond Ontology? Some Responses from the Clinical Realm*, by Gilles Bibeau  
*Becoming Yourself with Drugs and Surgery*, by Carl Elliott  
Discussant: Natalie Stoljar

### **III. Examining the Moral Horizons of Medicine**

*On Metaphorical Concentration: Language and Meaning in Patient-Physician Relations*, by Ronald A. Carson  
*The Ethical Significance of Illness Narrative: Toward a Theory of Hermeneutical Case Formulation as Gateway to Medical Ethics*, by Dawson S. Schultz and Lydia V. Flasher  
Discussant: Jane Rubin

### **IV. Political Problems in Medicine**

*The Politics of Alterity in the Clinical Encounter: Multicultural Medicine as an Arena for Building a Pluralistic Society*, by Laurence Kirmayer  
*How Should Political Philosophy Think of Health?* by Daniel Weinstock  
Discussant: Vardit Ravitsky

These papers will be published as a collection. The symposium was funded through the generous support of the Centre de recherche d'éthique de l'Université de Montréal (Principal Sponsor), with additional support from the School of Nursing and the Biomedical Ethics Unit of McGill University.

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## Book Review

### ***Toward a Moral Horizon: Nursing Ethics for Leadership and Practice***

**Edited by J. L. Storch, P. Rodney, and R. Starzomski  
Toronto: Pearson Education, 2004  
ISBN 0-13-139716-8**

**Reviewed by Jane Chambers-Evans**

Nurses are challenged on a daily basis by ethical dilemmas and moral struggles as they strive to foster and maintain healing and to empower their relationships with patients and families. It is becoming increasingly clear that nurses require knowledge and expertise in the domain of ethics in order to contribute to the identification, analysis, and resolution of ethical dilemmas. It is also clear that, as in all areas of nursing education, ethics requires a marriage between theoretical knowledge and the practical application of that knowledge in our complex society and our equally complex health-care system.

The editors of this volume have made every effort to ensure that its contributions are written in a reader-friendly style while not compromising depth or substance. One of the many strengths of *Toward a Moral Horizon* is the attention given to defining concepts and introducing unifying language and terms such as moral agency, moral dilemma, moral distress, and moral courage. This is most useful in creating a common understanding and common grounds for discussion and debate.

The book is divided into three organizational segments: the moral landscape, the moral climate, and moral horizons. The moral landscape comprises a series of chapters devoted to the development of ethics knowledge. The chapters on history and philosophy probe the roots of nursing ethics as it has developed. Those on complementary approaches (i.e., contextualism, cross-cultural ethics, ecology) document the breadth and depth of current thinking, which has pushed us to move beyond traditional approaches. Most impressive in this section is chapter 8, which examines moral agency. A brilliant contribution, it weaves from defining moral agency through the various determinants and barriers to its development. Exploration of the research on moral distress and development of the concept of moral courage are a positive and constructive approach useful for examining factors that foster the development of moral agency.

The second section, devoted to the moral climate, comprises a series of short chapters presenting ethics from different world views. Nursing



ethics is examined in the context of home health care and from the perspective of economics. Readers will be challenged by the chapter on an ecological framework. It poses a series of questions that call on us to examine our personal and professional integrity. The framework will also serve to help professionals expose systemic or environmental factors that can manipulate or influence both how we ask questions and how we hear the answers. Another chapter uses poetry by students and nurses to demonstrate how a narrative approach can result in rich texts that enhance understanding in the exploration of day-to-day moral issues.

The final section, on moral horizons, is a fascinating group of contributions covering myriad topics. The chapters on biotechnology, global health, genetics, and research offer the reader a broader perspective on the world as it is evolving. A chapter oriented towards children is a welcome reflection not on age of consent, which is often the focus in ethics texts, but, rather, on how nurses must understand and empower ethical practice in the care of children. The final four chapters in this section are creatively written to offer nurses knowledge about authentic relationships with themselves, their colleagues, and the patients and families whom they care for.

The editors of *Toward a Moral Horizon* state in the preface that their goal was to offer “a Canadian text in nursing ethics that both provided greater depth in nursing ethics and advanced the field of nursing ethics” (p. xv). The volume is intended specifically for use at the graduate level. My colleague and I have been using it as our primary text for the past 2 years in our Ethics in Advanced Practice course. The students have found it thought-provoking and comprehensive. The book includes comprehensive reference lists and study questions throughout. Many of the examples are clinical vignettes or conversations with practising nurses. Our students have found the clinical scenarios helpful for understanding the complex theoretical material. Appendices present ethical decision-making models, codes of ethics, and research guidelines.

This text fills a gap in the ethics education literature. While there are many texts describing the differences between “principlism” and other traditional frameworks, or focusing on case studies, this book makes an appeal for understanding roots and contexts, for building knowledge as a tool that will enhance nurses’ ability to evolve and adapt in the analysis of our practice and our profession.

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## **Bâtir un nouveau nid : l'expérience des femmes qui aménagent dans une maison à logements pour personnes âgées**

**Suzanne M. Dupuis-Blanchard**

Bien que l'expérience du relogement ait fait l'objet de recherches depuis 30 ans, peu d'études se sont penchées sur l'expérience d'emménagement dans un lieu de logement collectif pour aînés. Cette étude qualitative fondée sur une théorie à base empirique a pour objectif de décrire les expériences que vivent les femmes qui aménagent dans une maison à logements pour personnes âgées et les facteurs qui influencent l'expérience de relogement. Pour les 11 femmes interviewées, la principale problématique avec laquelle elles doivent composer dans le processus de relogement est celle du rétablissement du soi – un défi imposé par les changements physiques et psychosociaux inhérents à la reconstruction d'un espace de vie soutenant et esthétiquement agréable, et le maintien d'un sentiment de bien-être. Dans le cadre de l'étude, un processus social de base a été identifié, celui de bâtir un nouveau nid. Il s'agit d'un processus non linéaire qui comporte trois phases. Les résultats issus de cette recherche offrent de nouvelles pistes de réflexions portant sur un aspect du relogement rarement exploré par la recherche en sciences infirmières.

Mots clés : relogement, logement

# Building a New Nest: The Experience of Women Relocating to a Seniors-Designated Apartment Building

Suzanne M. Dupuis-Blanchard

Although relocation has been a subject of research for the last 30 years, few studies have described the experience of relocating to congregated housing for the elderly. The purpose of this qualitative grounded theory study was to describe women's experiences of relocating to an apartment building for seniors and the factors that influence relocation. The 11 women interviewed identified the central issue in relocation as *re-establishing the self*: the physical and psychosocial changes entailed in constructing a supportive and aesthetically pleasing living space while maintaining a sense of well-being. The basic social process that emerged was *building a new nest*, a non-linear process comprising 3 phases. The findings offer new insights into an aspect of relocation that is rarely explored in nursing research.

Keywords: Relocation, transition, older women, housing, community living

## Introduction

The word *home* is symbolic of family, warmth, love, and safety (Wait & Hughes, 1999). Home is a place where we gather to celebrate life events such as birthdays, anniversaries, or the arrival of a new baby in the family. It is the locus of critical social roles such as spouse, parent, and grandparent and also neighbour and community member (Wait & Hughes). The nostalgic associations of home with family life are important to elderly persons (Dupuis & Thorns, 1996). The meaning of home is a combination of the physical building, family, affection, and dwelling in time and space. Home also includes everything in the dwelling and immediately surrounding it (Swenson, 1998). For every individual, the concept of home has a very personal meaning that encompasses many feelings.

Although the choice to move from one's home in old age may be motivated by a crisis, physical decline, or simply a desire to live in a smaller dwelling that requires less maintenance (Glassman, 1998), the transition is not usually associated with positive feelings or celebration (Silver, 1998). In fact, relocation in old age is often considered a crisis by the senior as well as by family and friends (Kao, Travis, & Acton, 2004;

Oleson & Shadick, 1993; Tracy & DeYoung, 2004). Since approximately 30% of adults over the age of 65 will change residences in the next 5 years (Croghan, 1993) and only 7% of all seniors live in institutions (Statistics Canada, 2005), it is predicted that apartments for those 65 or over will become a popular alternative to the family home for Canadian seniors (National Advisory Council on Aging, 1999; Statistics Canada). Statistics Canada reports that 29% of all Canadian seniors reside in apartments and that by the age of 85 the figure jumps to 41%.

The purpose of this study was to describe the experiences of older women in relocating from the family home to a seniors-designated apartment. The research questions were: *What is the process for older women relocating to a seniors-designated apartment? What are the factors influencing the relocation process?*

### Literature Review

Relocation is a life transition that occurs frequently among seniors (Armer, 1996). In fact, older adults reveal two peak periods of relocation: at retirement, and in later life, especially during widowhood (Davidhizar & Dowd, 1997). Relocation in old age can be very stressful and even harmful, particularly if preceded by another transition such as the death of a spouse, retirement, or loss of the ability to care for oneself or to maintain the family home (Armer, 1993; Cotter, Meyer, & Roberts, 1998). Following relocation to a seniors-designated apartment, elderly persons tend either to adapt fairly quickly or to socially isolate themselves. Relocation can, therefore, affect the well-being of an elderly person, especially if no adequate support system is in place (Armer, 1996; Lawrence & Schiller Schigelone, 2002; Nay, 1995; Peace, Holland, & Kellaher, 2005).

Relocation is not a new concept. It has been the subject of research for the last 30 years. Previous studies have primarily concentrated on outcomes rather than the process of relocation or the meaning of relocation for the older adult (Nay, 1995). They have also focused on relocation to a nursing home. There has been little research on relocation to a seniors-designated apartment.

Relocation is often viewed as stressful for older adults (Armer, 1993). Elderly persons seem to be particularly affected by changes in physical location, in daily routines, and in social support (Lee, 1999). The loss of home and possessions can cause them to experience feelings of insecurity and loss of control over their lives, to feel cut off from their memories, and perhaps even to lose their sense of identity (Morgan, Reed, & Palmer, 1997). This response to relocation results from seniors' tendency to become attached to their environment — to places, animals,

belongings, and their living space (Cookman, 1996; Tracy & DeYoung, 2004). Remaining in one's home also represents continued independence and a denial of the negative changes that accompany advancing age.

Research on relocation to a nursing home has revealed that the experience can result in feelings of loss, a devaluing of self, or sensing that one is a burden (Nay, 1995) and that it can produce a range of emotional reactions, including fear and a decline in cognitive status and affect (Cotter, Meyer, & Roberts, 1998; Krichbaum et al., 1999; Lee, 1999). Iwasiw, Goldenberg, MacMaster, McCuthcheon, and Bol (1996) investigated the perceptions of nursing home residents during their first 2 weeks in the facility. The participants identified three conditions as important to relocation: their degree of involvement in planning for the move, the meaning attached to the experience, and their emotional state.

Iwasiw et al. (1996) identify four categories of response to relocation to a nursing home: emotional reaction, transition activities, reflection on the situation, and connection with a personal philosophy. Wilson (1997) describes relocation to a nursing home as comprising three phases: the overwhelmed phase, the adjustment phase, and the initial acceptance phase. Though admitting that the sample was notably homogeneous, Wilson reports that, for the sake of their families, participants tried to hide their feelings and maintain a façade of normality by not assuming the devalued role of nursing home resident.

While relocation has been characterized as a significant life event, not all research on nursing home relocation supports negative outcomes. A descriptive study by Holzapfel, Schoch, Dodman, and Grant (1992) with 49 nursing home residents found that the only physical change associated with relocation was in blood pressure. Similarly, Danemark, Ekström, and Bodin (1996) conclude that relocation and mortality are unrelated, while Johnson (1996) concludes that relocation has a positive relationship with mortality. A quantitative study conducted 2 decades ago also found that the mental status and functional health of nursing home residents were stable 4 days after relocation (Engle, 1985). In a study with 106 nursing home residents, no consistent evidence was found to indicate that relocation inevitably results in dependency, confusion, depression, or withdrawal (Mallick & Whipple, 2000).

Although research on the concept of relocation has produced significant findings, the literature is limited to quantitative studies investigating particular phenomena associated with the relocation experience. A number of findings are vague about the consequences of moving to a nursing home. Moreover, the findings lack clarity on the experience of older adults who relocate. Furthermore, the profiles of seniors who move to a nursing home are very different from those of seniors who move to designated housing, thus rendering the relocation process a different

experience for the two groups. In addition, more seniors move to apartments than to nursing homes. All of these factors pointed to the need for a qualitative study of the experiences of women who relocate to a seniors-designated apartment. Moreover, given the trend towards “aging-in-place” more and more seniors will remain in the community (Cannuscio, Block, & Kawachi, 2003; Cutchin, 2003; Flesner, 2004; Gitlin, 2003) and apartment buildings that cater to older adults will gain in popularity. Nurses must be kept informed about seniors’ experience of such relocation in order to promote healthy aging.

## **Method**

Grounded theory was used in this qualitative investigation of women’s experiences relocating to a seniors-designated apartment. Grounded theory was chosen because of its usefulness for understanding complex situations and human behaviours (Morse & Field, 1995). The aim of this approach is to examine the processes at play in a social setting. Grounded theory assumes that reality is multiple, subjective, and mentally constructed by the individual (Polit & Hungler, 1999). The use of existing conceptual frameworks (Hutchinson, 1993) was avoided; knowledge was obtained through narrative information and emerging interpretations grounded in the participants’ experiences (Polit & Hungler).

### ***Participants***

Because the initial sample was chosen so as to examine the phenomenon where it was found to exist (Chenitz & Swanson, 1986), the primary participants were women residing in a large seniors-designated apartment building. The building contained 300 units and was located in an urban area with easy access to a variety of support services such as in-house cafeteria, banking, a hairstylist, and public transportation.

Women aged 65 and older were recruited through a variety of strategies, including the assistance of a community health nurse, letters describing the study and inviting those interested in participating to contact the researcher, announcements on bulletin boards, and word of mouth (snowballing). All recruitment strategies were structured with a view to minimizing any feeling of coercion among potential participants.

Eight women were interviewed individually and then another three were interviewed in a focus group setting to validate the findings. Participants had to consent to be interviewed, be 65 or older (with the exception of one woman who was 62), and be able to fully recount their experiences. Most of the women were widowed. The women had been living in the building between 1 and 25 years. Because residents of a seniors-designated apartment building are considered capable of recounting

their experiences, the number of years living in the building was not a selection criterion.

### ***Data Collection and Analysis***

In grounded theory, data collection and data analysis take place concurrently. Eight women were interviewed in their apartments. The interviews lasted approximately 1 hour and were audiotaped. Guiding questions consisted of such probes as *Tell me how you came to live here. What was it like preparing to move here? How have things changed for you since you moved here? What advice would you give to other women considering a move to such an apartment building?* Neutral probes such as *Tell me more about that* and *How did that seem to you?* were used to elicit further description. Towards the end of the study, a focus group consisting of three additional women was conducted in order to confirm the findings of the analysis. The group discussion took place in a private lounge in a smaller seniors-designated apartment building.

Consistent with the constant comparative method of data analysis, whereby codes are compared for similarities and differences, the transcripts were analyzed line by line and coded according to clusters of data using the words of the participants (Morse & Field, 1995). In grounded theory, open coding, or first-level coding, reflects what was said and is then used to compare findings through constant comparison (Chenitz & Swanson, 1986). This comparison enabled the discovery of similarities and differences in the data. Continued data collection was guided by the theory or by the process resulting from the use of constant comparison and as the researcher generated informal hypotheses about themes and their relationships (Chenitz & Swanson).

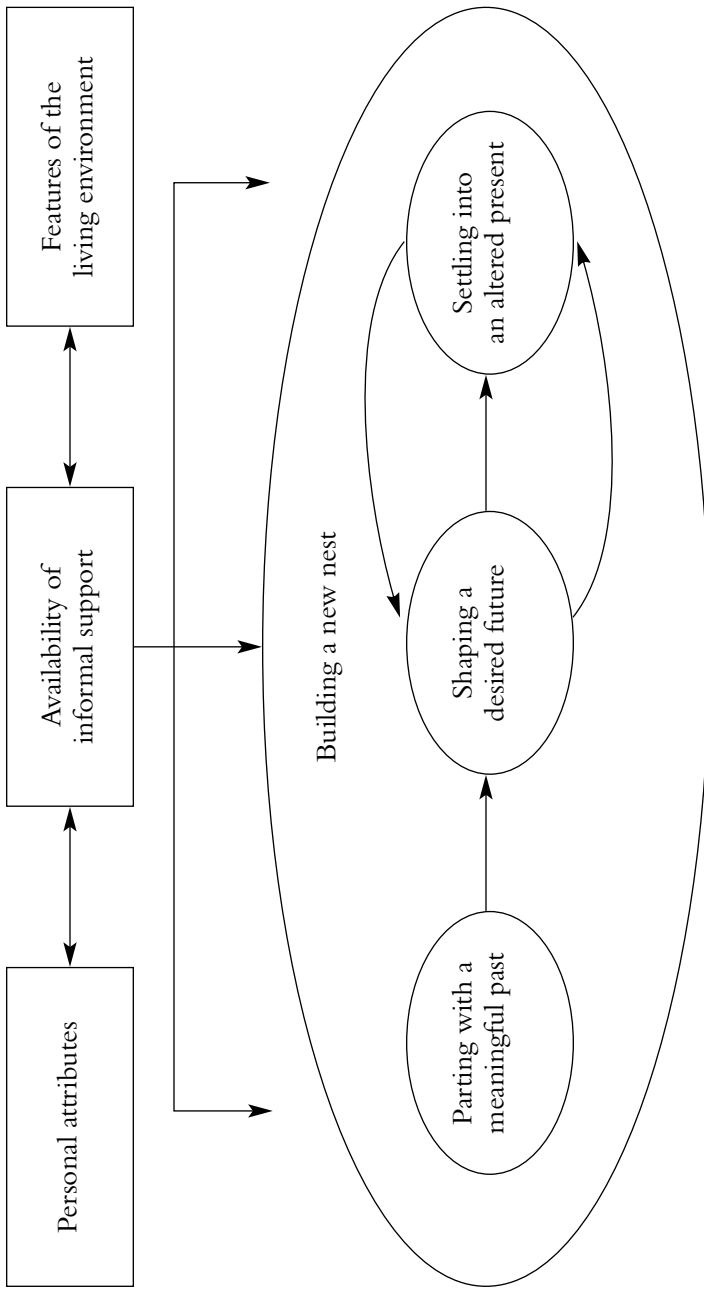
As analysis progressed, codes were categorized under themes (Chenitz & Swanson, 1986). These themes explained a larger process that became a construct for the social process, as demonstrated by the following excerpt:

*In a sentimental way, it was a bigger thing [to give up cherished memories], and physically to move, to empty a house you lived in for 20 years. It was the emotional ups and downs we had, and all the happiness, and so that was a heartbreak and you leave a bit of yourself there. It's only a structure, but what we did in those walls meant a lot to me.*

This excerpt was first coded as *leaving oneself behind*, which then became the common theme of *weaning* and the construct of *parting with a meaningful past*. Data collection continued until no new concepts emerged (saturation of categories).

The participants described the experience of relocation. However, because data collection was guided by the emerging theory, theoretical

Figure 1 *The Process of Building a New Nest*





sampling — a type of sampling that produces the full range of variation in the phenomenon under study — was needed in order to fully examine the relationships among data. Evidence that certain older women may experience a very different type of relocation was emerging. Therefore, residents of a smaller urban seniors-designated apartment building and women with chronic conditions, particularly hearing or visual impairments, were sought for the purpose of explaining certain variations in the process.

The final phase of data analysis entailed the identification of a core explanatory construct, *building a new nest*, a long-term process encompassing various conditions. Throughout data collection and analysis, field-notes and memos were written in order to capture ideas and recurrent themes (Chenitz & Swanson, 1986). Rigour was ensured by following Glaser's (1978) four criteria: the construct must be memorable (it must have "grab"), be reflective of the data, be descriptive, and be modifiable. In addition, the use of a focus group served as a means of "member checking," a technique for validating the researcher's interpretations of the data (Sandelowski, 1993). Members of the focus group also confirmed that the theory had "grab": "Being in an altered present is truly how I felt."

## **Findings**

The process of leaving the family home was a difficult one for the participants. It reflected the loss of memories and sense of belonging. In addition, upon relocating to a new and unfamiliar environment, the women were often faced with a lack of support and the need to build a new community:

*I lived over here on [name of street] and I knew all my neighbours, and while we didn't run back and forth all the time, there was a friendliness there... When I started looking for another place...I ended up where I didn't know anybody from that area and it got very lonely.*

For the women, relocating was mainly a process of *re-establishing the self*, both physically and psychosocially. They responded to this threat to their sense of well-being by *building a new nest* (Figure 1), a social process that was experienced by all of the participants.

### ***Building a New Nest***

The grounded theory method enabled the researcher to explore the process of relocation. Labelled *building a new nest*, this was a non-linear process consisting of three phases, as described by the participants: *parting with a meaningful past*, *shaping a desired future*, and *settling into an altered present*.

**Phase 1: Parting from a meaningful past** represented the women's gradual decision to leave the family home and the actions, both physical and psychosocial, necessary to relocate.

This phase began when a combination of factors resulted in difficulty maintaining the family home. The women described an increasing awareness of their loss of self-reliance, often due to widowhood, declining health, and increasing loneliness and sense of isolation. Accompanying this awareness was a gradual acceptance of the need to relocate.

While differing in length for each woman, this initial phase of *building a new nest* was gradual, as the women attempted to assert their independence and cope with household maintenance tasks. Only over time did they begin to accept the fact that their family home was no longer appropriate for their needs.

Having accepted the need to relocate, the women decided to seek housing in a seniors-designated apartment building because of their loneliness, isolation, and lack of social interaction. The decision was the logical outcome of a desire for more social interaction, an increasing sense of security, and a desire to remain independent. The women described the decision as a solution to the problems they encountered by remaining in the family home and the sense of relief they experienced once the decision was made. Thus they embarked on the processes of *weaning from the old home* and *locating a desirable new home*.

*Weaning from the old home* began with the decision to relocate. It included the physical tasks of disposing of personal belongings and putting the home up for sale and the psychosocial tasks of letting go of cherished memories and preparing to move forward. One woman described the process well:

*I had a lot of things in bags that I didn't know what to do with, and I had a friend who delivers things to poor families, so I'd say to [daughter], "This bag is for [friend] and this one is for a garage sale..." I'd just lie on the bed crying and tell her what to do.*

Essential to *parting with a meaningful past* was *locating a desirable new home*, a place where the woman would be content and where independence would be promoted. *Locating a desirable home* entailed multiple visits to apartment buildings and/or putting one's name on the wait list of an apartment building. One woman reflected on her experience:

*This was a very appealing place but it's not easy to get in here. You have to have your name on the wait list quite a long time, and you have to be interviewed and they have to screen you. But it's like everything else: If you don't bug them, they don't hear from you. You have to keep on calling and you have to sell yourself... And so I did... It took 2 years.*

Due to the frequently long wait list for seniors-designated apartments, waiting for a unit to become available was difficult. Some of the women described it as being “in limbo.” The women had to relocate to temporary housing during this period, and some did not make living arrangements before putting the family home on the market.

**Phase 2: *Shaping a desired future*** took place when the women moved into a temporary apartment while waiting for a unit to become available in the chosen building. Interestingly, all of the participants experienced this temporary living arrangement. *Shaping a desired future* necessitated both physical and psychosocial actions in response to the challenge of *re-establishing the self*.

This second phase began when the woman sold the family home and, because of the wait list for the desired seniors-designated building, moved to a regular apartment building. The women’s stay there varied from a few months to 5 years.

Throughout their stay in the temporary apartment, the women waited impatiently for a unit to become available in the chosen building. Since they had no idea when the second relocation would take place, the women found *shaping a desired future* to be the most unsettling phase in the process of *building a new nest*.

While accepting the loneliness and lack of social contact, the women kept in touch with their old friends. They also made frequent inquiries to accelerate the process of moving into the desired building. The loneliness, lack of services, and dearth of social contacts were motivating factors for them to continue the process of *building a new nest*. The actions inherent in *shaping a desired future* were *reconciling in-between arrangements*, *maintaining past social activities*, and *working to get in*.

The women described *reconciling in-between arrangements* as adapting to the temporary situation while waiting for an apartment to become available. The time frame for this action varied, with some participants waiting as long as 5 years. *Reconciling in-between arrangements* necessitated the renting of an apartment in a regular building whose residents were at all stages of social development and were usually younger, noisier, and employed. These buildings provided scant opportunity for socializing and the women quickly realized that the setting was inappropriate for them:

*I felt I was alone in those apartments. You just go in, you go out, there’s no [contact]. You have to make your own entertainment and your own activities. I felt very isolated, just the four walls.*

The realization that the temporary arrangements were less than desirable had a psychosocial effect on the women. They became even more determined to move into a seniors-designated building.

*Shaping a desired future* also involved continued socialization with friends and groups from the original community. This *maintaining past social activities* was a result of scarce opportunities to socialize in the temporary situation but was dependent on the women's maintaining social contacts in the original community.

The last action of *shaping a desired future* was *working to get in*: the woman's efforts to accelerate the process of securing an apartment in the chosen building. Because waiting for an apartment could take up to 5 years, those women who were unhappy with their temporary arrangements worked particularly hard to get into a seniors-designated building:

*It's like everything else: If you don't bug them, they don't hear from you. You have to keep on calling.... It's this thing you need [the apartment], and so you have to sell yourself. I didn't have any contacts and I didn't get in here because somebody spoke for me. ...I would come every month and I would sit there, the next time and the next time, and then they figured it was time.*

**Phase 3: *Settling into an altered present*** took place when the woman finally moved into the desired building and began adjusting to her new environment. Physically, the woman was setting up her apartment and adapting her possessions to a smaller space. Psychosocially, she was joining in, socializing with other seniors in the building while also maintaining her increasingly limited external social connections. In this third phase, the woman went back and forth between the two concurrent actions of *setting up* and *joining in*. The outcome of the two actions was appreciation: contentment in the new home.

*Setting up* refers to the physical part of moving, which included becoming accustomed to a new environment, a smaller living space, and a different lifestyle. Once the women received notification that an apartment was available, they moved quickly, often to avoid having to pay rent for two apartments. The move took place within a month and sometimes even within a few days, especially if the notification was received towards the end of the month.

As soon as the woman moved her belongings into the new apartment, she began *setting up*. Boxes were unpacked and personal possessions put in place. Participants often realized that they had too much furniture for the new apartment and had to divest themselves of more belongings. After a while, some women had a desire to further personalize their apartments, to create a more individualized home.

The second part of *settling into an altered present* was *joining in*, or making an effort to establish a sense of belonging by socializing with other seniors. *Joining in* occurred concomitantly with *setting up* and was a significant part of settling into the new apartment. The women were

emphatic about their need for social contact. The action of *joining in* explicitly demonstrated their participation in organized activities such as card games, bingo, or dances. During this action the women were challenged by such factors as a hearing or visual impairment. All the participants managed, at some level, to join in. The women also socialized by sitting in the building's common lounge and talking with other tenants. Not all participants, however, felt welcome:

*When I first came in here I thought there was a little clique, and I guess it was me more than they. And I thought I'd never get into that inner circle. But gradually...I think now I'm one of them, but it took a while.*

The result of *setting up* and *joining in* was *appreciating*: feeling fortunate, happy, and at peace with one's living situation. *Appreciating* was a direct result of the woman's successful adjustment to her new environment and *re-establishing of the self*. *Appreciating* was gradually developed by the woman, who eventually referred to her new apartment as home. Home had a different meaning for each woman but was usually associated with a place where she felt comfortable and secure. While the process of *building a new nest* seemed to resolve any difficulties encountered with *re-establishing the self*, the women clung to the memory of their former home: "I wouldn't want to have to do it all over again. No, I'd still want my own home. But that's not possible so you just do with what you have."

### **Factors Contributing to Variation**

While *building a new nest* was a shared process, variation was evident in the influence of three major conditions: *personal attributes*, *informal support*, and *features of the living environment*.

**Personal attributes** were distinctive, individual characteristics identified as influencing the process of *building a new nest*. They included a feeling of anxiety, a spirit of self-determination, ease with group membership, physical ability (including health status, vision, and hearing), and previous relocation experience.

Ease with group membership, specifically the ability to participate in organized social activities, was often a result of lifelong patterns of behaviour. Some of the women welcomed opportunities for new social activities while others were uncomfortable taking part in organized activities. One participant said:

*I went to the social clubs, the seniors, and unfortunately I had never played cards. I don't know why. My husband and I never played cards and our friends didn't either, and then try in your sixties to learn to play cards with people who have been playing all their lives — they got so impatient.*

*I tried different groups and came home with such a headache that I thought: It's not worth it.*

*Previous relocation experience* was described as a life history of moves within the same community or beyond. Attachment to the memories infusing the family home and difficulty parting with cherished belongings were especially evident among women who had no *previous relocation experience*:

*Well, what made it so difficult was closing up. I had four bedrooms, and there was vacancy there...to empty a house you lived in for 20 years. It was the emotional ups and downs we had, and all the happiness, and so that was a heartbreak and you leave a bit of yourself there. It's only a structure, but what we did in those walls meant a lot to me.*

**Informal support**, the availability of encouragement and assistance from family and friends, was identified as influential in all three phases of *building a new nest*. All of the participants identified the importance of knowing that significant others were interested in their well-being and available to assist them with *building a new nest*. Women who perceived the availability of support before and during the move from the family home were likely to experience less difficulty with relocation. The main sources of support were family members, especially daughters and sons. While wishing to maintain their independence and not be a burden to their family, the women valued informal support in the form of approval and assistance. Daily telephone calls and weekly visits from family members served to ease their anxiety following the move and to confirm the family's approval of the decision to relocate.

A second source of informal support influencing the process of *building a new nest* was the presence of friends or acquaintances already residing in the building. Women who knew someone already living there had the advantage of being introduced to people and activities. These contacts constituted a built-in social network. A participant who had a friend already living in her building explained:

*She took me to hymn sing on Sunday night and she took me to the senior citizens' club and she also took me to some of the sales, and each time I went I got to know other people, and I try to participate in activities and not be an onlooker, and they always want somebody to serve food or brew coffee.*

Those women who did not have acquaintances in the building had to initiate new friendships. Depending on the woman's *ease with group membership* and her health status, this could be demanding and difficult. For example, women with hearing problems were reluctant to participate

in group activities because they could not always understand what was being said.

**Features of the living environment.** The women's physical environment was a major influence in all three phases of *building a new nest*. For example, the characteristics of the family home, typically a large single-family dwelling, greatly influenced the women's decision to relocate. Routine maintenance of a family home, including structural repairs and landscaping, can be a significant burden for an older woman. "My husband was a gardener," said one participant, "and he had a lot of fruit trees in the backyard, and I couldn't take care of them because I had no idea how to." Unable to find help with maintaining the property, and not wishing to depend on family members, the women saw relocation as the only solution: "I was going to get out of that great big monstrosity." Had the women's independence not been compromised by their environment, they likely would not have opted to relocate.

The process of *building a new nest* was also influenced by the number of tenants in the new living environment. "We get very close to each other without interfering," said one participant, "and we have a wonderful library, the bank, the post office, a cafeteria, a hair salon — it's like a village." Some women expressed a preference for a building with fewer than 75 tenants. A small number of residents was seen as promoting a sense of community and mutual concern: "If you're not feeling well, people are concerned about you. They'll have little goodies tied to your doorknob. I think I appreciate a place where you have someone around you."

## Discussion

The process that emerged from the research data, *building a new nest*, contributes to our understanding of women's experiences with relocating to a seniors-designated apartment. This study was limited by the small size of the sample (11). Moreover, the participants were a homogeneous group of English-speaking city-dwellers reporting no financial problems. Other characteristics of the sample and the environment in which the study was conducted could also be considered limitations. Specifically, the women who agreed to take part in the study may have been particularly outgoing or may have had unusual difficulties with relocation. Also, regardless of the length of time they had lived in the seniors-designated building, the participants had experienced all three phases of *building a new nest*. Despite these limitations, the results of this qualitative study enhance our understanding of relocation to a seniors-designated apartment, a common experience among older women. The findings also illu-

minate variation in the experiences of elderly women as well as variation in their psychosocial and other needs.

In particular, the process describes a preliminary model of relocation among older adults. While previous studies on relocation have focused on relocation to an institution, the present study describes the experiences of 11 independent women. The findings add to our understanding of the emotional and physical process of relocating seldom discussed in the literature. In particular, the temporary housing phase (*shaping a desired future*) is not covered in the literature. Also, this study provides some insight into the early days after relocation, a period that is not explored elsewhere. Theoretically, this work explains some of the variations in the concept of relocation. Practically, it provides guidelines for supporting seniors undergoing this type of transition.

The participants in the study relocated as a result of the death of a spouse or loss of the ability to maintain a family home (Armer, 1993; Cotter et al., 1998). Consistent with the results reported by Morgan et al. (1997), the women felt as if they were leaving memories behind. The present findings do not confirm the cognitive and physical decline found in studies on relocation to long-term-care institutions (Cotter et al.; Krichbaum et al., 1999; Nay, 1995). A qualitative study by Wilson (1997) found that relocation to a nursing home occurred in three phases — the overwhelmed phase, the adjustment phase, and the initial acceptance phase. The present study describes in more detail the actions entailed in each of these phases. Moreover, the second phase identified in the present study, *shaping a desired future*, is not explored elsewhere.

Of relevance to health professionals, the findings suggest that women who are relocating to a seniors-designated apartment and who exhibit certain characteristics should be closely monitored, as they may be at high risk for difficulty *re-establishing the self*. They include women who have lived in the family home for a long time, have difficulty making friends, have a hearing or visual impairment, have a negative attitude, have a moderate or high level of anxiety, have no family in the immediate area, and are moving to a building where they have no acquaintances. Health professionals need to assess for such risks and intervene to prevent difficulties during the transition. Interventions should focus on both emotional and physical well-being.

Nurses should also familiarize themselves with the woman's perception of the relocation experience and assess her level of anxiety. A variety of therapeutic interventions are available to reduce anxiety. Since support is important throughout the process of *building a new nest*, professionals must not overlook the need for informal support when women are undergoing relocation. Professionals should assess the support networks of older women and make referrals to community agencies for those



who do not have family in the area.

Seniors tend not to plan for their future housing needs (Yesner, 1998), yet the amount of planning invested in a transition can influence the outcome (Schumacher & Meleis, 1994). As evidenced by the experience of the participants in this study, once the decision to relocate is made, other difficult decisions must also be made. These concern the disposal of belongings, the search for an apartment, and whether or how to socialize in the new environment. The findings suggest that professionals could intervene effectively by educating seniors and their families about housing options and the relocation process. This would provide a basis for seniors and their families to discuss future housing needs and facilitate decision-making when the time to relocate draws near.

Future research could focus on generalizing the findings to other populations such as elderly men and rural seniors. The experience of settling into a new environment or community could also be examined. A longitudinal study would elicit more details on each phase of the process. The concept of relocation by independent seniors needs to be further explored, especially considering the current trend towards aging-in-place.

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## **Auto-signallement de déficiences auditives et visuelles et satisfaction à la vie chez les aînés francophones**

**Paul Bourque, Christine Léger,  
Dolores Pushkar et François Béland**

La présente étude a pour but d'examiner la contribution des déficiences auditives et visuelles sur la satisfaction à la vie. L'analyse des données secondaires a porté sur un échantillon de 826 personnes âgées ayant participé à l'enquête *Vieillir dans la communauté : santé et autonomie*. Une analyse de régression multiple hiérarchique fut utilisée afin d'évaluer la contribution de quatre groupes de variables. Les variables démographiques incluent l'âge, le sexe, le niveau de scolarité et le revenu, tandis que les variables de santé comportent le nombre de maladies chroniques, les limites fonctionnelles et le rappel. Les quatre variables de style de vie sont le soutien social, les activités sociales et physiques ainsi que le contrôle de son sort. Le dernier groupe de variables comprend les déficiences auditives et visuelles. Le modèle final explique 36 % de la variance. Toutes les variables sont significatives, sauf le rappel et les activités physiques. Bien que les variables de santé expliquent une plus grande part de la variance, les déficiences auditives et visuelles contribuent significativement au modèle. Ces résultats indiquent l'importance des composantes visuelles et auditives dans la satisfaction à la vie.

Mots-clés : satisfaction à la vie, aînés, déficiences auditives et visuelles

# **Self-Reported Sensory Impairment and Life Satisfaction in Older French-Speaking Adults**

**Paul Bourque, Christine Léger,  
Dolores Pushkar, and François Béland**

The purpose of this study was to examine the contribution of sensory impairments to life satisfaction in the elderly. A secondary data analysis was conducted with 826 older French-speaking participants in a larger study. Hierarchical regression analysis was used to determine the role played by 4 sets of variables in life satisfaction. The demographic variables included age, sex, education, and income. The health variables included number of chronic illnesses, functional limitations, and story recall. There were 4 lifestyle variables: social support, social activity, physical activity, and perceived control. The sensory impairment variables included vision and hearing. The final model explained 36% of the variance. All variables except story recall and physical activity were found to be significant. Although health explained a larger percentage of the variance, the sensory impairment variables contributed significantly to the model. The findings indicate that vision and hearing are important components of life satisfaction.

**Keywords:** Life satisfaction, older adults, sensory impairments

The negative impact of vision loss on quality of life has been noted in many studies (Appollonio, Carabellese, Frattola, & Trabucchi, 1996; Lee, Spritzer, & Hays, 1997; Mulrow et al., 1990), as has hearing impairment (Dalton et al., 2003; Magilvy, 1985; Tesch-Römer, 1997). In spite of the negative impact of visual and hearing impairments on functioning, however, few studies have examined the effects of interactions among sensory systems on the well-being of older adults (Bazargan, Baker, & Bazargan, 2001). Although factors such as demographic, health, and lifestyle variables are often examined in the study of the subjective well-being of older adults, few studies have examined the relationship between sensory impairment and life satisfaction (Bazargan et al., 2001). Life satisfaction can be defined as a global cognitive appraisal of the affective quality of one's life as a whole (Diener, 2000). The judgement of satisfaction is usually based on one's own set of criteria and can be affected by situational factors (Diener & Suh, 1997). Even though the cumulative effects of both visual and hearing impairment exert a negative impact on the well-being of older adults, little attention has been given to dual sensory loss (Brennan, Horowitz, & Su, 2005). The present

study was intended to determine whether visual and hearing impairments and their interaction have an impact on life satisfaction.

Various studies indicate that 18% to 27% of older adults report visual impairment (Campbell, Crews, Moriarty, Zack, & Blackman, 1999; Kington, Rogowski, Lillard, & Lee, 1997). Visual impairment is often associated with increasing age but not with other demographic variables such as sex, education, or income (Branch, Horowitz, & Carr, 1989). Self-reported functional limitations are frequently associated with visual impairment (Branch et al.; Kington et al.; Lee et al., 1997; Salive et al., 1992). Vision loss in older adults often results in reduced independent mobility, travel, and leisure activities (Dargent-Molina, Hays, & Bréart, 1996; Long, Boyett, & Griffin-Shirley, 1996). When compared to older adults without vision loss, those with visual impairment are less socially active (Resnick, Fries, & Verbrugge, 1997) and report greater psychological distress (Bazargan & Hamm-Baugh, 1995; Hersen et al., 1995; Horowitz, 1995; Karlsson, 1998), more loss of control and self-esteem (Branch et al.), and diminished well-being (Brenner, Curbow, Javitt, Legro, & Sommer, 1993; Lee et al., 1997; Lee, Smith, & Kington, 1999).

In the case of hearing, 20% to 25% of older adults report having some impairment (Lee et al., 1999; Strawbridge, Wallhagen, Shema, & Kaplan, 2000). Hearing impairment is associated with increasing age; prevalence rates vary from 25% for those aged 70 to 74 to 50% for those over 85 (Bogardus, Yueh, & Shekelle, 2003). It is greater for men than for women (Strawbridge et al.). Cacciatore et al. (1999) found that the probability of having a hearing impairment increases with age but decreases with higher levels of education. Older adults with hearing impairment report psychological distress (Bazargan & Hamm-Baugh, 1995; Branch et al., 1989; Horowitz, 1995), loss of control and self-esteem (Branch et al.), and diminished well-being (Brenner et al., 1993; Lee et al., 1999). Dalton et al. (2003) found that hearing loss impacts on the quality of life of older adults. Findings of studies with older adults experiencing hearing loss have been inconsistent in relation to functional impairment and social involvement. Some studies have found hearing loss to be associated with low levels of social engagement, functional impairment, and reduced time spent on activities (Branch et al.; Kington et al., 1997; Lee et al., 1999; Mulrow et al., 1990; Resnick et al., 1997), while others have found the opposite or no difference (Norris & Cunningham, 1981; Rudberg, Furner, Dunn, & Cassel, 1993). Some of these discrepancies are due to the considerable variations that have been noted between objective and self-report measures (Nondahl et al., 1998). Finally, a link has been found between hearing impairment and cognition. Older adults with hearing loss perform less well than those without hearing loss on verbal tests of cognition but not on non-verbal tests (Thomas et al., 1983).

Approximately 9% of older adults report both visual and hearing impairments (Campbell et al., 1999). Although vision and hearing are associated with quality of life in older adults, the research findings vary. Carabellese et al. (1993) found that visual impairment impacts negatively on mood and on social relationships whereas hearing impairment impacts negatively on activities of daily living. Marsiske, Klumb, and Baltes (1997) found that visual and hearing impairment could account for most of the variance in everyday activities. Individuals with dual sensory impairment have increased risk of difficulty, compared to those with a single sensory impairment or with no sensory impairment, on some activities of daily living (Brennan et al., 2005). However, as noted by Kahneman, Diener, and Schwarz (1999), there remains a high degree of unexplained variance in the research literature even when personality and contextual variables are examined. Few studies have examined the combined effect of visual and hearing impairment on functional status and quality of life. The interaction effects of visual and hearing impairment on functional status and quality of life in older adults warrant further consideration (Bazargan et al., 2001).

The purpose of this study was to examine the role of visual and hearing impairment in self-reported life satisfaction while controlling for demographic, health, and lifestyle variables that also influence life satisfaction. It is possible that sensory deficits influence life satisfaction through their association with these variables. Controlling for relevant health, demographic, and lifestyle variables allows for the specification of possible direct independent effects of sensory impairment on life satisfaction, apart from their indirect effects through such variables. In addition, the study was intended to test the hypothesis that dual sensory impairment has a unique negative effect on life satisfaction beyond that caused by visual or hearing impairment alone.

## **Method**

### ***Participants***

This article reports on a secondary analysis of a large data set from the Aging in the Community Study (Béland et al., 1998) examining the health and well-being of older French-speaking adults in eastern Canada. The sample comprised individuals aged 65 and over residing in Moncton, New Brunswick. Researchers contacted potential participants by telephone to describe the study and to schedule an interview in the homes of those who consented to participate. Twenty interviewers were trained to administer the questionnaire and code the data. The response rate was 67%, which is typical for Canadian surveys (Marshall, 1987). This sample of 1,499 people was considered representative of the French-

speaking population of the province of New Brunswick for age, sex, marital status, and education (Béland et al.).

The responses of a subset of participants for whom complete data were available on study measures and who had consented to take part in further research were selected for the study. The subset totalled 826, of whom 531 (64%) were women and 295 (36%) were men. Sixty-two percent were married. The participants ranged in age from 65 to 94, with a mean age of 74. Education level was as follows: primary or less, 56%; secondary, 24%; postsecondary, 17%.

### **Measures**

The methodology for developing the survey questionnaire in the Aging in the Community Study is presented in Béland et al. (1998). Most of the measures for this questionnaire were adapted from the Established Populations for Epidemiologic Studies of the Elderly (EPESE) (Cornoni-Huntley, Blazer, Service, & Farmer, 1986). The present study selected measures on demographics, health, lifestyle, sensory impairment, and life satisfaction from the questionnaire.

**Demographic variables.** Demographic measures included age, sex, education, and income. Education was divided into six categories: *no schooling*, *some primary school*, *primary school completion*, *high school*, *technical school*, and *university*. Income was measured using total household monthly income, with 10 categories ranging from *no income* to *more than \$5,000*.

**Health, functional limitation, and cognitive function variables.** The health measures included number of chronic illnesses, functional limitations, and narrative memory. The number of chronic illnesses was determined by self-reported chronic conditions from the list of 16 common conditions included in the EPESE (Cornoni-Huntley et al., 1986).

Two items from the *Rosow-Breslau Functional Health Index* (Rosow & Breslau, 1966) and five items from the *Physical Performance Scale* (Nagi, 1976) were used to assess functional limitations. The items on these scales evaluate a person's ability to perform physical activities such as bending, walking, climbing stairs, and lifting heavy objects. Participants were asked to rate the level of difficulty experienced in performing the activity, from *no difficulty* (1) to *cannot perform the task* (4). The alpha reliability coefficient for the functional limitations measure is .80.

In order to determine whether cognitive deficits are associated with life satisfaction, the *Short Story Test* (Scherr et al., 1988) was used to assess narrative memory. The number of recall errors by participants on the *Short Story Test* was used to assess narrative memory. Responses to this



measure yield alpha reliability coefficients of .64 for both men and women (Bourque, Pushkar, Bonneville, & Béland, 2005).

**Lifestyle variables.** Lifestyle measures included social support, social activities, physical activities, and sense of personal control. The social support measure was adapted from a 21-item scale developed by Seeman and Berkman (1988). It evaluates degree of satisfaction with relationships with friends, children, and family on a five-point scale, from *dissatisfied* to *very satisfied*. A higher score indicates greater satisfaction. Alpha reliability coefficients for this scale are .80 for men and .71 for women (Bourque et al., 2005).

Social activity was measured using the following item: *How many times a month do you do each of the following: (a) go shopping, (b) participate in recreational or cultural activities, (c) attend religious services?*

The self-reported frequencies for the three types of social activity were added up to obtain a composite measure of social activity. The self-reported physical activity measure assessed three dimensions pertaining to household or leisure activities such as gardening, walking, swimming, or dancing. The first evaluates frequency of physical activity: *For a person your age, would you say that you engage in: very little activity (1), enough physical activity (2), or much physical activity (3)*. The second evaluates the importance of physical activity: *How important is physical activity in preventing illness in older adults? Unimportant (1), somewhat important (2), quite important (3), very important (4)*. The final dimension evaluates level of actual physical exercise: *What is your level of physical activity? Light (1), moderate (2), strenuous (3)*. The respective scores for the three questions were added up to obtain a composite of self-reported physical activity, with higher scores indicating higher levels of physical activity.

Sense of control was assessed using the seven-item *Sense of Mastery Index* developed by Pearlin and Schooler (1978). Possible responses range from *strongly agree* (1) to *strongly disagree* (5) on such items as *I have little control over things that happen to me* and *There is little I can do to change many of the important things in my life*. A higher score indicates a greater sense of personal control. The alpha reliability coefficient for this scale is .83.

**Sensory impairment.** The sensory impairment measures assessed the presence of visual and hearing problems using questions from the EPESE (Cornoni-Huntley et al., 1986). Self-reported visual impairment was established using three questions on such items as seeing at a distance, seeing at close range, and reading. Participants were asked to rate the level of difficulty from *no difficulty* (1) to *much difficulty* (3). Scores for the three questions were combined to obtain a composite score for visual impairment, with a higher score indicating a greater degree of impairment.

Self-reported hearing impairment was established using seven questions pertaining to hearing ability in various situations such as conver-

sations (with family members or friends) in specific areas (the home, restaurants, church) and during specific physical activities. Participants responded to each item with *no* or *yes*. Reuben, Walsh, Moore, Damesyn, and Greendale (1998) report that this screening questionnaire adequately detects hearing loss. Responses to the seven questions were combined to obtain a composite score for hearing impairment, with a higher score indicating a greater degree of impairment.

**Life satisfaction** was assessed using the following question from the EPESE (Cornoni-Huntley et al., 1986): *Are you satisfied with your life in general?* Options ranged from *not satisfied at all* (1) to *very satisfied* (5). The life satisfaction item has been found to be highly related to satisfaction with health, home, community, and income (Bourque et al., 2005). Single self-report items to measure global life satisfaction have frequently been used by researchers and have strong psychometric properties (Diener, 2000).

### **Procedure**

The key investigators for the original study obtained ethical approval from the research ethics boards of the Université de Moncton and the Université de Montréal to proceed with analysis of data from the original survey. Only the data of those participants who in the original study gave their consent to participate in further research were used. The data sets are coded such that participants cannot be identified.

## **Results**

### **Descriptive Statistics**

Almost 97% of the participants wore glasses. The self-rated vision scores revealed that of the participants, including those who wore glasses, 78% reported no difficulty or only mild difficulty with their vision and 23% reported moderate or much difficulty primarily due to cataract and glaucoma. Only 44% reported having an eye examination within the preceding year.

Self-rating of hearing revealed that 70% of participants had no hearing difficulty and 30% had some or much difficulty. Only 11% of participants reported using a hearing aid. Of these, 48% indicated that they constantly used their hearing aid. The percentages of those who reported using their hearing aid frequently, sometimes, or never were 11, 21, and 16, respectively; nevertheless, 56% reported having excellent to good hearing with their hearing aid, 30% fair hearing, and just 14% poor hearing.

### Data Analyses and Results

Data analysis called for comparison of those who reported mild or no sensory impairment and those who reported much difficulty with vision or hearing. Since it was expected that sensory impairment would be correlated with demographic, health, and lifestyle variables, a follow-up regression analysis was conducted. Subsequently, hierarchical regression analysis was used to examine the effects of vision and hearing difficulties after controlling for the effects of demographic, health, and lifestyle variables. The final step was to examine the combined effect of the interaction of vision and hearing deficits on life satisfaction after covarying the effects of the relevant variables.

Table 1 presents the means for study variables on sensory impairment. Comparison between participants with only mild or no visual impairment and those with much visual impairment revealed significant differences with respect to age ( $t(824) = -3.60, p < .001$ ), chronic illnesses ( $t(824) = -4.25, p < .001$ ), functional limitations ( $t(824) = -3.85, p < .001$ ), physical activity ( $t(824) = -4.20, p < .001$ ), perceived control

Variable	Level of Visual Impairment		Level of Hearing Impairment	
	None or Some ( $n = 732$ )	Much ( $n = 94$ )	None or Some ( $n = 769$ )	Much ( $n = 57$ )
Age	73.09	75.50***	73.19	75.75**
Education	3.44	3.28	3.40	3.68
Income	5.95	6.03	5.96	6.04
Chronic illnesses	1.98	2.49***	2.01	2.42**
Functional limitations	9.64	11.35***	9.69	11.79***
Story recall	.85	.96	.85	.95
Social support	70.66	70.24	70.74	70.16
Social activity	4.06	3.83	4.05	3.77
Physical activity	6.30	5.61***	5.82	5.67
Control	22.23	20.56***	22.12	20.84*
Life satisfaction	7.62	6.69***	7.68	6.72***

\*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$



( $t(824) = 4.11, p < .001$ ), and life satisfaction ( $t(824) = 4.23, p < .001$ ). Comparison between participants with only mild or no hearing impairment and those with much hearing impairment revealed significant differences with respect to age ( $t(824) = -3.05, p < .01$ ), chronic illness ( $t(824) = -2.71, p < .01$ ), functional limitations ( $t(824) = 3.77, p < .001$ ), perceived control ( $t(824) = 2.52, p < .05$ ), and life satisfaction ( $t(824) = 3.47, p < .001$ ). These results indicate that those with considerable vision or hearing loss are older and report significantly more chronic illnesses and functional limitations than those with little sensory impairment. The participants with visual impairment also reported significantly less physical activity. Both participants with visual impairment and those with hearing impairment reported less personal control and life satisfaction than those without sensory impairment.

### ***Regression Analysis***

Table 2 presents the correlations among the study variables. The significant correlations among predictors are low to moderate in value, indicating no multicollinearity among the variables. Because of the large sample size, however, most correlations are significant.

Hierarchical multiple regression analysis was used to examine the individual contribution of the four sets of variables — demographic, health, lifestyle, and sensory impairment — on life satisfaction. Table 3 presents the results of the standardized beta coefficients of these variables on self-reported life satisfaction.

In the first step of the hierarchical regression analysis, age, education, and income were significant predictors of life satisfaction and accounted for 4% of the variance. When health variables were entered in the second step, in addition to age, sex, education, and income, chronic illness and functional limitations were significant, with all variables accounting for 24% of the variance. The lifestyle variables were entered in the third step. In addition to the preceding variables, social support, social activities, and perceived control were all significant predictors of life satisfaction and accounted for 34% of the variance. Visual and hearing impairment were entered in the fourth step; all the preceding variables were significant, as was visual impairment. This step accounted for 36% of the variance. In the final step, which included interaction between visual and hearing impairment, all of the previous variables remained significant. The interaction between visual and hearing impairment was significant but did not significantly increase the amount of variance explained.

With regard to demographic variables, older women with lower levels of education and lower income reported less life satisfaction. Turning to health variables, participants with more chronic illnesses and greater functional limitations reported less life satisfaction. In addition, participants

**Table 3 Standardized Beta Coefficients for Hierarchical Regression of Effects of Demographic, Health, Lifestyle, and Sensory Impairment Variables on Life Satisfaction (n = 826)**

Variables	Step 1 β	Step 2 β	Step 3 β	Step 4 β	Step 5 β
<b>Demographics</b>					
Age	.07*	.18***	.18***	.19***	.19***
Sex	.05	.11**	.09**	.09**	.09**
Education	.13***	.11**	.08*	.08*	.07*
Income	.12***	.13***	.12***	.12***	.12***
<b>Health</b>					
Chronic illnesses		-.29***	-.24***	-.23***	-.23***
Functional limitations		-.25***	-.18***	-.17***	-.17***
Story recall		-.06	-.06	-.06	-.06
<b>Lifestyle</b>					
Social support			.13***	.13***	.13***
Social activity			.08*	.08*	.08*
Physical activity			-.06	-.05	-.05
Control			.31***	.30***	.29***
<b>Sensory impairment</b>					
Vision				-.07*	-.08*
Hearing				-.04	-.05
<b>Vision + hearing</b>					
					.06*
R	.20	.49	.59	.60	.60
R <sup>2</sup>	.04	.24	.34	.36	.36
R <sup>2</sup> change	.04	.20	.10	.01	.00
* $p < .05$ ; ** $p < .01$ ; *** $p < .001$					

with less social support, fewer social activities, and less perceived control also reported less life satisfaction. The interaction between visual and hearing impairment, although significant, did not contribute additional explanatory power to the regression. Visual impairment had an independent negative effect on life satisfaction even after controlling for all the effects of the other variables, while hearing impairment had no independent effect on life satisfaction.

## **Discussion**

This study examined the contribution of demographic, health, lifestyle, and sensory impairment variables on life satisfaction. As expected, the demographic, health, and lifestyle variables helped to explain life satisfaction. More interestingly, so did the sensory impairment variables. This demonstrates the importance of taking sensory impairment into account when considering the quality of life and life satisfaction of elderly people. The results show that, compared to people with little or no sensory impairment, those with visual or hearing impairment are older, have lower levels of education, and report significantly more chronic illnesses, functional limitations, and lack of control in their lives. The link between education and sensory deficits can be interpreted in different ways. It is possible that those with more education are more attentive to preventative care (Cacciatore et al., 1999) or that occupations requiring less education are wrought with greater health hazards. The results also suggest an adverse functional relationship between visual/hearing impairment and health status, functional limitations, and lower sense of control — that is, reduced sense of mastery — which appears to be a consequence of vision and hearing deficits in reducing life satisfaction. These results are similar to those of other studies, which have found that quality of life is adversely affected by hearing loss (Dalton et al., 2003) and poor vision (Lindö & Nordholm, 1999).

It is difficult to remain active and involved when confronted with a visual or hearing impairment. However, the participants with visual impairment reported significantly less physical activity than those with hearing impairment. This finding is consistent with that reported by Marx, Werner, Cohen-Mansfield, and Feldman (1992) for a sample of nursing home residents. The combination of vision loss and reduced sense of control could lead to greater fear of tripping and falling. Such fears can be real, as older people with visual impairment are at greater risk for falls (Lord & Dayhew, 2001; Tinetti, 2001). Similarly, the lower levels of physical activity among those with visual impairment can result in reduced ability to remain independent, such as travelling alone (Long et al., 1996). Although most elderly people in the sample wore glasses, several issues have been related to the use of glasses by older adults with visual impairment (Mann, Hurren, Karuza, & Bentley, 1993). Dissatisfaction with the devices may be related to the nature of the visual decline.

Consistent with the findings of Barzagan et al. (2001), differences were noted in the use of visual aids and the use of hearing aids. Participants with deficits were less likely to use hearing aids, confirming the findings of Popelka et al. (1998). Consequently, as noted by Dalton et al.

(2003), hearing impairment may more often go unrecognized and untreated, but even when listening aids are used, the results are less satisfactory, particularly in social situations. Therefore, it is likely that the effects of hearing difficulties on life satisfaction, in contrast to those of visual impairment, are more focused through social interaction, reducing their independent effects. These findings support the hypothesis that social and functional links can serve to predict hearing decline in the elderly (Levy, Slade, & Gill, 2006).

The results of this study suggest that individuals with self-reported visual and hearing impairment have significantly lowered life satisfaction. Even after the effects of other relevant variables that impact on life satisfaction are removed, vision deficits and the combination of vision and hearing deficits reduce life satisfaction. The failure to find a unique added adverse effect of the combination of hearing and vision deficits is surprising. Generally, however, the two types of deficit show the same pattern of association with health, age, and lifestyle variables. Consequently, it is likely that although their interaction has a significant effect on life satisfaction the limitations associated with the deficits are expressed similarly.

Although there are advantages and disadvantages to using secondary data sets when conducting research, secondary analysis of existing data sets has been employed by researchers as well by government agencies and various policy-making groups (Hakim, 1982; Hyman, 1972; Singleton, 1988). One drawback of such secondary analysis is that the researcher is forced to rely on the collection process used in the primary study, as well as the specific questions posed and the method of organization employed in that study (Hakim). The present study used basic self-report measures to determine sensory impairment status; this served to limit the findings because the validity of self-report measures in the assessment of vision and hearing has been questioned. Indeed, the use of self-report measures tends to underestimate the prevalence of hearing loss, as noted by Nondahl et al. (1998). Dalton et al. (2003) recommend that future studies consider using standardized audiometric techniques to investigate the relationship between hearing impairment assessed objectively or by self-report and life satisfaction. The present study was limited to the items developed for the survey conducted by Béland et al. (1998). Nevertheless, as noted by Barzagan et al. (2001), the subjective evaluation of sensory impairment is warranted because subjective beliefs also play a role in one's evaluation of life satisfaction. Another limitation stems from the selection of the sub-sample, since only those participants with complete data sets were chosen.

The findings have clinical implications for health professionals. Appollonio et al. (1996) argue that quality of life must be taken into



account in the provision of sensory aids to elderly people. Indeed, many studies have found that sensory aids improve quality of life (Reuben, Mui, Damesyn, Moore, & Greendale, 1999). For instance, Brenner et al. (1993) found that quality of life improved when visual function was improved. The use of hearing aids, if properly fitted, could serve to reduce poor quality for life in elderly people (Mulrow et al., 1990). However, older adults with a hearing impairment often fail to seek professional care (Yueh, Shapiro, MacLean, & Shekelle, 2003). Mahoney, Stephens, and Cage (1996) found that it is usually a family member who persuades the patient to consult a professional. Thus, from a clinical perspective, an emphasis should be placed on detecting sensory impairment and educating the elderly who are at risk; this could have a positive impact on their quality of life (Barzagan, Baker, & Bazargan, 1998; Barzagan et al., 2001; Dalton et al., 2003). More specifically, health-care providers such as nurses can play a key role in helping older adults to enhance their life satisfaction by identifying sensory impairments and providing information and assistance with adaptation (Bogardus et al., 2003; Kelly, 1995). For example, nursing personnel can be easily trained to use screening devices such as audioscopes or to provide information to both patients and families on the nature of hearing loss and means of increasing comprehension (Bogardus et al.). In addition, health professionals can encourage older people to extend their range of physical activities and help them to achieve a greater sense of control and well-being through the use of corrective devices and compensatory techniques.

Clearly, the findings reported here must be confirmed and extended. Research is needed to clarify the role that access to intervention services, health, and psychosocial factors play in screening for and the use of aids for sensory impairment and, ultimately, in life satisfaction (Green & Pope, 2001; Lee, 2001). In addition, the impact of sensory loss on physical activity and social participation should be further examined (Crews & Campbell, 2004). As noted by Levy et al. (2006), researchers need to take age stereotypes into account. Future research should also address the hypothesis that hearing deficits influence life satisfaction indirectly and that vision deficits have pervasive effects on functioning, including direct effects on life satisfaction.

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## **Étude exploratoire sur les mesures de sécurité obligatoires imposées aux gestionnaires de cas qui font des visites à domicile**

**Kathleen M. McPhaul, Jonathan Rosen, Shawn Bobb,  
Cassandra Okechukwu, Jeanne Geiger-Brown,  
Karen Kauffman, Jeffrey V. Johnson et Jane Lipscomb**

Cette étude qualitative avait pour but d'évaluer les perceptions des gestionnaires de cas à l'égard de la mise en œuvre et de l'efficacité de mesures de sécurité obligatoires destinées à ceux et celles qui font des visites à domicile. Les chercheurs se sont appuyés sur un cadre de recherche-action pour mener cinq groupes de discussion formés de gestionnaires de cas employés au sein d'un programme de services en santé mentale d'un État américain — ces gestionnaires intervenant auprès de personnes souffrant de maladie mentale grave et persistante. Les mesures de sécurité adoptées à la suite de l'homicide d'un gestionnaire de cas en visite sont jugées efficaces par certaines agences, mais pas par d'autres. La rigueur avec laquelle on met en œuvre ces différentes mesures, dont les protocoles de sécurité, méthodes de reddition des comptes, visites accompagnées dans les situations à risque élevé et programmes de formation, varie d'un établissement à l'autre. Par ailleurs, certains facteurs contextuels pourraient influencer sur la perception quant à la sécurité. Imposer des mesures de sécurité à tous les prestataires de soins à domicile est une solution envisageable, mais il faudra entreprendre d'autres recherches pour analyser les risques et les facteurs en jeu.

Mots clés : visites à domicile, gestionnaires de cas, personnes souffrant de maladie mentale

# **An Exploratory Study of Mandated Safety Measures for Home Visiting Case Managers**

**Kathleen M. McPhaul, Jonathan Rosen, Shawn Bobb,  
Cassandra Okechukwu, Jeanne Geiger-Brown,  
Karen Kauffman, Jeffrey V. Johnson, and Jane Lipscomb**

The purpose of this qualitative focus group study was to assess staff perceptions of the implementation and effectiveness of safety measures mandated for home visiting case managers. A participatory action research framework was used to conduct 5 focus groups of case managers employed by a state mental health system in the United States. The participants were employed by a program to provide case management for the severely and persistently mentally ill in the community. Safety measures instituted after the homicide of a visiting case manager were found to be effective in some agencies but not in others. There was variability between agencies in the strictness with which safety protocols, accountability procedures, accompanied visits for high-risk situations, and training were implemented. Contextual factors influenced perceptions of safety. Mandatory safety measures for home visiting health workers may be feasible but further research is necessary to explore risks and contextual factors.

**Keywords:** Workplace violence, home visiting, community health nursing, case management, mentally ill persons

## **Background**

Visiting human service workers are at risk for injury and death while in clients' homes (Barling, Rogers, & Kelloway, 2001; Bussing & Hoge, 2004; Department of Labor Statistics, 1997; Fazzone, Barloon, McConnell, & Chitty, 2000; Fitzwater & Gates, 2000; Schulte, Nolt, Williams, Spinks, & Hellsten, 1998). The home visiting workplace presents many of the same care-related risks as institutional settings, such as clients with a history of violence or with cognitive impairments, clients with mentally ill illness and a co-occurring substance abuse disorder, working alone, and exposure to weapons (Fazzone et al.; Fitzwater & Gates; Murphy, 2004; Powell & Lloyd, 2001). Home visiting workers are also exposed to risk factors associated with violent outcomes among workers in other occupations such as taxi drivers and late-night retail workers. These factors include working alone in the community, travel into crime-ridden areas, and working late at night (Fitzwater & Gates; Kendra & George, 2001;

Kendra, Weiker, Simon, Grant, & Shullick, 1996; Schulte et al.; US Department of Labor & Occupational Safety and Health Administration, 1996).

There has been no rigorous research on the risks of violence towards home visiting human service workers. However, case reports of homicide and the results of limited studies specific to home visiting suggest broad patterns of risk compatible with the literature on workplace homicide and violence (Kendra, 1996; Schulte, 1998). Even though home visiting human service workers are not identified in the literature as high risk for homicide, they exhibit several risk factors for homicide, namely travel into high-crime areas, working at night, exposure to firearms, and working alone (National Institute for Occupational Safety and Health, 1996a, 1996b). Homicides of home visiting human service workers have been reported in a number of US states, including Texas, Maryland, Michigan, Kansas, New York, and Washington (Gillespie, 2001; Killing in Texas, 2006; Ly, 2002; Martin, 2005; Newhill, 2003; Public Employee Safety and Health, 1999; Sedensky, 2004). In response, at least three states have introduced legislation to strengthen and/or require specific safety measures for these at-risk workers (Lipscomb, Silverstein, Slavin, Cody, & Jenkins, 2002). According to the Canadian Centre for Occupational Safety and Health (2007), several Canadian provinces have also adopted specific regulations or guidelines concerning workplace violence. In the United States, however, regulatory agency investigations and citations for workplace violence are rare, in spite of mounting evidence of violence as an occupational hazard in such industry sectors as health care, law enforcement, transportation, retail sales, and education (Bureau of Labor Statistics, 2001, 2002; Duhart, 2001; Jenkins, 1996a, 1996b; McCall & Horwitz, 2004; Moracco et al., 2000; Toscano, 1996; Toscano & Weber, 1995). An investigation *was* carried out in 1998 following the murder of a community mental health nurse in a northeastern state. In this case, the employer was cited by the state's occupational safety agency for failure to provide a "safe and healthy workplace." The citation required the employer (a state mental health agency) to institute five safety measures as remediation for all visiting mental health workers employed throughout the state:

- regular training in the handling of potentially assaultive patients
- a system to account for the whereabouts of all employees assigned to the field
- formal safety protocols to be followed by visiting mental health case managers, and adequately communicated to all employees
- accompanied visiting when the patient's history indicates assaultive behaviour



- a means to summon assistance when necessary (Public Employee Safety and Health, 1999)

This qualitative study was designed to assess whether the mandated safety measures implemented in the wake of the homicide improve the safety of home visiting case managers (HVCMs). In lieu of specific instruments to assess home visiting risk, a qualitative approach was taken in anticipation of developing measures for use in a future mixed-method study of this population of workers. This article reports the findings of a focus group study to assess the implementation and effectiveness of mandated safety measures for HVCMs several years after their implementation.

### **Conceptual Framework**

A participatory action research (PAR) framework was employed in the design and conduct of the study (Keith et al., 2001; Leung, Yen, & Minkler, 2004; Schurman, 1996). In the aftermath of the visiting nurse's murder, her labour union played a pivotal role in crafting safety measures. The PAR framework allowed for the workers and their union to be equal partners and for the investigators to be "co-learners" in gathering information on the effectiveness of the safety measures. University-based occupational health researchers collaborated with the health and safety department of the union that had represented the murdered nurse. The union identified the primary research question: *Are the required safety measures in place and working?* The union also advocated for the use of focus groups as the data-collection method, in order to engage frontline staff in this safety issue. Focus groups are an accepted method for PAR (Morgan, 2006) and have been used in other exploratory occupational health studies (Goldenhar et al., 1999; Keith et al.). The university-based investigator secured funding for the project and collaborated with the union to develop a plan for recruiting visiting mental health case managers for the study.

### **Methods**

#### ***Sample and Recruitment***

The union represented approximately 250 visiting mental health case managers throughout 12 geographic regions of a northeastern state. In 2003, five focus groups, representing urban, rural, and suburban settings, were conducted in 4 of the 12 regions. The union's health and safety staff publicized the project in their newsletter (circulation: 55,000). They described the purpose of the focus groups, listed dates and locations, and encouraged visiting case mental health case managers to register to participate. One month prior to each scheduled focus group session, a

memo was mailed to every visiting case manager listed in the union's database who lived in the targeted region. Additional efforts to reach out to case managers were made through the union's network of local union leaders (council leaders and stewards). Focus group participants were not compensated but were provided with food and reimbursed for travel expenses.

The focus groups were conducted either in a regional union office (3 groups), in a hotel conference room (1 group), or at the worksite (1 group, with the consent of management). All groups with the exception of the worksite group were conducted in the evening after work. The worksite group was conducted at midday. Each focus group was conducted by a trained moderator (the PI) and a trained co-moderator. Three of the five groups were also attended by a representative from the union's health and safety department. The focus groups consisted of between 4 and 12 persons currently working as visiting mental health case managers for the state mental health system. The sessions lasted approximately 2 hours. A total of 42 visiting mental health workers participated in the focus groups. Urban and suburban work settings were represented, with half of the participants making visits in both urban and suburban settings.

### ***Focus Group Questions***

The focus group questioning route was as follows: (1) Is a system in place and working to ensure accounting of employees? (2) Are there established safety and communication protocols? (3) Are accompanied visits available upon need? (4) Is adequate training provided to deal with potentially violent patients? (5) Are intensive case managers provided with a cell phone or some other means to summon assistance? The sessions were audiotaped and the tapes were transcribed by a professional medical transcription service.

### ***Analysis***

The transcriptions were analyzed and coded using Atlas.Ti, a qualitative data analysis program. The PI and two of her co-authors coded transcripts by searching for keywords reflecting any one of the five safety measures (visiting in pairs, cell phone, accountability system, etc.). Each of the five measures was analyzed and discussed in depth in order to elucidate every aspect of the staff's perceptions. Additionally, themes emerged that were not directly related to the safety measures but were, in the opinion of the case managers, significant risk factors for violence. These themes are discussed below. The study was approved by the university's human subjects committee and written informed consent was obtained from each participant.

## **Findings**

The availability and effectiveness of each of the five safety measures are described. Contextual themes regarding the safety of HVCMs are also described.

### ***Formal Safety Protocols***

Most of the focus group participants were unable to describe formal safety protocols. In the focus group for the HVCM unit that had experienced the tragic murder, however, the case managers were able to consistently describe specific policies governing accompanied visits, weapons in the home, household and family members under the influence of alcohol or drugs, and use of police escorts:

*If we were to send you our policy, you'd see that...calling in twice a day identifying that you are safe, and knowing [that] if you don't call in somebody is going to page you or call you to determine that you are safe — those things are in place and are working.*

Case managers from other locations thought that formal safety policies existed, especially for accompanied visits when a staff person felt uneasy or when the client had a history of violence, but they were unable to provide much detail about these policies:

*My understanding is, if you're not comfortable, don't [go]...take somebody with you...you have a right to ask.*

Some described policies governing accountability or check-in systems:

*There's a strict policy that actually the County developed as the result of...it's a policy... I'm not saying that we originated it, but if you're out in the community for more than 3 hours, you check in so that people know that you're safe.*

Case managers generally agreed that safety protocols were in place but believed that contextual issues at the societal and agency levels undermined their effectiveness. These contextual issues are described in the following sections.

### ***Accountability System***

Each community case management program is required to have an accountability system in place for visiting field staff. A member of the office staff is supposed to know the location and itinerary of case managers at all times. The visiting case managers, for their part, are supposed to communicate their itineraries in advance, provide current contact information, and periodically check in to the office, especially if

their itinerary changes. Staff itineraries change frequently throughout the day due to emergencies and the changing needs of clients. Case managers reported that some offices did not have adequate staff to effectively monitor field workers and their constantly changing itineraries. Furthermore, some offices would call the field worker if a check-in call had been missed. Some visiting case managers disliked being interrupted by a call from the office when they had failed to check in. Variations among programs emerged:

*I don't know how well it's adhered to... I know the main phone at [our program], you call for hours there and won't be able to get through...it's an automated system and it'll just ring and ring and ring.*

*You're supposed to call in...and schedules...things happen...the minute you walk out the door you're getting calls from the police, the hospitals, this client, that client, and, you know, you're always reassessing who you're going to see, what the priority is...and you can't always convey back to other people...*

The comments of participants from units with efficient accountability systems contrasted with those of participants who reported problems that revealed inconsistencies in the structure, implementation, and effectiveness of this abatement measure. Some units appeared to have an effective accountability system, some to have no functional accountability system at all, and others to have a system characterized by apathy and anger. For some visiting case managers, the accountability system was a hot-button issue, while for others it was an accepted part of their work life:

*We have a system...where we all have to call in every day between 2:00 and 2:30...and the secretary, she takes the message or she takes your call and she checks off who has called in... That's one accountability system... We also have a schedule that we read before we go out every day...in terms of the client, the location, telephone number, what car we are driving...daily...*

When case managers viewed the accountability system as ineffective or as unnecessary for their own safety, they were less likely to adhere to policies:

*But the actual execution is problematic either for organizational reasons or, in some cases, because the individual[s] themselves don't view it as helping with their safety.*

### **Training**

Case managers had almost nothing positive to say about their training experiences. When they were asked if safety training was required, they gave conflicting responses:

*They cancelled it due to lack of interest.*

*We do have a mandatory training every year.*

*I know we don't have it every year...that's not mandated.*

The larger issue appeared to be that it is difficult to engage experienced case managers in meaningful training. Some case managers recalled a training series at a local college with well-intended instructors and ample opportunity for discussion:

*It had a very good value...just the opportunity to ventilate and to brainstorm among us.*

According to the participants, this series of training sessions, which covered more than just safety, was suspended.

The involvement of local law enforcement bodies in safety training received mixed reviews:

*There's a local police officer that comes here and tells us to lock our car and keep our purse in the trunk...that's not cutting it.*

*We had brought in the police department, and that was effective...and parole people who literally did what we did but in a different system.*

Many case managers who had worked for the state mental health system reported having received the same training as the inpatient mental health staff. They found many of the same principles to be applicable, though not the “takedown” and seclusion and restraint procedures, which they could not and did not use in the community.

**Table 1** *Frequently Cited Conditions Impacting on Safety of Staff*

<p>Ability to choose accompanied visiting</p> <p>Quality of violence-prevention training</p> <p>Effectiveness of accountability system</p> <p>Assisted Outpatient Treatment Program requirement (involuntary treatment)</p> <p>Community environment</p> <p>Safety and communication procedures</p> <p>Role of representative payee</p> <p>Ability to summon help</p> <p>Erosion of resources for mental health care</p>
--

Some case managers reported viewing training videos that were almost entirely without merit — dated, redundant, and even offensive:

*Yeah, but those are tapes...that's inpatient.*

*It's tapes from 1960 that they have you sit and watch.*

*Same training for the past 5 years.*

Some HVCMS thought that they should be involved in the training design, or at least in the needs assessment:

*They develop this training without any kind of involvement from the case managers themselves.*

One HVCM felt that case managers could give the safety training themselves:

*It's the same training and, honest to God, it's generic and we could teach safety training.*

### ***A Means to Summon Assistance***

Cell phones are now universally issued or available to case managers who are state employees and union members. All participating case managers reported having a cell phone for their professional use: "Everybody has cell phones *now*." Staff in one program reported having to give up beepers now that cell phones are available. Other staff reported that cell phone service was inconsistent in rural areas. In New York State it is illegal to make or receive a call on a cell phone while driving. In general, a means to summon assistance from the field appeared to be widely available to case managers. Although one HVCM said, "Technology is probably not going to save us," a communications device of some kind was considered essential.

Cell phones allow HVCMS to report their whereabouts and alert the office to any changes in their schedules. Most HVCMS agreed that cell phones enhanced their therapeutic role by facilitating communication with providers, social services, police, and others. Cell phones appear to be a permanent addition to the safety armamentarium for case managers, but this safety measure must be viewed in the context of overall risk and hazard. A cell phone is a communications device, not an assault deterrent or a substitute for the presence of another person in the event of an assault.

### ***Accompanied Visiting***

The requirement that HVCMS visit high-risk clients in pairs is perhaps the most challenging of the abatement measures. This safety measure

forces case management programs to define a high-risk visit (usually, a first visit or a visit to a client with a history of violent behaviour) and to stretch already tight staff resources to accommodate pairing. Staff were often conflicted about whether and when to request accompaniment. HVCMs are aware of the risks but are also experienced mental health providers who develop a therapeutic bond with their clients. They do not want to jeopardize this therapeutic relationship by bringing in a stranger, nor do they want to be injured by a client or to be the victim of violence in a crime-ridden community. They are further conflicted by the knowledge that other HVCMs have a full caseload with no time to visit someone else's clients:

*I'm quite sure the supervisor would have accompanied me... I know that, but I also know that for her to come with me it's an hour out, it's an hour there, and it's an hour back, and then if she has a meeting and she can't come when I come, that's a hassle, you know.*

Some staff did not believe that accompanied visits were any safer:

*Two is not safer.*

*I don't always think going with someone else is necessarily any safer.*

*Two targets instead of one.*

Most, however, felt that it had a “deterrent” and “assistive” effect — “you can pull the other individual [out].”

The accompanied visit policy, though known and understood, is not always easy to implement:

*It's kind of easier to go there even though you know maybe you shouldn't, so that piece of the safety policy is difficult, and...really, I wrestled with this since [the murdered nurse] died, on how to cover that, and there is no way to cover it other than [my colleague] and I, we try to...we have between us, you know, 27 people, 26, 27 people between us. If we did double visits we'd need 80 hours a week to get all our work done and we only have 40 hours a week to get it done, so you have to make a decision at some point. But geographically it's easier in the city and in the surrounding suburbs to get a second person to go with you, much easier than [for] somebody to drive 35 miles for a 20-minute visit. That's a difficult thing.*

Accompaniment is more difficult to arrange for rural visits, yet isolation from neighbours is common and in some areas cell phone service is not available. One HVCM described the efforts of a new colleague to visit a client in an isolated area. The client was considered

high risk due to substance abuse problems. He lived without electricity, telephone service, or running water:

*He lives in a little hut that has no running water and no electricity...this was where he was put...he was a known drug user, and the case manager was instructed by the supervisor to go out and visit this client by herself... The first time she went to visit the client she took somebody with her. The second time she arranged to take somebody with her and then the HVCM coordinator pulled her aside and said, "You've got to learn to do this on your own," leaving her to go out to...visit this client in the middle of nowhere.*

Staff who had experienced a threatening situation appeared to be more confident when visiting in pairs:

*After the knife incident, where I found the guy with the knife, I didn't make single visits any more.*

### **Contextual Factors**

**Reduced resources for mental health care.** Case managers described and emphatically lamented the erosion of resources for intensive case management programs. The original mission of the program was to provide multiple supports, coordinated by the case manager, to enable the high-risk mentally ill to thrive in the community. Staff were saddened and demoralized by the inadequacy of the program. Case managers saw the deterioration in services as contributing to the risk of violence against staff. In their view, when the high-risk mentally ill have unmet needs in the areas of housing, social support, employment, safety, medication, and treatment, they are more likely to become aggressive towards case managers or others. The case managers across the state consistently described feeling like a "last resort" or "safety net" for a society that does not want to deal with the high-risk mentally ill while at the same time wishing to be protected from the dangers they represent.

**Involuntary treatment issues.** Related to this theme was another contextual finding specific to a state law providing for mandated treatment of the mentally ill who present a security risk to the community. The law was intended to reduce the risk to society when high-risk mentally ill persons become dangerous because they refuse treatment. The HCVMs reported that these "mandated" clients became their responsibility, and most felt that they represented a higher risk for violence because the mandatory nature of the provider-client relationship is a barrier to the establishment of trust and to an optimal therapeutic relationship. The HCVMs felt that an optimal therapeutic relationship is protective (i.e., reduces the risk of violence towards the case



manager) but that “mandated” relationships are less likely to achieve the level of trust necessary for the therapeutic relationship to thrive. A minority of the HVCMS, however, approved of one feature of the new law: the ability to call in the sheriff when a client fails to comply with treatment. They felt that, in general, it is better to force non-compliant patients to take their medications than to watch them decompensate and become violent.

**Conflict of interest.** In addition to the risks of dealing with mandated clients, HVCMS reported that, in the absence of a suitable relative, the case manager is often appointed “representative payee” for a client (managing the client’s finances). Many case managers said that this responsibility creates the potential for tension and conflict over money and increases the risk of violence towards the provider. Sometimes the risk of violence comes from individuals in the community who prey on the mentally ill and attempt to siphon their resources. This recurring theme bears further exploration by the mental health system. The case managers were practically unanimous in their view that representative payee and therapeutic case manager are conflicting roles that increase the risk of violence towards home visiting staff.

## **Discussion**

Home visiting human service workers and their employers use a variety of safety strategies, none of which are supported specifically by clear evidence. We evaluated staff perceptions of the effectiveness of required safety measures in one state case management program. The results add to our understanding of the factors associated with the effectiveness of occupational safety measures for home visiting mental health programs.

The study found that the five required safety measures are generally in place across the state but are inconsistently implemented. Notably, the participants from the unit where the murdered nurse had been employed did report strict compliance with all safety measures. This finding indicates the feasibility of the measures. The reason for variable implementation of the safety protocols in other agencies is not clear; it could be a training deficit, a communications breakdown, or inadequate management commitment to safety issues.

HVCMS across the state were satisfied that they had a means to summon assistance. Most participants reported having a cell phone and many said they had a beeper provided by the employer. Some rural areas do not have cell phone service. A review of possible technological solutions in such areas is beyond the scope of this article; however, in the absence of standard cell phone service, other technologies such as radios or satellite phones may be available.

Most staff reported some type of telephone check-in system and most said it was their practice to leave a written itinerary in their field office. Many HVCMs, however, were dissatisfied with the accountability procedures in place in their home office/unit. These procedures were often described as ineffective and many staff members were suspicious of the accountability system. The reasons for the variability in accountability systems throughout the system are not clear.

Most participants indicated that they felt they could request that a colleague or supervisor accompany them on home visits, although some case managers seemed to believe that doing so frequently was discouraged. In one unit it was the policy for a supervisor to accompany the case manager on all new client visits and for 1 month thereafter, as well as any time the case manager believed there was a risk. It appears that the other jurisdictions allow HVCMs to visit in pairs when there is a specific high-risk situation but do not provide the resources for frequent accompanied visits, nor, apparently, do they have an explicit definition for "high-risk visit."

One focus group included staff of a pilot project, Assertive Community Treatment (ACT), which reportedly *requires* home visiting in pairs or teams. According to the staff, the ACT model is newer than the intensive case management model and is being piloted in one county mental health department but is not widely used throughout the state. The mandatory nature of the visiting-in-teams requirement is significant because it eliminates possible tension between supervisor and case manager over staff resources. It also eliminates the need for the case manager or the supervisor to weigh staff resources against safety. This finding suggests that visiting in pairs is feasible, but details about the program and its resources are not available. Since only one of the focus groups included ACT staff members, this finding did not reach saturation. Models of care that provide community or home visitation by pairs or teams of providers should be explored from the standpoint of patient and staff safety outcomes.

Finally, violence-prevention training is an essential element of a comprehensive violence-prevention program (US Department of Labor & Occupational Safety and Health Administration, 1996). However, training must be considered in the context of "extra-training" factors (Cohen & Colligan, 1998), which include organizational attributes (such as adequate staffing) and quality parameters (such as trainer competency and a comfortable setting). It is useless to train staff for circumstances that require visiting in pairs without providing sufficient staff for visiting in pairs. Similarly, if staff are trained to check in at a set time during the day, this behaviour must be monitored or the training will not be optimally effective. A training method that insults the learner's intelligence not only

will be ineffective but will lower morale and foster resentment. Furthermore, training should be geared to the experience and skill level of the group. The training needs and requirements of seasoned mental health professionals are different from those of newly assigned HVCM staff. The murdered nurse was a veteran employee, which suggests that training for more experienced staff may need to address different issues, such as complacency or boundaries, and review data and risk factors. Furthermore, seasoned providers will simply dismiss irrelevant or meaningless training.

### ***Strengths and Limitations***

This project was a collaborative effort between the participants (HVCMs), their union, and the research team. The PAR framework is the most acceptable and appropriate means of studying an issue associated with severe trauma. The focus groups were well attended even though most were conducted after working hours and none of the participants was compensated beyond expenses. Contextual themes reached saturation and were raised repeatedly in each group. Other concerns were locally based or agency-based and reflected the broad theme of inconsistent application of safety measures. Furthermore, the project offered a unique opportunity to evaluate staff perception of mandated safety measures (which, to our knowledge, do not exist elsewhere).

The limitations of the project include the fact that it was carried out in only one state, thus possibly affecting the applicability of the findings to other states or other types of home visiting program. Also, information on the demographics, work experience, and assault/injury experience of the participants was not collected. Furthermore, the participants were self-selected, thereby increasing the likelihood of bias. Finally, the participants were all unionized HVCMs, restricting the applicability of the findings to non-union workplaces. The study might have been strengthened by the addition of a state-wide survey assessing the impact of the safety measures on the incidence of injury and violent assault since the introduction of the new measures.

### ***Implications for Practice, Policy, and Research***

The implications of the findings include the need to direct attention to the feasibility, effectiveness, and sustainability of five specific safety measures for visiting health and human service workers. To our knowledge, even in the few North American jurisdictions that have safety regulations regarding workplace violence and/or visiting human service and health-care workers, no evaluation of these measures has taken place. The findings of this study have direct implications for home visiting nurses and

other human service practitioners. First, safety of the community/home visiting workforce must be recognized as an essential element of operations. Workforce safety must be integrated into all aspects of patient care. Systems need to be developed to evaluate new clients for a history of violent behaviour and communicate this information to staff. Detailed protocols for specific high-risk situations must be developed and regularly reviewed with staff. Resources must be allocated to allow for visiting in pairs in high-risk situations. Finally, staff training must be evaluated for appropriateness and effectiveness.

The research implications of the findings include the need for exploration of the various types of home visiting programs, clients, services, and safety strategies, as well as the need for analytic research with respect to risk factors specific to home visiting. Given the paucity of evaluation data, a qualitative approach was considered the most appropriate for this study; however, surveys of current safety practices would also be helpful. Moreover, given the substantial risk even to experienced providers, more research attention should be focused on differentiating the training needs of novice and experienced home visiting staff. Ultimately, intervention effectiveness research must be undertaken to determine the effectiveness and sustainability of safety programs for home visiting health and human service workers.

The focus groups employed in this study have given voice to a workforce that is one of the chief supports for the mentally ill and other vulnerable individuals living in communities rather than institutions. This examination of mandated safety measures has implications for nurses, who, along with members of other professional groups, may be at risk for occupational homicide or “workplace violence” in the course of home visiting.

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## *Best Practices for Research*

# **Guidelines for Translating RCT Findings into Practice**

**Souraya Sidani and Laurie N. Gottlieb**

The epidemiologists and methodologists have gained control of the research agenda and, more recently, the clinical agenda. Over the past 20 years, the randomized clinical trial (RCT) has become the standard against which the effectiveness of a given intervention is measured (Shadish, Cook, & Campbell, 2002). The RCT has been used extensively in testing the effectiveness of drugs, medical and surgical treatments, psychotherapies, and social programs. As the demand for evidence-based practice increases, the pressure on clinicians mounts. Many clinicians are asked to translate the RCT conditions into their practice after a trial has been completed and the effectiveness awards have been handed out. But translating RCT into practice is not easy given the inherent differences, in terms of mission and execution, between the RCT and practice worlds.

What are some of the most obvious differences between these two worlds?

The RCT is credited with providing the best available evidence on the effectiveness of an intervention. The RCT design is characterized by control over the experimental conditions. Participants are carefully selected, on the basis of strictly defined eligibility criteria, to ensure homogeneity of the sample and to control for potential confounds. To minimize selection bias, participants are randomly assigned to the treatment or comparison group. The intervention under evaluation is implemented in a standard and consistent manner across all participants assigned to the treatment group, so as to minimize random irrelevancies in its delivery that might affect the outcome. Analysis of outcome data is conducted at the group level, aimed at demonstrating statistically significant between-group differences in outcomes at post-test.

Because of careful participant selection on the basis of strictly defined eligibility criteria, the generalizability of RCT findings is limited to patients who meet those criteria (Brown, 2002). The patient population served in the practice setting comprises subgroups of patients who differ



to some extent from those included in the RCT: Patients may present with characteristics that were considered exclusion criteria (Sidani & Epstein, 2003). To what extent are RCT findings and conditions applicable to different subgroups of patients? Can the intervention be used safely, and can it produce the outcomes observed under the RCT? Few if any RCT conditions are consistent with patient-centred care. Quality nursing practice is predicated on the tailoring of care to a particular patient situation in a particular context (Radwin, 2003). Random assignment of participants to a treatment or comparison group contradicts the principle underlying clinical decision-making and practice. Clinicians are trained to select and deliver interventions that are appropriate for and effective in addressing patients' conditions and to engage patients in the decision-making process. This process relies on interventions that are acceptable to patients — consistent with their beliefs, values, and preferences.

How can random assignment inform the clinical decision-making process and the procedure for encouraging patients to take part in decision-making or for eliciting their treatment preferences? To what extent will an intervention be effective if administered on the basis of patients' expressed preferences? (Sidani, Epstein, & Miranda, 2006) The standard and uniform implementation of an intervention in the RCT context limits its relevance for and use in practice. The intervention's components, dose, and mode of delivery must be adapted or modified to accommodate patients' needs and preferences as well as the resources available in the practice setting. To what extent can an intervention's components and method of delivery be modified yet produce the intended benefits?

Results of statistical analysis, carried out at the group level and guided by the intent-to-treat principle, demonstrate an intervention's effectiveness in achieving the outcomes for the "average" participant. The average participant is one who meets the eligibility criteria and responds as expected to the intervention (Barlow, 1996). An RCT's reported results do not indicate the presence of variability in the dose of the intervention received by participants or in their responses to the intervention. Yet such variability is important to clinicians (Jacobson & Truax, 1991). Clinicians need to know who will most benefit from the intervention, at what dose level, in order to make sound clinical decisions (Sidani & Braden, 1998).

It is clear that RCT design and the reporting of RCT findings have limited relevance for practice (Ferguson, 2004). Variants of the RCT design and modifications to research strategies and methods have been suggested as means of enhancing the applicability and transferability of intervention evaluation findings to the practice setting (Glasgow, Magid, Beck, Ritzwoller, & Estabrooks, 2005; Gross & Fogg, 2001; Rothwell,

2005; Sidani, Epstein, & Moritz, 2003; TenHave, Coyne, Salzer, & Katz, 2003; Tunis, Stryer, & Clancy, 2003).

Until such variant designs and modifications are accepted as mainstream methods for the design and conduct of intervention studies, what can be done to help clinicians translate RCT findings into practice? The most commonly recommended strategy is to develop collaboration between researchers and clinicians with the ultimate aim of generating guidelines for delivering the intervention, implementing it in such a way as to preserve its integrity, and evaluating its effectiveness (Titler, Mentes, Rakel, Abbott, & Baunker, 1999). The success of this strategy depends on the availability of the information and evidence necessary to draw up practice guidelines. What information and evidence do clinicians need in order to translate RCT findings into practice? And what can researchers do to enhance the relevance of their findings for practice? To address these questions, we developed four guiding principles that researchers can use in reporting the findings of an RCT. The goal is to help clinicians identify the conditions that determine the effects of an intervention.

### ***Principle 1: Clear Description of the Intervention***

Clinicians or frontline nurses cannot translate into practice that which they cannot understand or visualize. Clinicians require clear and accurate information on the nature and essential ingredients of the intervention in order to replicate or apply it. The essential ingredients of an intervention, like the essential attributes of a concept (Walker & Avant, 1995), are the features that distinguish it from all the others. They are the elements or activities hypothesized to bring about the intended change. Delineation of the intervention's essential ingredients tells clinicians what specific elements are needed to ensure fidelity of implementation and thus achievement of the expected outcome.

In reporting on an RCT evaluating the effectiveness of an intervention, the researcher must make explicit the implicit. What is obvious to the researcher may not be obvious to others. The investigator must describe the nature of the intervention and the procedure to be followed in implementing it. This includes all the w's and h's of the intervention: where, when, who, what, why, how. In pertinent sections of the research report, the investigator can specify the overall goal(s) of the intervention; the components of the intervention and the goal of each; the tasks to be performed in delivering each component, and their sequence, if any; the mode of delivery for each component; the dose at which the intervention is to be administered; the required characteristics of the staff responsible for implementing the intervention and details of any training that might be required; and the conditions under which the intervention was tested (e.g., setting, time). The researcher can also include information on

the availability of the intervention protocol. All of these details about the intervention are critical for its accurate translation into practice guidelines and hence its faithful application in the practice setting.

***Principle 2: Discussion of Variability in Intervention Dose***

In the reality of day-to-day practice, variability in the implementation of an intervention is the norm. In order to tailor the intervention dose to the needs and conditions of individual patients, clinicians need to know the dose range that is safe, is acceptable to patients, and is associated with the achievement of the intended outcome. Once informed about variability in the doses administered to study participants and about the outcomes observed at different dose levels, clinicians can make modifications to suit the needs of individual patients without jeopardizing the intended outcomes.

To enhance the clinical relevance of RCT findings, researchers can report on variability in the dose to which participants were exposed and the results of dose-response analysis. First, the researcher specifies the number of participants who did and did not complete the intervention at the specified dose level and the reasons for non-completion. Next, the researcher indicates the number of participants who received each level of the intervention dose, however defined (e.g., number of contacts between participants and staff; frequency of the key activities that make up the intervention); this information points to the acceptability of the intervention dose and the dose level tolerated by most participants, and can guide modification or refinement of the dose. Finally, and most importantly, in determining the effectiveness of the intervention the researcher can supplement traditional analysis with dose-response analysis; the latter is focused on the relationships between the different dose levels to which the participants were exposed and the observed differences in outcomes (Lipsey, 1990). The results indicate (1) the minimal and optimal dose required to produce a beneficial outcome, and (2) the extent to which dose variability is still associated with therapeutic effects. Consequently, a safe and effective dose range can be delineated to guide clinical decision-making. It informs clinicians' prescription of the most appropriate intervention dose and directs their efforts to tailor the intervention to individual needs and conditions.

***Principle 3: Explanation of Who Stands to Benefit the Most from the Intervention***

It is not enough to simply report group findings, as is the traditional practice. Except for those working in public health settings, frontline clinicians do not treat groups. Rather, they are responsible for the care of individuals within groups. Results reported at the group level mask

within-group variability, yet this variability must be examined so that those participants who benefited the most from the intervention can be identified. Equipped with this knowledge, clinicians can determine the intervention's appropriateness for their patients and its applicability and effectiveness for patients with diverse health backgrounds.

Researchers can complement traditional group-level analysis, in which the experimental and comparison groups are compared on post-test outcomes, with subgroup analyses. The purpose of subgroup analysis is to delineate the profile of participants who responded positively to the intervention (Tunis et al., 2003). The analysis consists of describing the sociodemographic and health characteristics of participants who, as anticipated, demonstrated large improvements (Gibson, 2003; Gottlieb & Feeley, 1996). When the RCT sample is rather small, the subgroup analyses can be exploratory, aimed at identifying differences in key, conceptually relevant, characteristics among participants who, between pretest and post-test, showed improvement, no change, or worsening. Change scores are computed to represent the magnitude of improvement in outcomes, as suggested by Rogosa and Willett (1985).

#### ***Principle 4: Assessment of Clinical Significance***

It is common knowledge that statistically significant findings are not necessarily clinically meaningful ones. They do not provide information on the extent to which the intervention was helpful for individual participants and made a difference in their lives (Jacobson & Truax, 1991). Yet knowledge about the impact of the intervention on participants' lives is needed for the purposes of decision-making. Clinicians use such information in planning their patients' care, in discussing the utility or effectiveness of an intervention with their patients, and in helping their patients to select an intervention that will address their presenting problem.

Researchers can take one of two approaches to examining clinical significance — statistical and individual (LeFort, 1993) — and report the results to enhance the relevance of RCT findings for practice. The statistical approach consists of computing the effect size (i.e., standardized difference in the post-test means of the experimental and comparison groups) for each outcome. The effect size is a statistical estimate of the magnitude of the intervention effect. Interventions demonstrating large effects are considered to produce outcomes that have a meaningful impact on patients' lives. The individual approach consists of reporting the number of participants in each experimental and comparison group who exhibit improvement between pretest and post-test. If a large percentage of participants in the experimental group show the anticipated level of improvement, the intervention is deemed clinically relevant.

Researchers and clinicians are partners in the delivery of nursing care. They need to form strong alliances and to create new dialogue in order to facilitate translation of RCT findings into practice. Clinicians are encouraged to voice their need for information that is relevant and that guides the prescription of interventions that respond to patients' conditions and preferences and that will maintain their integrity in day-to-day practice. Researchers must provide information and results that are meaningful for clinicians. Both stakeholder groups could discuss the appropriateness, comprehensiveness, and utility of our suggested principles for enhancing the clinical relevance of intervention research. Only through discussion and collaboration by all stakeholder groups will consensus be reached on the substance and reporting of intervention-related knowledge. The reporting of clinically relevant knowledge will promote clinicians' appreciation of research and facilitate the translation of research findings into practice.

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