Letter to the Editor

Dear Editor:

I support Janice Morse's call for a healthy debate on the best methods of preventing falls in hospitals, although I fear describing the research of others as immoral and unethical may not be the best way to begin such a debate.

I was lead author of the RCT (Healey, Monro, Cockram, Adams, & Heseltine, 2004) described as immoral and unethical [Janice M. Morse, "Response," Vol. 38, N° 2, pp. 95–96]. The study asked that, in addition to normal practice, patients with a history of falls or near misses before admission or who had a fall or near miss after admission receive an approach targeted at reducing their risk factors. It involved a format where each risk factor was linked to an intervention, for example free access to replacement slippers. The expectation was that the interventions themselves would become embedded in everyday practice rather than reserved solely for specific patients with a history of falls. The significant reduction in falls found in the study was achieved over the whole patient cohort, not at a cost of favouring specific patients to the detriment of others.

The study did not involve expensive medical tests; it was unfunded, and took place in a setting where medical therapy and nurse staffing levels were unlikely to provoke envy in our peers. The patients, staff, and ethical committee consulted during preparation for the study believe focusing on reducing individual risk factors was ethically and morally justified, since the evidence gaps in hospital falls prevention centred not on predicting who will fall, but on how to stop them falling.

As most patients admitted do not fall, and most patients who fall are not injured, power calculations suggest very large studies are required to detect changes in injury rates. Our study of over 3,000 admissions would have had to be extended over several years to detect a 10% reduction in injury rate at statistically significant levels. I am sure Janice Morse did not mean to imply that a non-significant fluctuation in injury rates should be taken as evidence the study caused harm.

The issues relating to falls prediction tolls have already been articulately expressed by the earlier contributors. I would only wish to add that assessment is always a means to an end, and falls assessment and prediction formats should be judged not in isolation, but on whether they lead to effective interventions to reduce falls in vulnerable patients.

Frances Healey

Reference

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EDITORIAL

ICMJE Guidelines for Assigning Authorship and Acknowledging Contributions

This editorial is a departure for me inasmuch as I have decided to devote much of it to reprinting authorship guidelines set forth by the International Committee of Medical Journal Editors (ICMJE). My decision to do so stems from a growing concern about the practice of assigning authorship of a manuscript to those whose contribution is limited or even questionable. Many nursing authors, knowingly or unknowingly, may be engaging in practices that are commonplace in other disciplines without questioning whether they are indeed ethical.

The practice of assigning authorship of a given scholarly work varies from discipline to discipline. Each field develops its own practices based on the nature and type of scholarship inherent in the discipline, its historical system of knowledge development, and the pressures and rewards from its various constituencies. In the humanities, for example, most scholarly publications are solo authored. The scholar is expected to make an original contribution and collaboration among scholars is not common practice. This tradition of solo authorship may stem from the nature of the work required in the discipline. In fields such as philosophy and literature, the development of new insights requires personal vision that is best achieved alone. Consider, for example, that a work of fiction is rarely a co-authored endeavour, and that the latest philosophical theorem is constructed by a single scholar. Within these academic circles, co-authored work is not encouraged, perhaps due to the difficulty in ascertaining each scholar's unique contribution.

Authorship practices in the medical and biomedical disciplines stand in stark contrast to those in the humanities. Here, solo authorship is rare. Teams of researchers are encouraged to address problems together, each scholar contributing a unique perspective and a unique set of skills. Historically, publications in the medical and biomedical sciences have always been multi-authored. However, the number of authors per manuscript has increased significantly and it is now common to see five or more authors listed on a manuscript. Anyone remotely associated with a project is given authorship, rather than simply having his or her contribution acknowledged. The pressure to assign authorship stems in part from the imperative to "publish or perish," whereby quantity of publications is considered just as important as quality. (Many academic promotions committees, aware of this practice, all but ignore the middle authors, regarding only the first two authors and the last author on a manuscript as the true contributors.)

The practice of authorship assignment is less clear in nursing. In our experience at *CJNR,* most manuscripts are authored by two or three scholars. The humanities model of solo authorship, once prevalent in nursing, has been on the decline since the 1990s (Norris, 1993). While the practice of assigning authorship to all members of a team on every publication resulting from a project does exist in nursing, it is not widespread. This observation is in keeping with the results of a survey conducted almost 10 years ago in which Canadian nurses expressed the view that only those who make a significant contribution to a study should be given authorship (Butler & Ginn, 1998). It would be interesting to know whether this view is prevalent today, and the extent to which it holds sway.

There is a growing belief among editors of nursing journals that some authors do not merit authorship, given the nature and extent of their contribution. In some circles, professors are being encouraged to put colleagues' names on manuscripts to increase their chances for promotion and tenure even though these colleagues have not participated in the project — a very unethical practice indeed. Other unsavoury authorship practices creeping into nursing journals are ghost-authoring and ghostwriting. In ghost-authored submissions, the author hires another person to write his or her article without disclosing or acknowledging the true authorship of the submission. This is a growing practice. In the case of ghostwriting, the research is written up by a second party with or without the knowledge of the "designated" author. This is a topic for a future editorial. These practices, plainly put, are dishonest; editors fear they may be publishing half-truths or even lies, which can have dire consequences for the veracity of the science. Because of these and other unethical practices, an increasing number of nursing journals are now demanding full disclosure of authors' names and the nature and extent of each author's contribution before proceeding with manuscript selection and review.

The editors of medical journals have been grappling for some time with the issue of how authorship should be assigned. In 1978 a small group of editors of medical journals met informally in Vancouver to establish guidelines for the submission of manuscripts. What became known as the Vancouver Group later expanded and evolved into the ICMJE, whose mission is to develop ethical principles and guidelines related to all aspects of biomedical journal publication (www.icmje.org), for the benefit of both authors and editors. Under the heading of "Ethical Considerations in the Conduct and Reporting of Research," they have set forth guidelines for authorship and other matters relating to journal contributions. These guidelines are reprinted here to signal that they are the ones signed on and to be followed by *CJNR*.

Laurie N. Gottlieb
Editor-in-Chief

ICMJE Authorship and Contributorship

1. Byline Authors

An "author" is generally considered to be someone who has made substantive intellectual contributions to a published study, and biomedical authorship continues to have important academic, social, and financial implications. (1) In the past, readers were rarely provided with information about contributions to studies from those listed as authors and in acknowledgments. (2) Some journals now request and publish information about the contributions of each person named as having participated in a submitted study, at least for original research. Editors are strongly encouraged to develop and implement a contributorship policy, as well as a policy on identifying who is responsible for the integrity of the work as a whole.

While contributorship and guarantorship policies obviously remove much of the ambiguity surrounding contributions, it leaves unresolved the question of the quantity and quality of contribution that qualify for authorship. The International Committee of Medical Journal Editors has recommended the following criteria for authorship; these criteria are still appropriate for those journals that distinguish authors from other contributors.

- Authorship credit should be based on 1) substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; 2) drafting the article or revising it critically for important intellectual content; and 3) final approval of the version to be published. Authors should meet conditions 1, 2, and 3.
- When a large, multi-center group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript (3). These individuals should fully meet the criteria for authorship defined above and editors will ask these individuals to complete journal-specific author and conflict of interest disclosure forms. When submitting a group author manuscript, the corresponding author should clearly indicate the preferred citation and should clearly identify all individual authors as well as the group name. Journals will generally list other members

of the group in the acknowledgments. The National Library of Medicine indexes the group name and the names of individuals the group has identified as being directly responsible for the manuscript.

- Acquisition of funding, collection of data, or general supervision of the research group, alone, does not justify authorship.
- All persons designated as authors should qualify for authorship, and all those who qualify should be listed.
- Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Some journals now also request that one or more authors, referred to as "guarantors," be identified as the persons who take responsibility for the integrity of the work as a whole, from inception to published article, and publish that information.

Increasingly, authorship of multi-center trials is attributed to a group. All members of the group who are named as authors should fully meet the above criteria for authorship.

The order of authorship on the byline should be a joint decision of the co-authors. Authors should be prepared to explain the order in which authors are listed.

2. Contributors Listed in Acknowledgments

All contributors who do not meet the criteria for authorship should be listed in an acknowledgments section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Editors should ask authors to disclose whether they had writing assistance and to identify the entity that paid for this assistance. Financial and material support should also be acknowledged.

Groups of persons who have contributed materially to the paper but whose contributions do not justify authorship may be listed under a heading such as "clinical investigators" or "participating investigators," and their function or contribution should be described — for example, "served as scientific advisors," "critically reviewed the study proposal," "collected data," or "provided and cared for study patients."

Because readers may infer their endorsement of the data and conclusions, all persons must give written permission to be acknowledged.

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Résumé

Des stratégies pour distancer la maladie : les cas de la schizophrénie précoce et des maladies chroniques du rein

Heather Beanlands, Elizabeth McCay et Janet Landeen

Même si les recherches indiquent que la perte d'identité est un thème universel qui concerne l'ensemble des maladies chroniques, peu d'études jusqu'ici ont abordé cette question en comparant la maladie mentale et la maladie physique. C'est ce qui amené les auteures à comparer ce phénomène chez des sujets souffrant de maladie mentale (schizophrénie précoce) et des sujets atteints d'une maladie physique (maladies chroniques du rein) dans le cadre d'une analyse secondaire. Elles ont étudié des données provenant de deux groupes échantillons afin de relever les points communs et divergents des thèmes émergents. Un but commun se dégage chez les sujets des deux groupes, soit de chercher à *développer le meilleur de soi-même et à reprendre sa vie en main*, mais les stratégies pour y parvenir diffèrent. Pour trouver un équilibre entre les exigences imposées par la maladie et les autres aspects de leur vie, les sujets ont rapporté s'investir dans des activités pour *apprivoiser la maladie, s'adapter* et *se retrouver*. Le désir de *développer le meilleur de soi-même* comportait des points communs dans les deux groupes, ce qui laisse croire que le désir de préserver l'intégrité du soi au-delà de la maladie ne découlerait pas du fait même d'être malade. Les résultats préliminaires de l'étude indiquent que la construction d'une identité positive est un facteur clé du processus d'adaptation à la maladie. Il reste donc beaucoup à apprendre sur l'éventail de stratégies mises en œuvre par les principaux intéressés pour distancer la maladie.

Mots clés : Maladies chroniques du rein, schizophrénie précoce, perte d'identité, groupes échantillons

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Strategies for Moving Beyond the Illness in Early Schizophrenia and in Chronic Kidney Disease

Heather Beanlands, Elizabeth McCay, and Janet Landeen

Although the literature suggests that loss of self is a universal concern across chronic illnesses in general, little consideration has been given to loss of self across physical and mental illnesses. The authors compare loss of self in individuals with a mental illness (early schizophrenia) and in those with a physical illness (chronic kidney disease). In this secondary analysis, focus group data from 2 samples are examined for similarities and differences in the emergent themes. While *striving to be my best self: getting on with life* was an overarching goal for both groups, the strategies for achieving it differed. The participants engaged in activities related to *approaching the illness, accommodating,* and *connecting* in order to strike a balance between the demands of the illness and non-illness aspects of their lives. The commonalities in the wish to *be my best self* that were found in both groups indicate that the wish to preserve a sense of self beyond the illness may not be illness-specific. The preliminary results of this secondary analysis suggest that building a positive sense of self in the face of illness is a critical part of illness adjustment and that there are opportunities for nurses and researchers to learn about the spectrum of strategies employed by individuals as they strive to move beyond the illness.

Keywords: Chronic kidney disease, early schizophrenia, loss of self, engulfment, focus groups, qualitative research

Introduction

Chronic illness is frequently accompanied by a host of social, economic, and personal issues, including social isolation, financial pressures, family stressors, emotional upheaval, social role constriction, and stigmatization (Charmaz, 1991; Devins, 1994; Strauss et al., 1984). In conjunction with this vast array of issues, chronic illness and its treatment challenge an individual's sense of identity (Charmaz, 1983, 1991). In some instances the effect is so pervasive that the person experiences a *loss of self,* whereby conceptions of the self are eroded (Charmaz, 1983; Corbin & Strauss, 1987). Some individuals living with chronic illness are never free of the influence of their illness on their self-concept (Curbow, Somerfield, Legro, & Sonnega, 1990) and this illness identity leads to decreased self-esteem, depression, and decreased satisfaction with life (Baker et al., 1994; Foltz, 1987).

While loss of self has been identified in a number of conditions, it is not known whether it is a universal concern across chronic illnesses in general. Charmaz (1983) eloquently describes the profound impact of serious chronic physical illness on the self. Based on in-depth interviewing of persons with various forms of medical illness, she observes that people with chronic illness suffer "from a loss of self in which their former images of self disappear without the development of equally valued new ones" (p. 68). Similarly, loss of self is described in the psychiatric literature as an often undeniable process in severe mental illness (Davidson & Strauss, 1992; Estroff, 1989; Lally, 1989). Despite similar descriptions of loss of self in mental and physical conditions, there is virtually no literature describing either the commonalities or the differences in the effects of mental and physical illness on an individual's sense of self.

As researchers working in the realm of chronic illness, we have observed that individuals living with either physical or mental illness may experience loss of self that transcends the physiologic nature of the disease. We have tested a theoretical model of *engulfment* in chronic illness that provides a means of understanding loss of self in mental and physical illness. Specifically, this model has guided research in schizophrenia and chronic kidney disease (CKD), since both of these illnesses challenge the sense of self and quality of life. Although it is readily apparent that the experience of the disorder and its treatment is very different for the two illnesses, research findings suggest that the impact of the illness experience on the sense of self is comparable (Beanlands, 2001; McCay, 1994; McCay & Seeman, 1998). Separate preliminary qualitative studies undertaken to explore the experience of living with early schizophrenia (ES) and CKD suggest that loss of self is a central and common concern for both disorders, which led the authors to raise the question of how these experiences compared. Thus the aim of this secondary analysis was to examine the experiences of loss of self in individuals with a mental illness (ES) and in those with a physical illness (CKD). Specifically, we sought to compare and contrast the experience of loss of self between these groups and the strategies employed by each to address issues related to loss of self.

Literature Review

Loss of Self and Early Schizophrenia

For individuals coping with ES, their sense of self is called into question as soon as they realize that they have an illness they have already identified as highly stigmatizing (Holmes & River, 1998; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001). This orientation towards self-stigmatization frequently results in feelings of powerlessness and uncertainty about the future. Specifically, many believe that previously held goals, as well as a positive future, are beyond their reach (McCay & Ryan, 2002). Efforts to move forward and cope with the illness become arduous, as young people recovering from ES may experience profound difficulty motivating themselves to follow through with self-set goals (McCay, Landeen, & Vishnevsky, 2005), reinforcing their negative perceptions of themselves. In conjunction with the numerous challenges associated with maintaining a healthy sense of self, these individuals frequently experience social withdrawal — specifically, the loss of social roles and relationships over time (Birchwood, Todd, & Jackson, 1998; Estroff, 1989; McGorry, 1992).

Despite the challenges inherent in living with schizophrenia, several studies have found that it is possible for individuals to acquire a positive sense of self, and this has been identified as a critical element in recovery (Czuchta & Johnson, 1998; Davidson & Strauss, 1992). Based on 15 life-history interviews with individuals living with schizophrenia, Williams and Collins (1999) propose a subjective theory of illness and recovery that identifies enhanced self-image and social connection as critical elements in moving beyond the illness. From this perspective the person's sense of self can be viewed as the agency of change. Similarly, McCann and Clarke (2004), using grounded theory, found that increased self-determination in recovery was related to increased well-being and self-control in young adults with schizophrenia. The results of these qualitative studies point to the central role of self in understanding the experience of illness and recovery, an approach that is consistent with the conceptualization of engulfment described below.

Loss of Self and Chronic Kidney Disease

Individuals living with CKD requiring dialysis face a number of physical, social, and psychological challenges that can profoundly influence how they view themselves. Researchers have consistently identified major life changes and restrictions experienced by individuals on dialysis, including alterations in body function and appearance, loss of roles, social isolation, and dependence on family, technology, and the health-care team (Eichel, 1986; Gurklis & Menke, 1995; King, 1994; Lindqvist, Carlsson, & Sjoden, 2000; Nagle, 1998; Welch & Austin, 1999; White & Greyner, 1999). Inherent in these challenges is a sense of limitation and loss that can profoundly influence persons' thoughts and feelings about themselves.

A growing body of empirical evidence indicates that these experiences with CKD can threaten an individual's conceptions of self (Devins, Beanlands, Mandin, & Paul, 1997; Gregory, Way, Hutchinson, Barrett, & Parfrey, 1998; Kutner, 1987; Nagle, 1998). For example, Gregory et al. uncovered *redefinition of self* as a major construct in their grounded theory study with individuals on dialysis. Similarly, participants in Nagle's phenomenological inquiry identified a loss of personhood and wholeness resulting from dialysis and described *a struggle to be the same while being different*. For some, the process of self-redefinition in response to CKD and dialysis may offer a "new lease on life" and consequently boost sense of self (Gregory et al.). In other instances, however, the illness-related changes associated with CKD are so pervasive that thoughts and feelings about the illness come to dominate the self-concept and individuals begin to view themselves solely terms of the disease (Devins et al.; Kutner; Nagle; O'Brien, 1983). In other words, the physical and psychosocial challenges experienced by those living with CKD place them at risk for engulfment. Persons being treated with continuous ambulatory peritoneal dialysis (CAPD) may be particularly vulnerable to engulfment, as this therapy is performed at home, several times a day, and requires a high degree of vigilance in order to avoid treatment complications.

Theoretical Perspective

The engulfment construct offers one perspective for examining the impact of chronic illness on an individual's self-concept. Adapted from the role engulfment perspective (Lally, 1989), engulfment is manifested by alterations in self-concept and the adoption of patient and illness roles. Engulfment occurs through a loss of normal roles, acceptance of the illness label, a sense of having been changed by the illness, comparing oneself unfavourably to others, loss of self-esteem, and viewing the change in self as permanent (Lally; McCay & Seeman, 1998). Unable to reconstruct a valued non-illness self-concept, the person defines himself or herself in terms of the disease, and activities become illness-centred (Nerenz & Leventhal, 1983); in other words, engulfment results.

Empirical evidence supports the theory that, in both mental and physical illness, engulfment is closely associated with low self-esteem, hopelessness, decreased self-efficacy, and poor social adjustment. In schizophrenia, engulfment, as measured using the Modified Engulfment Scale (MES), has been found to be associated with hopelessness, depression, low self-esteem, decreased self-efficacy, and poor social adjustment (McCay & Seeman, 1998). Similarly, research in CKD, also using the MES, has found increased engulfment to be associated with a range of psychological sequelae, including depression and dissatisfaction with life (Beanlands, 2001). These quantitative findings suggest that engulfment has implications for psychosocial well-being in both illness populations. However, it is not clear whether the subjective experiences of loss of self in these diverse populations will also be comparable. In order to address this issue, a secondary analysis of qualitative focus group data was undertaken to compare the experiences of loss of self in individuals with a mental illness (ES) and in individuals with a physical condition (CKD).

Design and Methods

Design

A secondary analysis of data from two preliminary descriptive qualitative studies was undertaken. The first project was designed to address unique challenges for individuals living with ES and the second addressed issues for individuals living with CKD. The two studies used focus group methodologies and employed similar approaches to data collection and analysis.

Data Collection

For both projects, semi-structured interview schedules were developed to guide focus group discussions. Each session was conducted by two members of the research team with expertise in focus group facilitation. All focus groups were held in private meeting rooms in the clinical setting where the participants were receiving care. They were attended by a research assistant, who took written notes, and were audiotaped.

For the participants with ES, the focus group questions were designed to invite discussion regarding issues of motivation and self-concept for young adults in the earliest phases of schizophrenia. Participants were asked if they had experienced problems becoming motivated as well as about barriers to motivation. They were also asked whether feelings about themselves affected their ability to be motivated and about strategies that might enhance their motivation and sense of life satisfaction.

For the participants with CKD, separate focus groups were held with individuals on CAPD and with health-care providers, in order to elucidate the challenges and stressors associated with the predialysis period. In this paper, only the results of the client focus group are considered. Questions in the CAPD sample centred on the participants' sense of self, experiences in learning about and preparing for dialysis, and strategies used to manage their illness and treatment. Participants were asked to discuss how dialysis affected their view of themselves and to describe the strategies that helped them manage their illness and treatment.

Participants

For the ES groups, participants had received a diagnosis of schizophrenia, schizoaffective disorder, or schizopreniform disorder within the preceding 2 years, could speak and comprehend English, and were deemed able to participate in a focus group by their clinician. Exclusion criteria were drug-related psychosis, significant medical illness, and organic brain syndrome. A total of eight individuals (six men and two women) participated in two focus groups. The mean age of participants was 30 years and the age at onset of the illness ranged from 16 to 34 years. Four participants lived independently, three lived with family, and one lived in a supportive setting.

Individuals on CAPD were invited to take part in the study if they had been on dialysis for more than 3 months, could speak English, and were willing to share their thoughts and ideas in a group setting. Individuals were excluded if they could not speak English or were deemed medically unstable by their clinician. A total of four participants (three men and one woman) took part in the CKD focus group. They ranged in age from 37 to 57 years (*M* = 46.2). Two of the four participants were married. One participant was employed.

The demographic characteristics of the two samples are compared in Table 1. The samples were similar with respect to sex and level of education, both comprising mostly males with 14 years of schooling. On average, the ES sample was younger than the CKD sample and comprised more single individuals; this is consistent with the course of ES, which tends to present in young adults, whereas the dialysis population generally consists of middle-aged or elderly adults.

Table 1 *Demographic Characteristics of Participants*

	Early Schizophrenia (2 focus groups, *n* = 8)	**Chronic Kidney Disease (1 focus group, *n* = 4)**
Sex		
Male	6	3
Female	2	1
Age		
Mean years	30.0	46.2
Education		
Mean years	14.6	14.2
Marital Status		
Single	7	2
Married/ living common law	1	2

Human Subjects Considerations

Ethics approval was obtained from the institutional review boards at the respective universities and participating institutions. All participants gave their written informed consent and agreed to maintain confidentiality of the information shared within the group. The research team ensured the participants' anonymity by removing any names or identifying information when transcribing the data and by assigning each participant an identification number. Audiotapes were stored in a locked cabinet accessible only to members of the research team and were destroyed upon completion of analysis. Prior to beginning each focus group, the investigators made provisions for support and referral in the event that a participant became upset during the session; however, no participant experienced distress or required referral.

Data Analysis

Original focus group studies. The primary approaches to data analysis were similar for the two samples. Audiotapes were transcribed verbatim and the transcripts from each sample were analyzed separately using an approach outlined by Miles and Huberman (1994). This approach involves a sequential process. First, the principal investigators from each project read the transcripts to identify initial reflections that emerged from the focus group discussions. The investigators then reviewed the transcripts in depth to develop a coding scheme reflecting salient categories emerging from the focus group discussions. The transcripts were coded, using this coding scheme, by the investigators and the research assistant, who assigned the appropriate category labels to sections of the text. The investigators then sifted through the coded data to identify patterns, themes, and differences within and between categories.

The result of the primary analysis in both groups was a comprehensive list of categories and themes emerging from the data. In the ES focus group, themes included the experience of motivation, motivation in the context of illness, making a difference, and envisioning the future. Although the themes focused on the experience of motivation, issues related to the impact of the illness on the self, the need to push oneself to feel well, and the importance of supportive relationships were clearly described. In the CKD focus group, similarly, the themes included preserving the self and negotiating patient-caregiver relationships, as well as themes related to stressors and supports associated with the predialysis period. In both instances, loss of self and strategies used to enhance the self emerged as relevant, which led the authors to raise the question of how these experiences compared.

Secondary analysis. The approach to secondary analysis was guided by the first stages of the synthesis process for qualitative data. In this approach, findings from different studies are translated into metaphors, which facilitates comparison across studies (Evans & Pearson, 2001; Noblit & Hare, 1988; Sandelowski, Docherty, & Emden, 1997). In order to compare loss of self in the two samples, the authors first read and reread the original focus group transcripts and the themes generated by the primary analysis for each sample separately. Particular attention was paid to themes related to loss of self and to uncovering key metaphors that described these themes. Separate metaphors were generated for the ES data and the CKD data.

Two authors (HB and EM) then engaged in an iterative process of dialogue and discussion in order to identify similarities and differences in the metaphors identified for each group. The third author (JL) then invited the others to participate in a "peer debriefing" process (Lincoln & Guba, 1985). In this process, HB and EM described the steps of the secondary analysis to JL, with a focus on the rationale for the choice of metaphors. Furthermore, JL contrasted the findings to those of previous qualitative research she had conducted with individuals with long-standing schizophrenia (Kirkpatrick, Landeen, Woodside, & Byrne, 2001; Landeen, 2000). According to Loiselle, Profetto-McGrath, Polit, and Beck (2004), this process is "a means of strengthening the trustworthiness of the data" (p. 479). Finally, overarching metaphors, which captured the themes that intersected the two groups, were identified and the inter-relationships between them were explored.

Findings

The key overarching metaphor arising from the two groups was *striving to be my best self: getting on with life*. Getting on with life meant moving beyond the illness in ways that allowed the individual to address both the immediate demands of the illness and the non-illness aspects of life — that is, striving to be *my best self.* While the overarching goal of getting on with life and being *my best self* was common to the two groups, the strategies for achieving it differed, particularly with regard to strategies for a*pproaching the illness, accommodating,* and *connecting.*

Approaching the Illness: Moderating versus Managing the Illness

Both groups described approaching life with the illness in such a way as to prevent the illness from taking over. The young adults with ES did this by *moderating the illness,* by accepting it so that they could resume their normal lives. Those with CKD, on the other hand, emphasized the importance of *managing the illness* by taking charge and being in control of their own care. The young adults with ES described moderating illness as involving both understanding and accepting it in order to move forward with their lives. One respondent said:

> *You learn. You understand what you went through, and you can accept it. When you can accept things, it's much…easier to go forward.*

Understanding and accepting enabled participants with ES to go forward and get on with their lives, because it put illness in perspective and made it less frightening. Similarly, maintaining a positive attitude was a strategy for reframing the perception of illness to help individuals with ES moderate the effects of their illness. One respondent with ES explained:

> *You have to think positive. That's a good thing about having the illness: you learn to think positively. …you have to or else you're not going to make it.*

For others in the ES group, moderating the illness meant taking time away from it so that illness was not the focus of daily activities:

> *I try to make time for enjoyment…going out with my friends…or being with my family or my dogs or whatever. To have time off my schooling…*

Taking "time off" allowed some respondents with ES to keep illness in the background in order to moderate its effects on everyday life. In contrast, those with CKD, in one respondent's words, "experience this whole thing day in day out, 24 out of 24, 7 days out of 7 days." Thus in order to prevent the illness from taking over, those with CKD became illness managers. By managing the illness, they took control and became time managers. One respondent explained that this required planning:

> *You have to manage your time as far as [dialysis] exchanges are concerned. And then you have to plan. If I'm getting up early tomorrow morning, I have to go to bed X hours, and so forth.*

Individuals with CKD not only were time managers but also saw themselves as being actively involved in managing all aspects of their illness. As one respondent put it, "You're in charge of your medical well-being; you have to be on top of things." Being knowledgeable was seen as the best way of being on top of things, and information enabled those with CKD to "stick up for" themselves. One participant with CKD explained:

> *I think you have to be an informed patient… I mean, I think you have to stick up for yourself, because no one in the end is going to do it for you.*

For both groups of respondents, approaching the illness through either moderating it or managing it allowed them to live with their illness without having it "take over." However, this approach was balanced with that of accommodating the unique challenges of their particular disease.

Accommodating: Pushing Myself *versus* Pacing Myself

In order to be their best selves and to get on with life, both the ES and the CKD participants highlighted the importance of *accommodating,* or tailoring their actions and activities to the illness in order to minimize its negative consequences. Young adults with ES described *pushing myself* to meet challenges related to motivation and reintegration into social settings that often accompany the illness. In contrast, those with CKD described *pacing myself* in order to conserve energy for valued activities and interests. For those with ES, *pushing myself* represented an acknowledgement of the need to stay motivated and active in order to "get well":

> *I'm pushing myself more. …I'm motivating myself to get well. I feel I got really ill very quickly…and I said, "I'm not going to take that long to get well," so I've been pushing myself to get really well quickly — medication and everything.*

For these individuals, "getting well" was a central concern; *pushing myself* reflected an awareness of the need to do what was necessary to get on with life:

> *Even when I was…very ill…I would do whatever I could do…not necessarily the level that I'm working at right now, but…I would try to keep going, I would try to not let my mind stall, I would sort of continue with my life.*

While for those with ES getting well required an effort to be involved and to "continue with life," individuals with CKD were conscious of the need to pace themselves in order to conserve energy for important activities. Like *pushing myself, pacing myself* was a conscious effort to get on with life, which required both planning and balancing:

> *Everything that I have managed to do is basically accomplished by planning and an effort of will.*

Pacing myself and conserving energy were necessary not only for activities and interests, but also for interpersonal interactions. Respondents with CKD acknowledged that a lack of energy could affect their relationships by causing them to be "abrupt" or, as one man put it, "snarky":

> *I tend to just measure myself out in terms of how to use my energy, because I'd rather be my good self for 4 hours a day than act as a son of a bitch for 18… So there's just pacing yourself…*

Thus, *pacing myself* allowed individuals with CKD to be their best selves by conserving their resources for activities, interests, and personal interactions. For both the ES and the CKD participants, establishing and maintaining personal relationships was crucial to moving beyond the illness. Hence, *connecting* was a common strategy identified in both groups.

Connecting: Making Connections beyond the Illness versus Making Illness-Centred Connections

Connecting was a strategy used to develop or maintain relationships. It helped respondents either to mitigate the negative consequences of their illness, in the case of the ES sample, or to manage their illness, in the case of the CKD sample. Connecting was seen as an active, purposeful approach to establishing or maintaining relationships. Participants with ES described the importance of *making connections beyond the illness,* while those with CKD highlighted the need to make *illness-centred connections.* For those with ES, having a support network outside their illness was central in helping them to accept their illness. Reconnecting with friends was a pivotal means of gaining support:

> *…the sharing that you have in a friendship…you can discuss anything with a friend, and you can talk to them about everything…and the good advice that they give if you respect their opinion…*

For the ES participants, friendships not only provided opportunities for sharing and being respected, but were also sources of tangible support. One respondent explained that talking with friends could be motivating:

> *…well, these days anyways, I'm having more success…supportive friends as well, I would say…they talk a lot of sense. It helps. That keeps me going…*

Clearly, for those with ES, supportive friends were essential in order for them to "keep going" and to move beyond the illness. Respondents actively sought out opportunities to reconnect with their friends, even if this required them to push themselves.

While making connections beyond the illness was the predominant strategy described within the ES group, these participants made little if any reference to relationships with members of the health-care team. In contrast, participants in the CKD group stressed the need to establish relationships with members of the health-care team. It should be noted that CKD participants also described non-illness relationships (with family and friends) as crucial to their moving beyond the illness. However, the focus of their discussion of connections requiring active, purposeful interactions was the health-care team. Thus, *making illness-centred connections* was the predominant strategy described by this group. The need to be active in establishing these relationships is exemplified by a comment made within the CKD group: "I was prepared to wrestle it out with the doctor in the beginning, to get some understanding."

While not all respondents felt the need to "wrestle it out" with their health-care team, the importance of establishing relationships with members of the team was an identifiable thread. The sheer number of health professionals with whom participants interacted necessitated vigilance in both making connections and balancing information and guidance received from various sources. Several participants with CKD felt that they alone had a perspective on their overall health:

> *Part of the problem is…I've got, like, five or six doctors…Dr Lipids, Dr. Heart, Dr. Kidney… So I've got these guys all lined up…they all own their little piece of me…but nobody seems to own me…*

Participants established connections that enabled them to play a part in decision-making about their own care because of the absence of ownership by any one member of the health-care team. One participant in the CKD group had worked with his doctor to establish the best approach to his care:

> *I was able to be part of the team that made decisions about my treatment…we were a couple of good minds working on a problem is the way I'd see it.*

Participants did not view all interactions with the health-care team as collaborative, and making successful illness-centred connections often took considerable effort. However, being a part of the treatment team was viewed as essential, and in many instances making illness-centred connections not only provided opportunities for gaining information and understanding but also allowed participants with CKD to take greater control of their illness and to get on with life.

Striving to Be My Best Self: *Getting on with Life*

The strategies of approaching the illness, accommodating, and connecting employed by individuals with ES and CKD enabled them to strike a balance between addressing the demands of the illness and enjoying non-illness aspects of their lives. Underlying this balance was a need to preserve a fundamental sense of the person that existed before the illness in order to move on. *Striving to be my best self* involved both an acknowledgement of the illness having changed the individual and an awareness of the persistence of an essential self. One participant in the ES group reflected on coming to this realization:

> *I didn't used to act this way, and when I started taking my medication… I noticed that I was coming back to my original self.*

This sense of an original self that persisted even in the face of illness-related changes was echoed by a participant in the CKD group:

> *Of course the same things bring me joy as before…you are essentially the same person.*

One way that respondents got on with life and minimized the engulfing effects of their illness was by continuing to find joy in valued activities, interests, and relationships. Some participants described finding new "activities that I enjoy doing," whereas others made plans or set goals. A will to move beyond the illness and get on with life was common to the two samples. A respondent with ES stated:

> *You have to move on. You have to get on with your life… You can't stay in the past forever, wondering what happened. …I have to get up every morning and get going and do the things I do. So there's a place in my past for what happened.*

Finding a place for the illness was essential in order for the participants to move beyond the illness, because, as summed up eloquently by a member of the CKD group, "being sick does not make you immune to life."

Discussion

Relatively little consideration has been given to examining similarities and differences in the experiences of individuals living with physical and mental illnesses. The results of this analysis suggest that moving beyond the illness is a goal common to individuals with early schizophrenia and those with chronic kidney disease. Consistent with the engulfment construct, the participants described a range of strategies used to preserve a positive sense of self in order to mitigate the engulfing effects of illness. The findings also suggest some illness-specific differences in the strategies used in this pursuit. In general, participants with ES described strategies for keeping the illness in check *(moderating it)* while at the same time employing strategies for connecting with healthier aspects of themselves (*pushing myself* and making connections beyond the illness). In contrast, participants with CKD described strategies for minimizing the impact of the illness on their activities and interests (*managing it* and *pacing myself*) and for establishing relationships that enabled them to participate in decisions related to their care (making illness-centred connections). Such differences may be explained in part by the characteristics of the participants (e.g., age and marital status) and the distinct nature of their illness experiences.

The onset of schizophrenia often occurs in late adolescence or early adulthood when individuals are typically facing developmental transitions related to establishing independence and preparing for their future. For example, Williams and Collins (1999) report that people in their sample with a first episode of schizophrenia were cognizant of the paradox of being young yet having no sense of the future. Peer groups also play a central role at this developmental stage as young people make the transition to adulthood (Coleman, 1980). In our study the participants with ES identified the importance of having supportive friends. The focus on making connections beyond the illness, as described by the participants with ES, may therefore be reflective of a developmental need to remain connected to peers in order to get on with life. The importance of peer-group interactions at this developmental stage may have resulted in a group discussion centred on peers and social relationships, to the exclusion of health-care providers, and may not necessarily be indicative of the importance, to individuals with ES, of relationships with health professionals.

The unique developmental needs of young people with ES are challenged by the highly stigmatizing nature of schizophrenia (Schulze & Angermeyer, 2002; Skinner, Berry, Griffith, & Byers, 1995) and the symptoms of the underlying disease (e.g., amotivation, social withdrawal), which can greatly inhibit social interaction. Thus, the strategies of moderating it, *pushing myself,* and making connections beyond the illness may have been the participants' way of responding to the unique social concerns posed by such a stigmatized illness. Similar findings are reported in the literature. For example, in a phenomenological study with 10 adults with schizophrenia, Walton (2000) found that participants made an effort to stay engaged with others despite the challenges they encountered in "living with others."

The course and treatment of chronic kidney disease are very different from those of schizophrenia. Whereas the symptoms associated with schizophrenia may be considered somewhat manageable or episodic, persons with CKD must deal with their illness and treatment 24 hours a day, 7 days a week. CKD requiring dialysis is "not just another chronic illness" (Sensky, 1993). The daily demands of dialysis treatment, the physical symptoms of CKD, and the complex medication and diet regimens demand that individuals on dialysis be illness managers. The

CKD participants in our study expressed a need to be vigilant in their interactions with the health-care team and to take charge of their own well-being. They identified the importance of being on top of things and "sticking up" for themselves. Other authors similarly report that the strategies used by individuals with CKD to manage their illness often involve managing relationships with the health-care team and managing the health-care system; they describe such strategies as "vigilant oversight of care," "active self-advocacy" (Braun Curtin & Mapes, 2001), and "trying to maintain control" (Eichel, 1986).

Despite the fundamental differences in the nature of their illnesses, both groups of participants described a will to move beyond their illness. While their strategies were necessarily illness-specific, in both cases the purpose of the strategies was to allow the person to strike a balance between addressing the demands of the illness and enjoying non-illness aspects of his or her life. This finding is consistent with Paterson's (2001) observation that individuals with chronic illness must learn to manage their illness in order to participate in valued non-illness activities: "the illness requires attention in order not the have to pay attention to it" (p. 24). While Paterson is reporting on results of studies in chronic physical illness, our findings suggest that this paradox may also apply to individuals with mental illness.

Further, the commonalities in the wish to *be my best self* revealed in both samples suggest that the self is central to illness adjustment and that maintaining a sense of self beyond the illness is not disease-specific. Other authors have described the centrality of the self to adjustment in chronic illness. For example, in a phenomenological study with eight people with various chronic conditions, Lindsey (1996) discovered the phenomenon of being healthy while living with a chronic illness. Health within illness as described by Lindsey's participants includes the themes "honouring the self" and "seeking and connecting with others." Consistent with our findings, Lindsey's participants described the importance of celebrating life by living it to the fullest. Lindsey's sample was focused in nature, yet this conceptualization is consistent with all of our participants' descriptions of the importance of moving beyond the illness, thus demonstrating the significance of this aspiration for those living with either physical or mental illness.

Our analysis concerns two specific illnesses, schizophrenia and chronic kidney disease, and represents a first step in identifying strategies used to maintain a healthy sense of self in two populations. While the results highlight the strategies employed by two specific groups of individuals, they indicate that it may be important to attend to the person's sense of self regardless of the health condition. Future research on the impact of chronic physical or mental illness on the sense of self, specifically engulfment, could examine whether the themes of approaching illness, accommodating, and connecting identified in this analysis are meaningful for persons with other chronic conditions. Work in this area could eventually provide direction for the development of interventions to reinforce an individual's sense of self. Further, the observation that participants with ES did not discuss their interactions with health-care providers suggests the need for studies that explicitly examine these relationships. Such research is critically important, since it is well known that engagement of this young, vulnerable population in treatment is most challenging. Research to address the formation of therapeutic relationships may provide direction for nursing practice with this population.

Nurses are in a unique position to support individuals' strategies aimed at moving beyond their illness. Preliminary findings suggest that there may be opportunities for nurses to learn about the spectrum of strategies employed by people as they strive to cope with their illness. This knowledge may provide perspective for nurses in understanding the impact of living with chronic illness on individuals' self-definition and to support their efforts to move beyond their illness.

Limitations

The results of this analysis should be considered in the context of limitations underlying the methodologies used in the original studies. Focus group methodologies, while offering possibilities for rich dialogue, can be limited by the manner in which participants respond to each other; since no two groups are the same, the generalizability of the findings is necessarily restricted (Carey, 1995). Both samples included a relatively small number of participants who were willing to share their perspectives in a group setting; their views may not reflect the experiences of others with the same illness. Finally, the metaphors described in this paper are only those that intersected; they therefore do not necessarily reflect all of the themes identified in the two samples.

Conclusions

Above all else, chronic illness and its treatment challenge an individual's sense of who he or she is (Charmaz, 1983, 1991). Ultimately, an individual with a chronic illness requires a redefinition of the self (Biordi, 1995), one that incorporates and accommodates the illness in a positive and realistic light and avoids the risk of engulfment. It may be that an ability to redefine the self in a way that accommodates the illness while preserving the original self based on meaningful traits or values will allow persons with a chronic physical or mental illness to avoid the engulfing effects of the illness and to rebuild their lives. We encourage researchers in the field of chronic illness to broaden their scope of study to include participants across the full range of chronic illnesses and disabilities. Researchers and clinicians may then begin to address the stigma that is endured by individuals living with mental illness, with the understanding that the will to move beyond illness and disability is truly a human phenomenon.

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Résumé

Profil sur six mois de personnes âgées coordonnées recevant des services en milieu communautaire

Cecily Bierlein, Heather Hadjistavropoulos, Michelle Bourgault-Fagnou et Mark Sagan

Cette étude visait à évaluer les besoins de clients âgés coordonnés recevant des services de santé communautaire par l'examen des changements survenus dans l'état cognitif, l'état de santé physique et mentale, le soutien social, le risque de placement en établissement, et l'utilisation des services sur six mois, de l'accueil initial jusqu'aux soins à domicile. Elle a également comporté l'examen d'indicateurs prévisionnels importants des soins de santé professionnels et des soins à domicile, ainsi que du recours aux urgences et des journées d'hospitalisation. Des entrevues dirigées ont été menées auprès de 234 clients au moment de l'orientation; des entrevues de suivi ont été menées auprès de 179 de ces clients après une coordination de cas de six mois. Selon les résultats, une amélioration de la santé physique et mentale a été notée, tandis que l'état cognitif est demeuré stable. Bien que l'interaction sociale et le soutien instrumental aient diminué, le soutien subjectif est demeuré stable. Le risque de placement en établissement a diminué. Les services les plus fréquemment utilisés ont été l'ergothérapie, les soins infirmiers et l'aide familiale. Le barème de risque de placement en établissement a constitué le meilleur indicateur prévisionnel des soins professionnels et des soins de soutien à domicile. Les besoins de cette population de personnes âgées ont changé, même au cours d'une période aussi relativement courte que six mois. Il pourrait être justifié de mettre en place un système d'évaluation fréquente des besoins pour pouvoir maintenir des plans de services efficaces.

Mots clés : Personnes âgées, coordination de cas, état de santé, risque de placement en établissement, utilisation de services

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A Six-Month Profile of Community Case Coordinated Older Adults

**Cecily Bierlein, Heather Hadjistavropoulos,
Michelle Bourgault-Fagnou, and Mark Sagan**

The purpose of this study was to assess the needs of older case coordinated clients receiving community health services, by examining changes in cognitive status, physical and mental health status, social support, risk for institutionalization, and service use over a 6-month period from initial intake into home care. Significant predictors of professional and supportive home care, as well as emergency room use and hospital days, were also examined. Standardized interviews were conducted with 234 clients at the time of referral; follow-up interviews were conducted with 179 of these clients after 6 months of case coordination. Results reveal that physical and mental health improved, while cognitive status remained stable. Although social interaction and instrumental support decreased, subjective support remained stable. Risk of institutionalization decreased. Occupational therapy, nursing, and homemaking were the most frequently used services. The best predictor of professional and supportive home care was a risk of institutionalization score. The needs of this older adult population changed even within the relatively short span of 6 months. Frequent review of needs in some form may be warranted in order to maintain effective service plans.

Keywords: Older adults, case coordination, health profile, risk of institutionalization, service use

The needs of older clients need to be examined and understood given that this population is growing and at risk for chronic illness and functional limitations (Lee, Kovner, Mezey, & Ko, 2001). With the trend towards reduced acute and long-term care (Shapiro, 2000), frequent monitoring of needs within this population is critical. Decision-makers, service providers, and case coordinators must understand the profiles of the clients they serve. Comprehensive aggregate information collected from clients can provide essential information for program planning and resource allocation. Diwan, Ivy, Merino, and Brower (2001), for instance, demonstrate how analysis of case-managed client characteristics can assist with understanding client needs and can inform case managers about required health-care resources. By reviewing clients in a home- and community-based services program, Diwan and colleagues identified a number of issues that predicted the need for intensive case management (e.g., dementia, non-compliance, poor informal caregiver health and mental health). This type of information, in turn, assisted with allocation of case manager time and expertise.

Different measures and approaches can be used to obtain a portrait of the needs of community care clients. The purpose of this study was to better understand this older case coordinated population through an exploration of the changes that occur in clients over a 6-month period and an examination of the best predictors of health service use. More specifically, we examined changes over time in physical and mental health status, cognitive status, availability of social support, risk of institutionalization, and predictors of use of professional and supportive home care, emergency room (ER) visits, and hospital days.

Few previous studies have addressed change in health status over a short period, such as 6 months, within this older population. This is a unique group of clients, who are typically assigned to case coordinators because they require multiple community health services that are expected to last for an extended period and because they are believed to be at more than minimal risk for institutionalization. Reassessment of the need for case coordination and home care typically takes place on a case-by-case basis — whenever there is a significant change in the client's status — and services and resources are discontinued or intensified as required. A better understanding of trends among case coordinated clients has the potential to result in useful information for coordinators and managers who are attempting to plan and anticipate health-care needs and resources.

Change in Health Measures over Time

It is widely known that a proportion of seniors experience some change in cognitive function as they age (Huppert, 1994). Relatively few studies, however, have examined how cognitive function changes over a relatively short period, such as 6 months, especially in a vulnerable patient group (Brayne, Gill, Paykel, Huppert, & O'Connor, 1995). In order to measure real decline, repeat measures of cognition, using tests sensitive to change, must be administered on more than one occasion so that change between interviews can be recorded (Brayne et al., 1995). Brayne and colleagues (1995) found a median drop of one point in the Mini-Mental State Examination (MMSE) over a period of 2.4 years.

Both physical and emotional functioning are also important measures, as they are essential to maintaining independence (Cress et al., 1995). Many studies have addressed changes in physical health by analyzing activities of daily living (ADL) and instrumental activities of daily living (IADL) over time (e.g., Han, 2002). Others have used measures of self-reported health such as the Short Form-36 (SF-36; Wolinksy, Wan, &

Tierney, 1998), finding both improvements and decline over a 1-year period in subscales for a sample of adults (aged 50 to 99) at risk for acute deterioration in their clinical condition. Measurements of emotional health usually address levels of depression. Bruce and colleagues (2002) report that 13.5% of elderly home care clients exhibited Major Depressive Disorder (MDD). Raue and colleagues (2003), in publishing follow-up data to those presented by Bruce and colleagues (2002), report that 42% of the participants who met MDD criteria on initial interview continued to do so at follow-up.

Because social support plays such a large role in how clients adapt to the difficulties of aging (Martire, Schulz, Mittelmark, & Newsom, 1999), it is important for us to understand the changes that occur in these supportive relationships even over a short period. Martire and colleagues observed a significant average increase in tangible support over a 5-year period as well as the perception that one had individuals to talk to when needed, but no significant changes in contacts with family or close friends. Van Tilburg (1998) noted that instrumental support (degree of help from others) and emotional support increased for older respondents over several years.

Risk profiles relating to a client's risk for institutionalization can also provide helpful information about health changes (Steeman, Abraham, & Godderis, 1997). Our literature review, however, revealed no studies measuring a change in risk of institutionalization in community-dwelling seniors receiving case coordination services.

Previous research shows that the above variables, along with demographic variables, can distinguish between high and low users of health services. In a retrospective study of home care use over a 3-month period, Stoddart, Whitley, Harvey, and Sharp (2002) found that increasing age and unmarried status (separated/divorced, widowed, single), reduced physical functioning, poor emotional health, and cognitive impairment were associated with greater use of home care. In a cross-sectional study, Tennstedt, Sullivan, McKinlay, and D'Agostino (1990) found certain social factors, such as living alone, to be associated with greater use of home care. In terms of acute care, again using cross-sectional data, high users of acute health services (e.g., hospital admissions and ER visits) were more likely to have lower social support, poor self-rated health, and greater functional dependency. While some studies such as those described above have researched service use, the studies have not been prospective in nature.

The purpose of the present study was to better understand the needs of older case coordinated clients receiving community health services, by examining changes in cognitive status, physical and mental health status, social support, risk for institutionalization, and service use over a 6-

month period beginning at initial intake into home care. We hypothesized that over the 6 months clients would experience improvements in physical and mental health status, cognitive status, and risk of institutionalization, and would show decreased need for social support. The study was not designed to attribute changes in health status to case management alone, as this would require the random assignment of participants to either a control group or a case management group, which is not feasible with this population. The purpose, rather, was to gain a better understanding of the degree of change that occurs over time, as well as to examine predictors of service use over a 6-month period. We hypothesized that demographics (older age, unmarried status), health (reduced physical, mental, cognitive health; higher risk for institutionalization), and social variables (lower subjective support, instrumental support, social interaction) would predict increased hours of professional and supportive home care, number of ER admissions, and hospital days.

Design and Methods

The study was approved by the research ethics boards of the University of Regina and the Regina Qu'Appelle Health Region. Data were collected from 234 people (of 527 referrals) over the age of 65 referred consecutively for community case coordination of health services in the city of Regina, Saskatchewan, Canada, over a period of 8 months. Clients were eligible for this service if they were expected to need multiple community health services for more than 1 month, were considered at risk for institutionalization, and were not receiving palliative care.

After giving their consent, the participants were interviewed by a research assistant in their home an average of 12 days after starting home care. Most participants (n = 140) also took part in a follow-up interview 6 months later. In some cases this second interview was held before the end of 6 months, at the time of termination of services (n = 39). A total of 55 participants (23% of the sample) did not have a follow-up interview: six had received less than 1 month of care, six had moved out of the health region, 12 had died, four had transferred to palliative care, and 27 (11.5%) refused to participate. During both interviews, the participants were asked a variety of questions regarding their cognitive status, emotional status, physical health, and social support (the measures are described below). In addition to demographic and clinical data, information was obtained (with the participant's consent) from health region databases on use of home care, hospital admissions, long-term-care admissions, and related community long-term care over the 6-month period.

Mini-Mental State Examination

The MMSE (Folstein, Folstein, & McHugh, 1975) consists of 30 items measuring factors such as orientation to time and place, recall, and visuospatial construction, with scores ranging from 0 to 30 (Folstein, Robins, & Helzer, 1983). The normal range of scores on the MMSE for persons aged 65 and over is 22 to 28 (Crum, Anthony, Bassett, & Folstein, 1993). The MMSE has been widely used in longitudinal studies and clinical trials to track cognitive change (Brayne et al., 1995; Brayne et al., 1999). There is evidence that the MMSE has good test-retest and interrater reliability and a high degree of internal consistency (Tombaugh & McIntyre, 1992).

Short Form-8

The SF-8 (Ware, Kosinski, Dewey, & Gandek, 2001) is an eight-item version of the Short Form-36 (SF-36), which yields a comparable eight-dimension health profile and comparable estimates of summary scores for the physical and mental components of health. The instrument has good internal consistency, good test-retest and interrater reliability, and known groups validity (Ware et al.). It has been used to measure change in health status over time (Hemingway, Stafford, Stansfield, Shipley, & Marmot, 1997).

Duke Social Support Index: Abbreviated

The DSSI (Hughes, Blazer, & Hybels, 1990) consists of 23 items that measure three major dimensions of social support: social interaction, subjective support, and instrumental support (Koenig et al, 1993). Abbreviated versions have been found to have good test-retest and interrater reliability as well as construct validity (Goodger, Byles, Higganbotham, & Mishra, 1999) and concurrent validity (Goodger et al.; Koenig et al., 1993). The DSSI has been used to measure change in social support over time (Lynch et al., 1999).

Regina Risk of Institutionalization Tool

The RRIT (Neville, 2001) is a 23-item screening tool used primarily as an aid in assessing risk of institutionalization and/or utilization of health services. Points are assigned based on the presence of attributes known to be associated with risk of institutionalization. Previous research has indicated that the RRIT has good interrater reliability, test-retest reliability, and predictive validity (Gillis, Parsons, Neville, & Stein, 2004; Hadjistavropoulos, Bierlein, Neville, White, & Sagan, in press). The RRIT is divided into five risk categories — Minimal, Low, Some, At, and High — with scores ranging from 0 to 54.

Table 1 *Repeated Measures ANOVA Examining Changes in Scores from Time 1 to Time 2*

Measure	Range	Time 1 M	 SD	Time 2 M	 SD	F	Scores Obtained in Other Samples M (SD)
MMSE^a	8–30	25.09	4.38	24.99	5.01	.17	22.00–28.00^1
PCS-8^b	12.14–62.18	34.47	11.55	38.89	11.11	19.19**	45.46–47.13 (9.75–9.97)^2
MCS-8^b	13.12–65.80	47.35	11.10	51.11	8.71	18.95**	51.98–52.33 (7.95–8.91)^2
DSSI social interaction^c	4–12	8.17	1.66	7.91	1.62	4.53*	6.30 (2.69)^3
DSSI subjective support^d	10–21	18.58	2.24	18.60	2.54	.02	10.30 (2.50)^3
DSSI instrumental support^e	13–24	21.25	1.77	20.72	2.18	10.48***	26.10 (2.70)^3
RRIT^f	0–32	14.70	4.50	13.99	5.69	4.95*	———

$^a n = 172$. $^b n = 170$. $^c n = 178$. $^d n = 177$. $^e n = 176$. $^f n = 179$.

$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$

[1] Crum et al. (1993). [2] Ware et al. (2001). [3] Hughes et al. (1990).

Note: Numbers vary due to missing data on some measures. Higher scores on a measure are indicative of a better or more positive score, with the exception of the RRIT. *p* based on repeated measures ANOVA.

Service Use

Units of service for home care refers to time used in 1-hour increments, whereas units of service for long-term care and hospitalization refers to days used.

Data Analysis

Descriptive statistics, including means and standard deviations, frequencies, and percentages, were computed for all variables studied. Repeated measures ANOVA was used to analyze the changes in physical and mental health status, cognitive status, risk of institutionalization, and social support over the 6-month period. Correlations (and *t* tests where appropriate) were calculated to examine the relationships between client background variables (age, sex, education, marital status) and the measures employed in this study at the first interview. Multiple regression analysis was used to examine predictors of home care use (professional and support services) as well as ER admissions and days of hospitalization.

Results

Preliminary Data Analysis

The average age of participants was 80 years (*SD* = 7.38) and there was a higher percentage of women (65%) than men. Of the 234 participants interviewed at time 1, 48% were widowed, 40% married or living common law, 6% single, and 5% separated/divorced. Over half (55%) of the participants reported less than high school education. Most participants (86%) lived at home, although the percentage dropped slightly (to 77%) by the second interview. The majority of participants (84%) exhibited stable support, while 16% reported unstable or no significant support.

In total, 55 clients (23%) did not take part in the second interview. To determine whether our sample at time 2 was different from that at time 1, chi-square and *t* tests were used to examine differences between the participants and non-participants in the second interview. The two groups did not differ significantly on any of the variables.

Change in Cognitive Status, Physical and Mental Health Status, Social Support, and Risk of Institutionalization

Repeated measures ANOVA was used to examine changes in cognitive status, physical and mental health status, social support, and risk of institutionalization during the 6-month period (Table 1). Cognitive status scores (MMSE) at the first interview were not significantly different from those at the second interview (F (1, 172) = .17, p = .68), with a mean change of -.01. At both interviews, most participants scored in a range indicating few cognitive difficulties (24–30) and had scores comparable to those of others their age (Crum et al., 1993). Approximately 22% of participants scored below 24 points at the first and second interview, indicating possible cognitive decline.

In contrast to MMSE scores, participants showed improved scores, from the first interview to the second, on the SF-8 on the subscales for both physical health ($F\ (1, 169) = 19.19, p < .001$) and mental health ($F\ (1, 169) = 18.95, p < .001$). At the first interview, over half of the participants (57.3%) scored in the poor physical health range (35 or less), with average scores (M = 34.47, *SD* = 11.55) significantly below the norms for their age group (M = 45.46–47.13, *SD* = 9.75–9.97; Ware et al., 2001). By the second interview, only 35% scored in the poor physical health range and the overall mean of 38.89 (*SD* = 11.11) was closer to the age-adjusted norm. At the first interview, about one third of participants (31%) scored in the poor mental health range (43 or less), with average scores (M = 47.35, *SD* = 11.10) significantly below the norms for their age group (M = 51.98–52.33, *SD* = 7.95–8.91; Ware et al.). By the second interview, however, only 18% scored in the poor mental health range and mental health scores were improved (M = 51.11, *SD* = 8.71), becoming similar to the norms for their age (Ware et al.).

Measures for social support showed a statistically significant decrease in the mean score for social interaction ($F\ (1, 177) = 4.53, p < .04$) and instrumental support ($F\ (1, 175) = 10.48, p < .001$), indicating that social interaction and instrumental support decreased over the 6 months. However, subjective support (perception of support) did not significantly change ($F\ (1, 176) = .02, p = .88$) during the same period.

Risk of institutionalization (RRIT) significantly decreased, on average, by the 6-month interview ($F\ (1, 179) = 4.95, p < .03$). However, case-by-case analysis for the period revealed that 21% of the participants advanced to a higher risk category, 54% stayed in the same risk category, and 25% went into a lower risk category. The majority remained in the low and some risk categories at both interviews.

Correlations (and *t* tests where appropriate) were calculated to examine the relationship among client background variables (age, sex, education, marital status) and the scores obtained on measures at the first interview. Due to the number of correlations calculated, a Bonferroni correction was employed, such that *p* was set at .002 to ensure a conservative approach to interpretation. Most of the health measures were not significantly correlated with participant background variables, although a few significant relationships were found. Specifically, education level ($r = .30, n = 227, p < .001$) was significantly correlated with cognitive status at the first interview, indicating higher cognitive status in those participants with higher education levels. Sex (*t* (228) = -84.42, $p < .001$) was related to cognitive status as women exhibited higher cognitive scores than men (M = 25.82, *SD* = 3.91 versus M = 23.63, *SD* = 5.01). Sex was also related to social support (Duke Social Interaction Subscale *t* (234) = -72.25, $p <.001$, Duke Subjective Support Subscale *t* (232) = -127.00, $p <.001$). Women reported higher social interaction (M = 8.46, *SD* = 1.52 versus M = 7.65, *SD* = 1.73) and slightly higher subjective support scores than men (M = 18.89, *SD* = 2.02 versus M = 18.11, *SD* = 2.39).

Service Use

Table 2 includes units of varying service use over the 6-month period for home care, long-term care, and hospitalizations for all 234 participants; since these data were available through health region administrative databases, data for all participants were available. The most frequently used home care services were occupational therapy (68%), which typically involved an assessment of the home along with recommendations for improving safety and activities, nursing (41%), and homemaking (40%). However, the largest average numbers of hours used over the 6 months were for homemaking (31.65 hours, $n = 94$) and nursing (19.84 hours, $n = 38$). Use of services was greatest in the first month and then stabilized over the 6 months, with the exception of an increase in homemaking and a decrease in physical therapy. Only a small number of long-term-care programs were used, with convalescent beds being used most frequently (9%), averaging 31 days per admission. About 26% of participants were hospitalized at some time over the 6 months, with an average stay of 23 days (*SD* = 21.92). Further analysis of the hospital days revealed that 34% of those hospitalized were waiting for long-term-care beds, which can inflate lengths of stay unrelated to medical status. Twenty-seven percent of participants accessed the ER at some point during the 6 months.

Regression was used to examine whether demographics (age, marital status, sex, education), health (physical, mental, cognitive health status, risk for institutionalization), and social variables (subjective support, instrumental support, social interaction) predicted hours of professional home care, hours of supportive home care, number of ER admissions, and number of hospital days. We conducted four regression analyses; in each case all variables were entered and examined for their ability to uniquely predict service use while controlling for the other variables (see Table 3).

The results show that the variables together contributed significantly to the prediction of supportive home care: F (10, 212) = 5.35, $p = .0001$, $R^2 = .45$. In particular, however, the RRIT uniquely predicted the amount of supportive home care: $t = 4.14$, $p = .0001$ (*Beta* = .33).

Table 2 ***Service Use***

Service	**% Who Used Service**	**Mean over 6 Months**	***SD***
Home Care			
All service units (hours)	86.3	28.64	42.98
Professional home care (hours)*	84.2	13.33	16.43
Supportive home care (hours)**	41.5	31.81	44.48
Nursing (hours)	41.0	19.84	22.75
Physical therapy (hours)	16.2	7.72	7.32
Occupational therapy (hours)	68.8	2.83	2.27
Social work (hours)	7.3	4.59	4.31
Intravenous therapy (hours)	.4	39.50	—
Homemaking (hours)	40.2	31.65	44.82
Community support (hours)	4.7	5.05	3.16
Volunteer service (hours)	1.3	16.50	23.88
Meals (hours)	6.4	43.87	27.84
Laboratory (hours)	12.5	3.74	3.11
Long-Term Care			
Respite approvals	9.83	1.09	.29
Respite days used	3.42	15.50	8.26
Convalescent bed days	8.55	30.45	13.90
Quick response placements	6.84	1.19	.40
Quick response bed days used	6.84	14.06	10.33
Hospital/ER			
Hospital admissions	25.64	1.50	.72
Hospital days	25.64	23.42	21.92
ER visits	27.35	1.70	1.09
ER days	27.35	1.89	1.26

* Nursing, occupational therapy, physical therapy, social work, intravenous therapy.

** Home-health aide, community support, volunteer services.

Note: Data on use of home care, long-term care, hospital, and ER were available for all 234 clients, as consent was obtained to access this information from health region administrative databases.

Table 3 ***Predictors of Supportive and Professional Home Care and ER Visits***

Service	**β**	***t***	***p***
Supportive Home Care			
Regina Risk for Institutionalization	.33	4.14	.0001
Professional Home Care			
Regina Risk for Institutionalization	.25	3.14	.002
ER Visits			
Instrumental support	–.18	–2.51	.01

Similar results were obtained when predicting hours of professional home care, but much less variance was explained: F (10, 212) = 1.85, $p = .05$, $R^2 = .08$. Again, the RRIT was found to be the best predictor of amount of professional home care: $t = 3.14$, $p = .002$ (*Beta* = .25). Finally, while the variables did not significantly predict number of days in hospital, they predicted number of ER visits: F (10, 212) = 1.91, $p = .05$, $R^2 = .08$. In this case, however, it was found that lower perceptions of instrumental support uniquely predicted ER use: $t = -2.51$, $p = .01$ (*Beta* = –.18).

Discussion

Although case coordination of seniors requiring multiple community health services is increasingly common, the needs of these clients over a short period are not well understood. This limitation in knowledge acts as a barrier to our ability to anticipate the needs of these clients. The results of the present study suggest that change in physical and mental health can occur over a relatively short period among older clients receiving community case coordinated services. On average, the community seniors as a group had significantly improved scores over 6 months in physical and mental health status.

In contrast to physical and mental health, cognitive status remained stable, although approximately one quarter of participants were experiencing cognitive difficulties and were potentially at risk for developing dementia (Braekus, Laake, & Engedal, 1995). Overall, however, cognitive decline was not observed, and this finding is consistent with published results showing that clients show very slow cognitive decline over time (Brayne et al, 1995).

Clients' subjective perception of the support they received from relatives or friends did not change over the 6 months, reflecting previous findings on stability of family support over time (Martire et al., 1999). As hypothesized, indicators of amount of social interaction and instrumental support declined. This may indicate that although social support and interactions declined, the level of social support was still perceived by clients to be sufficient. The decline in social interaction and instrumental support is possibly explained by both an average increase in health status (e.g., less support is needed) and community health services taking the place of informal social network supports.

Risk of institutionalization slightly decreased, on average, over the 6 months. Of particular note is the fact that the risk category distributions for this population were skewed towards the low and some risk categories. This distribution is consistent with observations that case coordination should be offered to individuals who are at low to some risk of institutionalization.

Compared to all services provided to clients, a large amount of homemaking and nursing care was required over the 6-month period, with homemaking being the greatest need. A low number of long-term-care programs were used for these new referrals to case coordination, which is consistent with their level of risk, as noted above.

The findings of the present study are not free from limitations. Because the sample consisted of seniors who received community case coordination, the results apply only to this client group and not to the general population of seniors. In addition, the assessment of mental health could have been improved with a more thorough measure of mental health status and/or depression (e.g., Sickness Impact Profile or with a diagnostic interview). Although the SF-8 health questionnaire is a widely employed tool for measuring different dimensions of health (and like other self-report tools is an efficient and convenient way to acquire knowledge about symptoms; Molarius & Janson, 2002), a more comprehensive tool may have elicited further information.

Even though most clients maintained stability over the 6 months, the variability in this population cannot be overlooked. During the study, 5% of participants died and 2% were transferred to palliative care. Although the majority of participants improved in health status, a small proportion of the sample that completed both interviews declined over the 6-month period. For example, 5% had a decrease of five points or more in their MMSE score and 31% had a decrease of 10 points (one standard deviation) or more in their SF-8 physical health score. Additionally, 27% had a decrease of 10 points (one standard deviation) or more in their mental health score and 21% had an increase in their risk of institutionalization. This information is important, because not all clients improve in health status and the ability to anticipate trends can serve to ensure that program planners are aware of diversity among clients. Interestingly, the best predictor of supportive and professional home care over the 6-month period was the risk for institutionalization score, and the best predictor of number of ER visits was client perception of instrumental social support when services first began.

Implications

Given the significant improvements in the participants' physical and mental health status over a relatively short period, it is important that case coordinators give consideration to frequent service reviews during the initial 6 months of care. Many clients will not necessarily need the same degree of services after 6 months, due to either stabilization of their condition or, conversely, a change in health or functional status warranting the use of additional resources. When case coordinators act as brokers of services, it is imperative that those providing services stay in touch with coordinators, to ensure that services continue to be appropriate. The findings of this study led to the development of a Professional Service Feedback Form (see Appendix 1), which is now being sent by providers to coordinators every 3 months (or more frequently in the case of specified triggers such as completion of care plan, ER visit, or hospital admission, or if there is a change in behavioural, cognitive, emotional, social, or functional status of sufficient concern to warrant the involvement of a coordinator). This allows for improved yet efficient monitoring of clients that is need-based rather than time-based.

The results show that a significant number of clients improved in health status and may have been in a position to have services reduced. However, a large number (31%) declined in health status, warranting an increase in services. Additional attention could be directed towards those clients whose health status declines, in order to target resources to their care. Program planners should also note that most new referrals to community case coordination fell within the low and some risk of institutionalization categories and were maintained in the community with few admissions to long-term care over the 6 months. Higher risk for institutionalization and lower instrumental social support are particularly promising as predictors of service needs and may prove to be useful indicators for case coordinators to gauge when attempting to anticipate client needs.

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Appendix 1 *Professional Service Provider Review Form*

Client Name	Client Number
Service Provider Name	Date Sent
Coordinator	Date Received

NURSING

CURRENT CONDITION ____________________

NEW ISSUES ____________________

CURRENT SERVICES / TASKS ____________________

☐ General Monitoring ____________________

☐ Hypertension Monitoring ____________________

☐ Med Monitoring / IV therapy ____________________

☐ Pathway ____________________

☐ Catheter Change / Bladder Irrigation ____________________

☐ Diabetic Management ____________________

☐ Dressing Change ____________________

☐ Respite ____________________

☐ Other ____________________

VISITS Frequency ____________ Duration ____________

PLAN / GOAL ☐ Maintain Current Service ☐ Increase Independence

☐ Projected Discharge ____________

GENERAL STATUS

☐ Improving ☐ Deteriorating ☐ No Change

COMMENTS AND CONCERNS ____________________

THERAPIES

CURRENT CONDITION ____________________

NEW ISSUES ____________________

CURRENT SERVICES / TASKS ____________________

☐ Bath Assessment ____________________

☐ Chest Physiotherapy ____________________

☐ Equipment ____________________

☐ Exercise program ____________________

☐ Mobility ____________________

☐ Other ____________________

VISITS Frequency ____________ Duration ____________

PLAN / GOAL ☐ Maintain Current Service ☐ Increase Independence

☐ Projected Discharge ____________

GENERAL STATUS

☐ Improving ☐ Deteriorating ☐ No Change

COMMENTS AND CONCERNS ____________________

SOCIAL WORK

CURRENT CONDITION ____________________

NEW ISSUES ____________________

CURRENT SERVICES / TASKS ____________________

☐ Advocacy ____________________

☐ Counselling ____________________

☐ Financial ____________________

☐ Psycho Social Assessment ____________________

☐ Relocation ____________________

☐ Other ____________________

PLAN / GOAL ☐ Maintain Current Service ☐ Increase Independence

☐ Projected Discharge ____________

GENERAL STATUS

☐ Improving ☐ Deteriorating ☐ No Change

COMMENTS AND CONCERNS ____________________

Résumé

Les obstacles à la promotion de la santé axée sur la population : l'expérience des infirmières hygiénistes du Manitoba

Benita Cohen

Tout porte à croire qu'un ensemble de grands facteurs socio-environnementaux influent sur la santé de la population, ce qui nécessite l'adoption de stratégies de promotion de la santé axées sur cette dernière. L'auteure rapporte les conclusions d'une étude sur les perceptions des infirmières hygiénistes à l'égard de leur travail dans la province canadienne du Manitoba, notamment en ce qui concerne les obstacles à la promotion de la santé axée sur la population. L'étude repose sur un plan expérimental descriptif et exploratoire; on a mené des entrevues qualitatives auprès de 24 infirmières hygiénistes, qui travaillent sous trois autorités sanitaires présentant chacune des caractéristiques géographiques et démographiques distinctes. On a défini trois catégories d'obstacles à la promotion de la santé axée sur la population : obstacles d'ordre individuel, liés aux infirmières; obstacles d'ordre organisationnel (culture, politiques, processus); obstacles d'ordre extra-organisationnel, concernant l'ensemble d'une localité ou de la province. Dans chacun des trois sites étudiés, on a constaté un écart entre la théorie, voulant que la promotion axée sur la santé de la population constitue l'essence même du travail des infirmières hygiénistes, et l'expérience de celles-ci. L'auteure conclut que seul un effort concerté permettra de lever ces obstacles, pour faire en sorte que les infirmières hygiénistes du Manitoba puissent jouer un rôle déterminant dans la création d'un système de santé qui investit réellement dans la santé de la population.

Mots clés : Infirmières hygiénistes, promotion de la santé, obstacles, Manitoba, Canada

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Barriers to Population-Focused Health Promotion: The Experience of Public Health Nurses in the Province of Manitoba

Benita Cohen

There is growing evidence that population health is influenced by broad socio-environmental factors that require population-focused health promotion strategies. The author reports on a study of the perspectives of public health nurses (PHNs) on the nature of their health promotion practice in the Canadian province of Manitoba, highlighting their perceptions about barriers to population-focused health promotion. A descriptive, exploratory research design was used to conduct standardized open-ended interviews with 24 PHNs in 3 geographically and demographically diverse health authorities. There were remarkable similarities in PHNs' perceptions about their practice. Three categories of barrier to population-focused health promotion were identified: barriers at the level of individual PHNs; organizational barriers (culture, policies, processes); and extra-organizational barriers at the level of the community or province. The results point to a gap between the theory that population-focused health promotion is at the heart of PHN practice and the experience of PHNs at the 3 sites. A concerted effort to address the barriers is needed so that PHNs in Manitoba can play a leadership role in creating a health-care system that truly invests in population health.

Keywords: Public health nursing, health promotion, population level, barriers, Manitoba, Canada

Introduction

In 1997 the health ministry in the province of Manitoba, Canada, developed a framework for health planning that recommended a shift in focus from a *medical*-care system based on short-term action with sick individuals to a *health*-care system emphasizing health promotion among groups and populations (Manitoba Health, 1997). One year later a health ministry document outlining the role of the public health nurse (PHN) within the newly established Regional Health Authorities noted that "PHNs provide the leadership in health promotion" (Manitoba Health, 1998, p. 9). This suggests that PHNs, the largest group of community health nursing practitioners in Manitoba, should be in the forefront of population-focused efforts to create a health system that truly invests in health. Does the reality of PHNs' practice in Manitoba fit with the rhetoric? This is the question that will be explored in this paper.

The Discourse on the Health Promotion Practice of PHNs: Literature Review

There is mounting evidence that population health is influenced by broad socio-environmental factors that require population-focused health promotion strategies such as advocacy for healthy public policy, strengthening of community action, and the creation of supportive environments (Community Health Nurses Association of Canada [CHNAC], 2003; Raphael, 2004). A salient feature of the discourse on the health promotion practice of PHNs is the tension between two ideas, one articulated frequently in the theoretical literature and the other articulated primarily in empirical studies of PHNs' practice. The former is that the heart of PHNs' health promotion practice is a population focus (Anderson & McFarlane, 2000; Baldwin, O'Neill Conger, Abegglen, & Hill, 1998; Butterfield, 1997; McKnight & Van Dover, 1994; Norton, 1998; Williams, 1996) and the latter that nurses most commonly focus on promoting health at the individual and family level — *and feel most comfortable and competent when doing so* (Chalmers & Bramadat, 1996; Craig, 1991; O'Brien, 1994; Reutter & Ford, 1998).

The general preference of nurses for working with individuals has been attributed to an uncritical acceptance within nursing of the dominant societal ideology of individual responsibility for health, an ideology that is perpetuated by many of the popular nursing models and texts, by course content in nursing, and even by clinical placements in nursing curricula (Latter, 1998; O'Brien, 1994; Rush, 1997; Williams, 1989). Some authors argue that nurses historically have been shaped by society to be passive and non-confrontational (Chalmers & Kristjanson, 1989; Laffrey, 1989; Maben & MacLeod Clark, 1995). This could be an inhibiting factor in terms of nurses' involvement in social change activities such as community development (CD) and advocacy for policy change. The lack of well-developed collaborative skills and difficulty relinquishing professional control are additional barriers to effective community development work by PHNs (Chalmers & Bramadat, 1996).

One of the barriers to population-focused health promotion is the organizational structures within which PHNs practise. Chalmers and Bramadat (1996) state that the public health agencies and community health centres that employ nurses may support the CD role to various degrees, in that articulated policies may be lacking or may not be backed up with adequate resources. In addition, few standards exist for the evaluation of nurses' CD work. There are other organizational barriers to population-focused practice: the non-participatory structures within which nurses work, and the process of role socialization within those structures (Chambers, Underwood, & Halbert, 1989; Williams, 1996); conceptual frameworks that are based on the individual and on observable and measurable behaviour, as well as the manner in which nurses' work is audited (e.g., numbers of patient and client contacts as a measure of performance) (Latter, 1998); and the inability of community nursing administrators to serve as role models for frontline nurses because they have never developed the skills necessary for population-focused nursing (Chalmers & Kristajanson, 1989).

Chalmers and Bramadat (1996) note that some barriers to population-focused health promotion originate outside of the health organizations in which PHNs practise. For example, there may be resistance from sections of the community to particular CD initiatives that are not perceived to meet their interests, including initiatives that challenge established gender roles. Demand for government-mandated programs such as postpartum visiting and communicable disease follow-up is another factor that may preclude CD work.

Whatever the reason or reasons for the phenomenon, at least one nursing educator has concluded that, right or wrong, and in spite of rhetoric to the contrary, in reality the nurse's role is and will likely continue to be that of health educator with a focus on individual-level change, primarily behavioural (Norton, 1998).

Another salient feature of the literature is that there are relatively few first-person accounts of what frontline PHNs view as the main challenges to their health-promoting practice, especially in the context of the Canadian health-care system. Several Canadian studies have explored the perceptions of community and public health nurses about their role (Craig, 1991; Leipert, 1996; Meagher-Stewart, 2001; Rafael, 1999; Reutter & Ford, 1998), but only a few have specifically explored PHNs' perceptions regarding barriers to population-focused practice. In one of the earliest such studies, Craig documented the experience of nurses in two Ontario public health units following the implementation of a new (1989) public health policy requiring practitioners to develop, implement, and evaluate programs and services using a CD approach. The findings demonstrated a strong sense of loss among PHNs about giving up traditional practice, considerable confusion about the concept of community development, a lack of confidence in the knowledge and skills required, and fear that individuals and families with complex needs would no longer be served.

In Reutter and Ford's (1996) study of the perceptions of 28 PHNs in the province of Alberta regarding their practice, the nurses admitted feeling powerless to bring about changes that might benefit their socially and economically disadvantaged clients, due to a lack of the skills and resources necessary to address the underlying social problems. Barriers to their population-focused health promotion practice included insufficient time for planning and implementing innovative programs in the community; the organizational constraint of having to provide mandated programs, which prevented them from engaging in CD work and advocacy for healthy public policy (which most PHNs viewed as part of their expanded role); uncertainty about their own job security and the future direction of public health nursing, which negatively affected their commitment of time and energy for new initiatives; and a perception that other professionals and the general public did not fully grasp what their role was, associating PHNs with concrete tasks such as immunization but not with broader functions such as CD work where the outcome is not immediately apparent.

Meagher-Stewart (2001) explored the discourse of 13 PHNs in a large urban public health department in southern Ontario regarding their CD practice with women in high-risk environments. A predominant concern was the gap between the rhetoric about CD in departmental policies along with verbal support by nurse managers and the reality, which was characterized by a lack of resources and the absence of valuing of the PHNs' CD practice.

Lastly, MacDonald and Schoenfeld (2003) surveyed Saskatchewan PHNs regarding their ability to function in an expanded role. The nurses stated that they lacked the time, flexibility, autonomy, knowledge, and skills to implement population-focused strategies — in spite of the fact that many of them acknowledged that those strategies would best address the needs of the population that they served.

In summary, a review of the literature suggests that there are several types of barrier preventing PHNs from feeling comfortable and confident engaging in community- or population-focused health promotion. However, the literature addressing this issue is largely theoretical in nature. The study reported here contributes to our knowledge by specifically exploring the views of PHNs regarding barriers to their engaging in population-focused health promotion within the context of an integrated, regionalized health-care system in Manitoba.

Research Objective

This study was part of a larger research project exploring the discourse on health promotion within selected Regional Health Authorities (RHAs) in Manitoba. Key stakeholders in governance, administrative, and public health practitioner positions were asked to describe the climate for, content of, and barriers to health promotion within their RHAs. This paper reports on the discourse among PHNs, with a focus on perceived barriers to their population-focused health promotion practice.

Methods

A descriptive, exploratory design was used. According to Marshall and Rossman (1989), the purpose of an exploratory study is to investigate little-understood phenomena, while the purpose of a descriptive study is to document the phenomenon of interest. An exploratory design was chosen because the intention was to document the perceptions of PHNs in Manitoba RHAs regarding a phenomenon (the nature of their health promotion practice) about which little was known. Three geographically and demographically diverse RHAs were selected (a northern, primarily resource-based region with a large aboriginal population; a southern, primarily rural region with two prominent non-aboriginal cultural communities; and a small urban region with a sizeable aboriginal population). This allowed the researcher to determine which aspects of the discourse on health promotion were present in all three regions (in spite of their very different contexts) and which aspects were unique to each area.

The primary method of data collection during the phase of the study reported here was the standardized open-ended interview. All PHNs in the three regions were invited to participate. Twenty-four PHNs (80% of PHNs in each region) agreed to take part in an interview, which was conducted by the author. According to Patton (1990), a standardized open-ended interview consists of a set of questions carefully worded and arranged, with the intention of taking all respondents through a similar sequence and asking them the same questions using essentially the same words. Any clarifications, elaborations, or probing questions are written into the interview itself. The main advantage of this type of interview design is that it minimizes the potential for the interviewer to pose questions on a single topic in a different way with different respondents and thus to obtain more comprehensive data from some respondents than from others (Patton). The PHNs were asked about the organizational context of their health promotion practice, the nature of their health promotion practice, and the barriers to their engaging in population-focused health promotion activities. A small pilot test of the question guide was conducted in an RHA that was not part of this phase of the study and adjustments were made accordingly.

The interviews were audiotaped and transcribed verbatim. The transcript files were entered into a qualitative data management program

(ATLAS.ti) in order to facilitate analysis of the large volume of data, which was conducted by the author using "question analysis," a type of content analysis that is carried out via question number (Berg, 1998). Each transcript was read twice in order to identify and refine specific categories of information, or themes, for the three sites. Codes were used to indicate both the origin (individual, organizational, extra-organizational) of barriers to health promotion practice and the type of barrier (e.g., attitudes, educational background, funding, policies, processes). This method allowed for comparison of answers to similar questions within and between the three study sites. Answers or comments that were unclear or ambiguous were not included in the analysis.

Approval for the study was obtained from the Research Ethics Board at the University of Manitoba. While there is no risk of physical harm to participants in a study such as this, the issue of anonymity is an important one — especially since employees of the RHAs were being asked to express their opinions about organizational changes or issues related to their workplace. Every effort was made to protect the anonymity and security of participants. Although RHA administrators were aware that PHNs were eligible to participate in an interview, all comments are reported in a manner that protects individual identity. The participants were given the option of being interviewed at a location of their choice, such as away from the workplace.

Findings

In spite of three very different geographic and demographic contexts, there was remarkable similarity in the PHNs' perceptions about the climate for, nature of, and barriers to health promotion practice. For example, there was consensus across the sites that the discussion within the RHAs about the need to increase the emphasis on health promotion continued to be overshadowed by the priorities of the acute-care system and the need to respond to public demand for acute services. There was also consensus across the sites regarding the nature of PHNs' health promotion practice. In spite of the universal acknowledgement of the importance of population-focused health promotion, for the most part the PHNs' own practice was characterized by a strong focus on providing health information and emotional support to individuals and families, especially childbearing families.

The level of consensus across the three sites regarding the barriers to population-focused health promotion was especially noteworthy and will be the focus of the remainder of this paper. Three categories of barrier to population-focused health promotion were identified.

Barriers Originating at the Level of the PHN

PHNs at all three sites acknowledged that they were often more comfortable working with individuals on a one-to-one basis or with families than engaging in health promotion at the community or population level. They attributed their discomfort with the latter to individual personality traits, attitudes, and beliefs; their professional education; and a perceived lack of population-level health promotion skills. Each of these factors will be discussed below.

PHNs at all three sites stated that population-level health promotion strategies such as advocacy for healthy public policy (ADHPP) and community development (CD) require a certain personality type or maturity level. "I'm not a political person," "It's not my style," or "I'm a cautious person" were typical comments made by PHNs to explain their discomfort with ADHPP or CD work. Many PHNs stated that it was simply a matter of personal interest — that there is quite a bit of variety in nursing practice and everyone has his or her favourite areas of concentration.

PHNs at all three sites stated that there are still some nurses who view health promotion as primarily teaching people about healthy behaviour, who believe they know what is best for people, and who would have great difficulty giving up control if they were involved in CD work (although no respondents admitted to holding these views themselves). There also seemed to be a persistent view among PHNs that ADHPP might represent a conflict of interest due to their previous position as a government employee or that it might conflict with current RHA policy.

The majority of PHNs stated that resistance to engaging in health promotion strategies beyond the level of the individual was often due to lack of confidence and perceived lack of competence as a result of inexperience with this type of work. This was especially true for nurses who had just transferred from a hospital setting (a common situation in the northern RHA). The PHNs suggested that it was natural for these nurses to be more comfortable working on a one-to-one basis with individuals and families. CD work was something new and perhaps frightening for many of these nurses. "Sometimes there's safety in just doing what you've been doing...you're a little bit more out there and in the public eye and vulnerable when you're doing some of the community development [work]."

All but one of the PHNs stated that their nursing education program had prepared them to work primarily at the individual/family level. Although PHNs who had recently completed a nursing degree program felt they had theoretical knowledge about population-level strategies such as ADHPP and CD, they all believed they could learn more and very few stated that they had much practical experience with these strategies. Most frontline practitioners stated that if one is not involved with something on a regular basis, one will not feel comfortable doing it:

> *…the group dynamic skills you need, and the facilitation skills, are really very important. And I don't know if we have those. We're learning. We've had our workshops and we've practised. But it's kind of a scary place out there. I mean, you are in a position that people look to for knowledge and information and leadership. And you're saying to them, well, what would you like to do about that? How do you see that happening? …you have to be able to know how to work a group.*

Participants felt that, even when nurses see the value of engaging in population-level practice, there are differences of opinion regarding the amount of time that should be spent on this type of work versus individual-level work. Many frontline practitioners stated that they were reluctant to get involved in such initiatives because they had many other responsibilities. One PHN expressed this sentiment particularly eloquently:

> *I think that some of my co-workers at times resent or are fearful that they're being pulled away from field work and one-to-one situations.… A good example of that is if you're away at a meeting in the community all day…you're not available to that new mom who's home breastfeeding and maybe there's concern about whether the baby's getting enough milk, so the whole risk business of dehydration in newborns is an issue. How can you feel comfortable that you've covered and are still providing safe practice for your individual clients [when you're] undertaking these broader things at the same time? It's a juggling act. And some people aren't as prepared to juggle.*

Barriers Originating at the Level of the Organization

One set of barriers at this level related to organizational attitudes towards health promotion in general. PHNs at all three sites stated that staff in the acute and long-term-care sectors were reluctant to "buy into" the health promotion philosophy. The PHNs noted (sympathetically, for the most part) that facility-based direct-care providers were having enough difficulty coping with their roles as it stood without having to adjust to a whole new way of thinking. While there was general agreement among participants that staff in the acute and long-term-care sectors showed greater resistance to increasing the emphasis on health promotion, not all PHNs blamed the problem on their colleagues' mindset. There were

PHNs in each region who placed the blame at the top of the organization, criticizing their board of directors and senior administrators for "buying into" the need for more doctors and for lacking commitment to the idea of stepping up health promotion. One PHN stated that she thought her board was not ready to commit itself to a health promotion focus because this might require it to withdraw some other service.

PHNs in all regions expressed a belief that their supervisors viewed population-focused health promotion as something you do if you have time left over after finishing your "regular" work. Several participants stated that taking the time to make a presentation in the community or to attend a community meeting was not valued by their supervisors. PHNs in all regions also expressed concern that public health managers often lack the background and skills in health promotion needed to act as role models for frontline practitioners.

Participants in all regions commented on the lack of human resources available for adequate health promotion. In the northern RHA, participants said that the difficulty of recruiting and retaining qualified personnel in general, and a high turnover of community health and mental health staff in particular, posed unique challenges that drained energy and attention away from any form of health promotion. In the other two regions PHNs also mentioned staff shortages, especially in the area of community/public health. PHNs practising in outlying areas, especially in the north, pointed out that nurses are often requested to carry out many tasks beyond those included in their job description, leaving little time for health promotion. If the PHN was the only health professional in the area, then the demand for individual care increased. One nurse remarked, "You can't say to someone who walks into your office and needs help, 'Sorry, but this time is reserved for health promotion work'." In outlying areas of the northern region, this problem was compounded by the fact that PHNs were responsible for providing home care in addition to their public health duties. One PHN stated, "We're too busy dealing with all of these diabetics that are getting diagnosed, which prevents us from focusing on health promotion."

Another organizational barrier to population-focused health promotion mentioned at all three sites was a workload measurement system based on the number of individual client contacts. One PHN described the problem very succinctly:

> *I always have enjoyed community development work. But compared to the one-to-one type of involvement that we have with clients, it doesn't seem to have quite as much validity or something when you look at the time spent. And I say that because we realized that our ratio of nurses to population is one of the lowest in the province of all the health regions... We've*

> *been lobbying with our CEO and board members whoever we can to try to improve upon that. But one of the things they looked at were our daily stats forms. And actually, over the past year, they came to realize that our number of [individual] patient contacts, based on these statistical forms, had dropped quite substantially because we're doing more community development. But that was seen as a negative.*

Addition barriers identified were a lack of resources for both internal in-servicing and continuing education in the field of population-based health promotion and a dearth of opportunities for PHNs to share their experiences with population-focused work.

Extra-organizational Barriers

PHNs at all sites identified several extra-organizational factors that reinforced an individual/family-level focus at the expense of a community- or population-level one. One drain on human resources was cited by virtually every PHN in all three regions. This was the dramatic increase in the workload of frontline PHNs related to expansion of mandatory provincial public health programs, leaving less and less time for population-focused health promotion. Three contributing factors were mentioned by participants in all regions: the expansion of provincial immunization programs (especially the hepatitis B program for Grade 4 pupils); the introduction of the provincial Baby First program (requiring PHN assessment and supervision of home visitors); and a change in health policy resulting in early discharge from hospital of mothers and infants postpartum (requiring PHNs to make immediate, and more frequent, home visits, involving in-depth maternal-child physical assessments as well as health education). One PHN summed up the general frustration expressed by the participants: "They keep piling more and more things on the plate, but no one ever took anything away."

Several other extra-organizational barriers to population-focused health promotion were cited by nurses at all sites: the difficulty of engaging in an activity such as ADHPP in a relatively small community when one lives in the community and may know (or even be related to) those involved; public ignorance about the scope of the PHN role (e.g., failure to see that ADHPP and CD are valid activities for PHNs); the lack of public understanding about the broad determinants of health and the need to act on them; and the tendency for the public, the media, and politicians to focus exclusively on acute-care issues. One participant explained:

> *When we were out doing the community health needs assessment…we talked about the determinants of health, what they were and why we were doing the community health needs assessment. And you could tell,*

> *depending on what group you got to speak to, that they were not with it. Like, this terminology is news to them. It's just not where they're at. Where they're at is, why can't I have my MRI when I need it? Why did my mother have to wait 6 months or 10 months before she could have this done? Those are the kinds of questions that are asked, not whether or not Suzy Smith is out there doing prevention kinds of activities. So, until you get the population to start thinking that's where the money should go, it's not going to happen.*

Other issues brought up by nurses at all sites were lack of human and material resources, on the part of potential or actual community agency partners, needed to engage in collaborative work; the inability of some communities to engage in CD work due to a high degree of social dysfunction; and a dearth of potential leaders with whom to partner.

It is worth noting that PHNs at all sites mentioned the loss, following regionalization, of the traditional link to a centralized health promotion infrastructure that had provided them with support and resources. Although not a barrier to population-focused health promotion specifically, this change did cause the nurses to feel isolated with regard to their health promotion efforts.

Discussion

The experience of PHNs at the three Manitoba study sites does not bear out the claims in the literature that population-focused health promotion is at the heart of PHN practice. These nurses identified many of the individual, organizational, and extra-organizational barriers to engaging in population-focused health promotion that were found in the theoretical and empirical literature, as well as additional ones (e.g., specific challenges facing PHNs working in rural, northern, and isolated areas). A few of these barriers related to the specific context of the transformation to a regionalized, integrated health-care system (demands for acute-care services dominating the RHA agenda; loss of traditional links to a centralized, provincial health promotion infrastructure). However, most barriers appeared to be related more to individual practitioner attitudes, professional education, organizational infrastructure and culture, and extra-organizational constraints at the community and government levels. Very much in evidence at all three sites was the tension that runs through the literature between the idea that the heart of the health promotion practice of PHNs is a population focus and the idea that nurses most commonly focus on promoting health at the individual/family level — *and feel most comfortable and competent when doing so*. While lack of knowledge and skills for population-focused health promotion work was a factor in PHNs' greater involvement in individual-level health promotion, lack of time and flexibility (primarily related to increased demands for mandatory programs) and lack of organizational support were equally important. These findings support those cited in the literature and suggest that a focus on improving knowledge and skills for population-focused health promotion will not on its own be a sufficient strategy for building PHNs' capacity for engaging in this type of work.

One limitation of this study relates to the generalizability of the findings. Although the three study sites were selected to represent the geographic and demographic diversity of Manitoba RHAs, any commonalities found in these sites cannot be assumed to exist among PHNs practising in other Manitoba RHAs or in other jurisdictions. It must also be acknowledged that, in the period since data collection ended, some of the barriers identified by key informants may have been eliminated and new barriers may have arisen.

Nevertheless, the findings have important implications for PHN policy, practice, and research. The Community Health Nurses Association of Canada recently developed a set of *Canadian Community Health Nursing Standards of Practice* (CHNAC, 2003), which are expected to be met by each community health nurse after 2 years of experience. The *Standards* reflect a strong emphasis on population-focused community health nursing: support for collaborative interdisciplinary and intersectoral partnerships to address risks to community or population health; support for community action to influence policy change with respect to health; and use of a comprehensive mix of community-based and population-based strategies such as coalition-building, intersectoral partnerships, and networking to address issues of concern to groups or populations. Several Canadian studies exploring the perspectives of PHNs on their population-focused health promotion practice have reported similar findings, which points to a gap between theory and practice. Two questions in particular require further research: (1) What is a realistic expectation regarding PHNs' role in population-focused health promotion versus individual/family-focused health promotion? (2) How should we go about building capacity for PHNs' population-focused health promotion practice, at the level of both the nursing education system and the organizations in which PHNs are employed?

In conclusion, it has been suggested that nurses in general and PHNs in particular have a leadership role to play in health promotion (MacDonald, 2002; Manitoba Health, 1998). Individual/family-focused health promotion has traditionally been, and will likely continue to be, an important part of PHN practice, and it can serve as a basis for identifying issues that require further action at a community or population level (Diekemper, Smith-Battle, & Drake, 1999). However, PHNs in this Manitoba sample, as in other Canadian jurisdictions, have identified multiple barriers to population-focused health promotion, originating both within and outside of the health-care systems in which they work. Without a realistic assessment of the capacity of the public health system to truly invest in population-focused health promotion, and without a concerted effort to address the barriers to doing so, the noble goal of developing a health-care system that emphasizes health promotion among groups and populations will never be attainable and PHNs will never have an opportunity to play the leadership role in health promotion that has been envisioned for them.

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Résumé

Les incidents dans un contexte de psychiatrie légale : association des caractéristiques des patients et du personnel

Michael W. Decaire, Michel Bédard,
Julie Riendeau et Rylan Forrest

Les incidents liés aux patients sont d'un intérêt particulier pour les personnes qui travaillent avec les populations recevant des services de psychiatrie légale. Les témoignages suggèrent que la personnalité, le stress et l'épuisement professionnel du personnel infirmier permettent de prédire certains incidents. Cependant, la relation existant entre ces facteurs et les interactions personnel-patient et les incidents qui se produisent dans ces interactions n'a pas fait l'objet d'une étude approfondie. Les auteurs ont recueilli des données sur la nature des incidents survenus dans un service de médecine légale d'un hôpital psychiatrique pendant un an, ainsi que des données sur les caractéristiques des 13 membres du personnel. Ils ont trouvé que 10 % des patients étaient responsables de 58 % des incidents. Les patients souffrant de schizophrénie étaient ceux qui étaient les plus impliqués dans les incidents. La fréquence d'incidents non violents variait d'une équipe de soins infirmiers à l'autre d'une façon plus importante que ne peut l'expliquer le hasard. Il a également été constaté qu'il existait une relation entre les incidents et certaines caractéristiques du personnel. Ces résultats mettent en lumière la nécessité de faire de plus amples recherches sur les incidents qui se produisent dans les situations où les attributs des patients, ceux du personnel soignant et les facteurs environnementaux produisent des interactions complexes.

Mots clés : Psychiatrie, légal, établissements psychiatriques, personnel infirmier hospitalier, personne placée en établissement, incidents avec des patients

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Incidents in a Psychiatric Forensic Setting: Association with Patient and Staff Characteristics

Michael W. Decaire, Michel Bédard,
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Patient-related incidents are of particular concern for those working with forensic psychiatric populations. Evidence suggests that personality, stress, and burnout of nursing staff are predictive of incidents. However, the exact relationship of these factors with staff-patient interactions and the incidents that occur within these interactions have not been thoroughly explored. The authors collected data on the nature of incidents on a forensic unit within a psychiatric hospital over a 1-year period, as well as data on the characteristics of 13 staff members. They found that 10% of patients were responsible for 58% of the incidents. Patients with a diagnosis of schizophrenia were disproportionately involved in incidents. The frequency of non-violent incidents varied among nursing teams to an extent greater than that expected by chance. A relationship between incidents and some staff characteristics was also found. These results highlight the need for further research into the incidents that occur in situations where patient attributes, nurse attributes, and environmental factors produce complex interactions.

Keywords: Psychiatric, forensic, mental institutions, hospital nursing staff, institutionalized persons, patient incidents

Mental health facilities have clear concerns regarding the issue of patient-related incidents. Rates of aggression and violence, as well as the number of incidents per patient, have been increasing on psychiatric wards (Bond & Brimblecombe, 2003). For example, in an investigation of 1,144 incidents within a secure psychiatric facility, 61% were characterized as serious and 31% as life-threatening to either staff or patients (Larkin, Murtagh, & Jones, 1988). Researchers have found that the majority of incidents are caused by a disproportionately small number of patients (Hardie, 1999; Kennedy, Harrison, Hillis, & Bluglass, 1995; Morrison et al., 2002; Owen, Tarantello, Jones, & Tennant, 1998), the majority of whom meet diagnostic criteria for either a personality disorder (Pullman & Lorbergs, 2001) or a substance abuse disorder (Abeyasinghe & Jayasekera, 2003; Volavka et al., 1995). Volavka and colleagues note that the offending patient is demographically more representative of the general criminal population than the psychiatric inpatient population. Research by Bowers, Simpson, and Alexander (2003) suggests that there may be different motivations and causes behind the violent behaviour of inpatients. For example, conflict behaviour may be the result of a refusal to accept mental illness status, disagreement about the treatment being received, or learned aggression.

Incidents on forensic wards have also been explored from the staff perspective. Staff injuries occur with greater frequency and are more serious in forensic settings than in other high-risk settings (Love & Hunter, 1996; Zimmer & Cabelus, 2003). The majority of injuries sustained in psychiatric settings are reported by nursing staff (Erdos & Hughes, 2001). Psychiatric nurses are at risk of assault by patients (Morrison et al., 2002; Whittington & Wykes, 1994a, 1996), and those nurses who have been assaulted on multiple occasions are significantly more likely to have been assaulted by the same individual (Morrison et al.; Whittington & Wykes, 1994a, 1994b, 1996). Nurses' personality attributes, stress levels, and perceived work environment may contribute, both individually and interpersonally, to work behaviours that lead to patient-related incidents. Stress hypotheses suggest that, up to a certain level, stress is beneficial to job performance (Miner, 1992). Stress at an optimum level leads to arousal and increased attention, but when it rises above optimum levels there is evidence of increased levels of poor performance, job dissatisfaction, and absenteeism (Ivancevich & Matteson, 1980; Miner). Clearly related to stress is the concept of burnout. Burnout entails a chronic stress reaction, including emotional exhaustion, loss of interest and trust, and increased feelings of concern (Maslach, 1982). Practitioners experiencing burnout tend to display a decreased ability to deal effectively with clients due to reduced idealism and increased irritability (Miner). The interaction between personality traits and environmental context may be predictive of a staff member's involvement in patient-related incidents and possible victimization.

Since little of the research on incidents occurring in forensic settings has been conducted in Canada, the generalizability of findings to the Canadian context is limited. A further challenge in interpreting the results is the lack of a global definition of "incident" (Soliman & Hashim, 2001). Existing definitions include attacks on nursing staff or others, threatening behaviour, absconding, self-harm, and property damage (Armond, 1982; Bowers et al., 2003; Dietz & Rada, 1982; Fottrell, Bewley, & Squizzonni, 1978; Haller & Deluty, 1988; Owen et al., 1998). While it is clear that personality, stress, and burnout can be predictive of incidents, the exact relationships of these factors with interactions between nurses and patients, and the incidents that occur within these interactions, have not been thoroughly explored.

The purpose of this study was to examine the nature of the relationship between nursing staff and patients on a Canadian psychiatric forensic unit. It was hypothesized that there would be variability in the number of incidents across teams given their unique composition. In terms of the personality characteristics of staff members, it was hypothesized that agreeableness would be negatively correlated and neuroticism positively correlated with incidents. It was also expected that low levels of work satisfaction and high levels of burnout would be correlated with incidents.

Method

Participants

We approached all full-time registered nurses (*N* = 25) working on a 20-bed minimum-security forensic unit in a medium-security psychiatric hospital that provides inpatient, outpatient, and community-based services to participate in the study. The staff was organized into four equivalent teams working together on a regular basis. A team was defined as a group of people communicating, sharing knowledge, and ultimately working towards a common goal (Cott, 1998). We also accessed the medical records of approximately 80 forensic psychiatric patients institutionalized currently or previously (within the 1-year retrospective period).

Measures

Staff personality. Personality characteristics were determined using the 60-item NEO Five-Factor Inventory (NEO-FFI). The NEO-FFI is a valid and highly reliable measure of neuroticism, extraversion, openness, agreeableness, and conscientiousness. Significant correlations between the NEO-FFI and the NEO-Personality Inventory, a more comprehensive measure of the same five factors, suggest strong convergent validity (Costa & McCrae, 1989).

Work satisfaction. Work satisfaction and employee burnout were measured using the 22-item Maslach Burnout Inventory-Human Services Survey (MBI-HSS). The MBI-HSS evaluates the manifestations of employee burnout within human services institutions and socially relevant health-care professions such as nursing and psychology. Items are evaluated using a six-point Likert-type scale resulting in overall scores on three subscales: emotional exhaustion, depersonalization, and personal accomplishment. Psychometric evaluations of the MBI-HSS show that the instrument possesses acceptable reliability and validity (Maslach & Jackson, 1986). The internal consistency of the three scales ranges between .71 and .90.

Work environment. Quality of the work environment was evaluated using the Work Environment Scale (WES), a 90-item true-or-false questionnaire. The WES measures social climate within work settings on 10 subscales: involvement, peer cohesion, supervisor support, autonomy, task orientation, work pressure, job clarity, control, innovation, and physical comfort (Moos, 1994). The subscales display internal consistency, with Cronbach's alpha ranging from .69 to .86.

Staff demographics. Demographic information on nursing staff was collected using the Human Services Demographic Data Sheet, a comprehensive demographic checklist that is a component of the MBI-HSS (Maslach & Jackson, 1986).

Incidents. The incidents were classified within the institution through a centralized process. Each incident was reported to the unit manager, who then categorized it according to hospital protocol into one of three types: non-violent, violent, or verbal. Non-violent incidents included non-aggressive actions such as failure to return from a leave of absence or violation of ward rules. Violent incidents included any outward expressions of physical aggression directed at an individual or property in order to intimidate. Verbal incidents included any non-physical expressions of aggression such as verbal threats. In addition, verbal and violent incidents were combined to form a unique category identified as aggressive incidents; this category represented all external forms of aggressive behaviour.

Incident data were constructed for each staff member by using attendance data to establish whether the person was present on the unit when an incident occurred. Since staff members who worked more days would have had increased exposure to incidents, the frequency of incidents for each staff member was divided by the number of days he or she worked during the year, the result being an exposure-controlled incident ratio.

Procedure

All aspects of the study were approved by the local ethics committee. Participants were independently administered the psychometric evaluation package, which included: (1) the NEO-Five-Factor Inventory, (2) the Maslach Burnout Inventory-Human Services Survey, (3) the Work Environment Scale, and (4) the Human Services Demographic Data Sheet. The participants signed a consent form and were informed of their right to not participate in any part of the study and to withdraw at any time. The questionnaire package required approximately 30 minutes of their time and was completed by participants at their leisure.

Administration records were abstracted to determine each staff member's rate of absenteeism over the period September 1999 to August 2000. In addition, a retrospective analysis of incident records was carried out in order to determine the type of incidents that occurred on the forensic unit over the same period. Demographic and diagnostic information on the forensic inpatients involved were then determined, as well as the nursing staff and team members who were present when the incidents occurred.

Statistical Analysis

The incidents were categorized by patient diagnosis (according to DSM-IV criteria) into the following categories: mood disorders, schizophrenic/psychotic disorders, substance abuse disorders, personality disorders, deferred diagnosis, and other. Comparisons of incident rates by diagnosis and team were analyzed using chi-square goodness of fit tests. Associations between staff variables and the exposure-controlled incident variable were examined by means of Pearson correlations.

Results

Patient Incidents

During the retrospective period, 80 unique patients were hospitalized in the forensic unit. The population consisted primarily of individuals diagnosed with schizophrenia or a related psychotic disorder (32.5%, n = 26). Personality disorders accounted for 13.8% (n = 11), mood disorders for 11.3% (n = 9), substance abuse disorders for 10% (n = 8), deferred diagnoses for 8.8% (n = 7), and mental retardation for 5% (n = 4). Seven patients (8.8%) were categorized as "other." Eight individuals (10%) were undiagnosed. The ward used working diagnoses with inpatients; formal diagnoses were required upon discharge only.

Of the 80 patients, 24 (30%) were involved in one or more of the 52 recorded incidents. Of these 24 patients, 10 were involved in only one incident and 14 were multiple offenders, involved in 43 of the 52 incidents (81%). Eight patients, representing a mere 10% of the population, were responsible for 30 of the 52 incidents (57.7%).

The 24 patients (15 male, 9 female) who were involved in incidents ranged in age from 22 to 71 years (M = 38.21). The mean age of the men was 40.33 years (SD = 14.55) and of the women 34.66 years (SD = 7.89). The age difference for the males and females was not statistically significant: F (1, 22) = 1.14, p = .297.

Of the 52 incidents, 22 (42.3%) were categorized as non-violent and 30 (57.7%) as aggressive (verbal and violent).

The frequency of incidents varied according to diagnosis ($\chi^2(5)$ = 14.69, p = .012). Patients with a diagnosis of schizophrenia or psychotic disorder were responsible for the greatest number of incidents (*observed* = 29, *expected* = 17.7). Those with a diagnosis of substance abuse disorder or with a deferred diagnosis were the perpetrators of fewer incidents than expected (*observed* = 1, *expected* = 5.4 and 4.8, respectively). The association between a diagnosis of schizophrenia or psychotic disorder and frequency of incidents reflected the greater frequency of violent incidents among this diagnostic group (phi coefficient = .39, p = .005).

Team Incidents

Of primary interest in this study was the possible variation in frequency of specific incident types among the nursing teams within a forensic psychiatric ward. The frequency of non-violent incidents ranged from zero to nine per team. This difference was statistically significant ($\chi^2(3)$ = 8.91, p = .031). However, no association was found between nursing teams and either violent incidents ($\chi^2(3)$ = 2.33, p = .506) or verbal incidents ($\chi^2(3)$ = 1.43, p = .699).

Staff Incidents

Of the 25 members of the forensic nursing staff who were approached to participate in the study, 13 (four men, five women, four unreported gender) completed and returned the questionnaire package. The mean age of participants was 39.77 years (*SD* = 7.63). The average number of years of departmental experience was 9.56 (*SD* = 6.05) and of organizational experience 10.49. Use of the exposure-controlled incident variable revealed a significant relationship between non-violent incidents and departmental experience ($r(10)$ = –.73, p = .017). Staff members with higher levels of departmental experience had a lower frequency of non-violent incidents. A significant positive correlation was found between age and frequency of violent incidents ($r(10)$ = .74, p = .014).

The only significant relationship between staff personality characteristics and incidents was that between "openness" and non-violent incidents ($r(10)$ = .73, p = .017). No other relationships achieved statistical significance or a correlation ratio of .40 (see Table 1).

Table 1 ***Correlations between NEO Factors and Frequency of Incidents***

		Non-violent Incidents (probability value)	**Violent Incidents (probability value)**	**Verbal Incidents (probability value)**
Neuroticism	*r*	–.32 (.330)	.07 (.845)	.23 (.488)
Extraversion	*r*	–.14 (.690)	–.17 (.622)	.10 (.770)
Openness	*r*	.72 (.013)	.19 (.582)	.22 (.523)
Conscientiousness	*r*	–.27 (.425)	–.27 (.415)	.33 (.328)
Agreeableness	*r*	–.21 (.537)	.18 (.600)	.39 (.235)

Incident variables as measured using the WES subscales revealed three correlations exceeding .50, two achieving statistical significance (see Table 2). Staff members who perceived themselves as having a higher level of clarity in their work environment were present during fewer verbally aggressive incidents ($r(10) = -.75$, $p = .013$). Those who perceived themselves as having more autonomy within their work environment were associated with a greater frequency of non-violent incidents ($r(10) = .67$, $p = .033$).

Table 2 ***Correlations between WES Factors and Frequency of Incidents***

		Non-violent Incidents (probability value)	**Violent Incidents (probability value)**	**Verbal Incidents (probability value)**
Involvement	*r*	.24 (.499)	.17 (.636)	.26 (.469)
Peer cohesion	*r*	.34 (.341)	.26 (.461)	.15 (.680)
Supervisory support	*r*	.08 (.837)	–.34 (.335)	–.13 (.722)
Autonomy	*r*	.67 (.033)	.48 (.157)	.23 (.517)
Task orientation	*r*	–.12 (.733)	–.25 (.490)	–.02 (.947)
Work pressure	*r*	–.15 (.680)	.00 (.996)	.14 (.700)
Clarity	*r*	–.35 (.329)	–.54 (.111)	–.75 (.013)
Control	*r*	–.29 (.423)	.27 (.447)	.11 (.766)
Innovation	*r*	–.09 (.813)	–.35 (.323)	–.11 (.756)
Physical comfort	*r*	–.43 (.216)	–.15 (.689)	–.37 (.288)

No association was found between the burnout subscales and incidents (see Table 3).

Table 3 ***Correlations between MBI-HSS Factors and Frequency of Incidents***

		Non-violent Incidents (probability value)	**Violent Incidents (probability value)**	**Verbal Incidents (probability value)**
Emotional exhaustion	*r*	.43 (.214)	.29 (.414)	.47 (.175)
Depersonalization	*r*	.42 (.229)	.41 (.245)	.30 (.398)
Personal accomplishment	*r*	.01 (.977)	–.02 (.958)	.25 (.488)

Discussion

Patient-related incidents are a significant concern for managers of forensic psychiatric units. The purpose of this study was to explore the relationships between those incidents and characteristics of patients and nursing staff. We found that a small group of patients were responsible for the recorded incidents, a phenomenon that has been reported globally. Just 10% of the inpatient population was directly responsible for more than half of the documented incidents. Multiple offenders were involved in all but 19% of the incidents, a result that closely replicates those of previous studies with forensic psychiatric populations (Kennedy et al., 1995; Morrison et al., 2002).

However, while previous studies suggest that typical high-risk inpatients exhibit high frequencies of personality and substance abuse disorders more typical of the criminal offender population (Abeyasinghe & Jayasekera, 2003; Volavka et al., 1995), we found that schizophrenic and psychotic patients were responsible for the majority of violent incidents. The differences in the diagnosis-based incident ratio seen in this investigation may be explained by a number of possibly unique factors. For example, the study was conducted in a medium-security facility. Furthermore, the ward environment, including treatment methods, ward policies, and the general context of the forensic unit, may have differed from those of previous investigations. This suggests that the findings may not generalize well across types of institution or across jurisdictions. Perhaps future studies should focus on triggering factors of inpatient conflict to determine whether there are common factors that generate conflict in forensic settings. Researchers could then explore whether those factors are predominant within particular disorders. The paucity of Canadian studies in this area underscores the need for more research comparing incident data within and across institutional types and across provinces.

In examining nursing teams, we also found a difference in the frequency of non-violent incidents, which included such behaviours as violation of basic ward rules, failure to return as scheduled from authorized leaves, and violation of smoking prohibitions. This variation across nursing teams has several possible explanations. One is that team characteristics may have varied in some important aspects. However, it is unclear what such variations might have been and how they would affect incidents. A more likely explanation is that the variation in frequency is in fact a variation in the rate of reporting across teams. The reporting of non-violent incidents could entail a higher level of staff discretion than the reporting of violent incidents (for which we found no differences across teams). Furthermore, as with any finding close to the statistical threshold of $p < .05$, we cannot rule out a Type I error as an explanation. Nonetheless, this finding illustrates the need for more work so that we can better understand the role of team dynamics in forensic settings. From a methodological perspective, this finding suggests that in future research we may need to approach "teams" as the unit of analysis, necessitating larger-scale studies.

The frequency of non-violent incidents also appeared to vary at the individual level. Nursing staff with extensive departmental experience were present during fewer non-violent incidents than their colleagues with less forensic experience. Previous studies have found that certain staff members are victimized by patients more often than others, which indicates that incidents may be non-random (Erdos & Hughes, 2001; Poster, 1996). Bond and Brimblecombe (2003) found that a majority of forensic staff members (98 out of 102) believed that characteristics of individual staff members were related to whether or not they encountered violence at work. For example, it was suggested that some staff members may lack the skills required to handle difficult inpatients or may have racist attitudes. However, as with the analyses comparing teams, variability in the rate of reporting, rather than in the actual frequency of incidents, is a viable explanation. Future investigations may benefit from incident data that do not rely entirely on staff-based reporting methods.

Staff age was found to be positively related to the reporting of violent incidents. The reported rate of violent incidents was significantly higher among older staff members than among their younger counterparts. The expected low tolerance for violence on the unit suggests that the relationship between staff age and violence is unlikely to be a rate-of-reporting effect, though this may still exert some influence.

The staff member NEO openness factor was positively correlated with non-violent incidents. Such incidents were more frequent when staff members with increased openness were present. However, no relationship was found between staff openness and incidents defined as aggressive. One explanation for this finding is that staff members who are open are perceived by patients as easygoing and therefore likely to tolerate small misdemeanours.

Regarding the role of the work environment, staff with increased work clarity experienced a lower frequency of aggressive incidents (verbal and violent). However, staff with high levels of autonomy experienced greater frequency of aggressive incidents. An examination of supervisory support, policies, and management styles would be beneficial in identifying causal relationships between management philosophies and incidents.

The staff of mental health facilities should be attentive to high-risk patients as well as to factors that may trigger incidents among staff and patients. In-service training to promote alternatives to restraint, effective communication skills, and non-violent methods for managing violent patients may serve to reduce the number of patient assaults (Flannery & Walker, 2001).

The results of this study support the presence of complex relationships between inpatient incidents and forensic nursing staff. The work environment may also be a relevant factor. While a number of relationships were observed, the hypothesized personality and burnout patterns were not found. However, the limited effect size of this investigation should be considered. Due to the small sample size, the limited response rate, and the potential heterogeneity of the participants, it is possible that some relevant findings would reach statistical significance in a larger study.

Future research should include multiple institutions and ward types in order to address issues of sample size and unit of analysis. Future replications of similar research should consider using a more objective measure of incidents; this would require the development of reliable procedures to code incidents. In addition, future research should consider replicating recent studies in various environments, possibly increasing generalizability and recognizing successful forensic practices.

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Authors' Note

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Résumé

La recherche, le traitement et le partage de l'information sur le cancer du sein par les femmes souffrant de cette maladie

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La majorité des femmes auxquelles on a diagnostiqué un cancer du sein cherche à obtenir de l'information sur la santé pour faire face aux effets de la maladie. Cependant, peu d'études ont documenté la façon dont les femmes s'y prennent réellement pour chercher, traiter et partager l'information sur le cancer Cette étude qualitative explore le processus de gestion de l'information sur le cancer de la perspective de 12 femmes ayant le cancer du sein. Parmi les données, trois éléments principaux de la gestion de l'information (GI) ressortent : les déclencheurs d'information initiaux sur le cancer, les réactions émotionnelles et comportementales à l'information, et le sentiment de soulagement, d'espoir, de soutien ou de détresse résultant de la GI. Selon les participantes, la GI est un processus continu dans lequel le choix de continuer de partager l'information sur le cancer avec d'autres personnes dépend du soutien que cette information leur a apporté.

Mots clés : Gestion de l'information, besoins d'information, recherche d'information, révélation de soi, adaptation psychologique au cancer, cancer du sein

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The Searching, Processing, and Sharing of Breast Cancer Information by Women Diagnosed with the Illness

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Most women diagnosed with breast cancer seek health-related information to cope with the demands of the illness. However, few studies have documented how women actually seek, process, and share cancer-related information. This qualitative study explores the process of managing cancer-related information from the perspective of 12 women with breast cancer. Three core components of information management (IM) emerged from the data: initial cancer-related informational triggers, emotional and behavioural reactions to the information, and the IM outcomes of feeling relieved, hopeful, supported, or distressed. According to the participants, IM is an ongoing process in which the choice to continue sharing cancer-related information with individuals depends on women's perceptions of how supportive they have been.

Keywords: Information management, information needs, information-seeking behaviour, self-disclosure, psychosocial adjustment to cancer, breast cancer

Overview

Despite advances in detection and treatment, breast cancer remains one of the most common cancers in women around the world (Mills & Sullivan, 1999). Once diagnosed with breast cancer, women often find themselves in unfamiliar learning environments with little time to react to their diagnosis while being asked to consider various treatment options with their accompanying side effects. The potential spiral of negative events following diagnosis often represents a significant crisis in the lives of affected women and their families (Mills & Sullivan; Rees & Bath, 2000b; Stanton, Danoff-Burg, & Huggins, 2002).

Information-seeking is documented as a key coping strategy in the context of a challenging illness experience (Bilodeau & Degner, 1996; Hoskins & Haber, 2000; Jahraus, Sokolosky, Thurston, & Guo, 2002; Long, 2001; Rees, Bath, & Lloyd-Williams, 1998). The benefits of seeking timely cancer-related information are well documented. They include decreased anxiety and emotional distress (Beaver et al., 1996; Bilodeau & Degner; Chelf-Harper et al., 2001; Craddock, Adams, Usui, & Mitchell, 1999), increased sense of control (Long), enhanced coping (Edgar, Remmer, Rosberger, & Fournier, 2000), and more informed decision-making (Beaver et al.; Bilodeau & Degner). Research efforts have focused on examining how women with breast cancer seek cancer-related information, including the antecedents and circumstances of women's search for information (Boudioni et al., 2001; Rees & Bath, 2001), their discretionary actions when seeking the information (Jahraus et al.; Rees & Bath, 2001), and types and amounts of information sought (Jahraus et al.; Rees & Bath, 2001). This research has enhanced our understanding of women's information-seeking behaviours. However, there remains a need to specifically document how individuals manage the information once they have obtained it. Another important area of research is how information is managed with significant others and health-care providers and the differential consequences of information management (IM) strategies on health-related behaviour and outcomes (Brashers, Goldsmith, & Hsieh, 2002).

The purpose of the present study was to examine the process of IM from the perspective of women diagnosed with breast cancer, including women's interactions with others and the consequences of IM for adjustment outcomes. Women with a diagnosis of breast cancer were the target population for the study, as information-seeking is reported to be a key strategy in coping with this diagnosis (Hoskins & Haber, 2000; Jahraus et al., 2002; Long, 2001; Rees et al., 1998).

Background

The diagnosis of breast cancer often comes as a terrible shock, involving feelings of anxiety, uncertainty, denial, fear of dying, depression, and anger (Epping-Jordan et al., 1999; Hoskins & Haber, 2000; Lavery & Clarke, 1996; Schnoll, Harlow, Stolbach, & Brandt, 1998). The rapid succession of events following diagnosis, including complex decisions, arduous treatments, and possibly inadvertent life changes, places extraordinary demands on women's coping abilities (Hoskins & Haber; McCaul et al., 1999; Mills & Sullivan, 1999; Stanton et al., 2002). To better cope with the psychological and physiological demands imposed by a breast cancer diagnosis, women often actively seek illness-related information (Bilodeau & Degner, 1996; Hoskins & Haber; Jahraus et al., 2002; Long, 2001; Rees et al., 1998).

Several studies have examined the information-seeking behaviours of women diagnosed with breast cancer. Findings to date suggest that many of these women seek as much information as possible, particularly on the nature of the diagnosis, the likelihood of cure, treatment options and side effects, investigational tests, the stage of the disease, and the possibility of recurrence (Bilodeau & Degner, 1996; Degner et al., 1997; Harrison, Galloway, Graydon, Palmer-Wickham, & Rich-van der Bij, 1999; Rees & Bath, 2000a). Although most women report a desire to have illness-related information, there is considerable variability in the type and amount of information they prefer (Chelf-Harper et al., 2001; Harrison et al.; Leadbeater, 2001; Rees & Bath, 2000a, 2001). Some women report seeking cancer-related information that is perceived to be essential but avoid highly detailed information (Jahraus et al., 2002; James, James, Davies, Harvey, & Tweddle, 1999; Long, 2001), others seek the information they need to care for themselves and avoid other types of information (Jahraus et al.), and still others prefer to obtain information gradually as the illness experience unfolds to avoid being overwhelmed by such information (Shaw, Wilson, & O'Brien, 1994). Some women even report a need to avoid all illness-related information (Rees & Bath, 2001). Women diagnosed with breast cancer who shun illness-related information may do so to avoid associated distress (e.g., worry, fear) (Rees & Bath, 2001). The information-seeking behaviour of women diagnosed with breast cancer also may vary over time. For instance, a woman may avoid further information following an exhaustive information search (Rees & Bath, 2001) or may first seek information from health professionals and then turn to other sources (e.g., books, the Internet) (Johnson, 1997). In addition, women may have a stronger desire for information on prognosis at the onset of the illness or when they embark on therapeutic regimens (Mills & Sullivan, 1999; Rees & Bath, 2000a, 2001). Information about self-care and risk to other family members becomes more important later on (Rees & Bath, 2000a). In general, when seeking illness-related information, women diagnosed with breast cancer often control the type and amount of information that they attend to and use particular strategies to obtain the information they need (Jahraus et al.).

Brashers et al. (2002) use the term information management (IM) to capture all strategies or activities undertaken by individuals to seek, appraise or interpret, avoid, and provide selective information. They point to the need to understand if and how patients and family members coordinate IM strategies that may impact on their interactions and health outcomes. In the context of women with breast cancer, significant others also have been found to take on different roles related to IM (Chalmers, Thomson, & Degner, 1996; Kilpatrick, Kristjanson, Tataryn, & Fraser, 1998). Sometimes they are sources of cancer-related information for each other (Rees & Bath, 2000b). Sometimes family members collaborate with patients in gathering the desired information (Echlin & Rees, 2002) and in evaluating it (Chalmers et al., 1996; Echlin & Rees, 2002; Kilpatrick et al., 1998; Rees & Bath, 2000b). Significant others also may act as buffers against the incoming information (Chalmers et al.; Echlin & Rees; Kilpatrick et al.; Rees & Bath, 2000b). At times, IM strategies of patients and significant others are coordinated and information is shared unrestrictedly (Chalmers et al.; Rees & Bath, 2000b). At other times, their IM strategies are divergent, which, in turn, may result in different preferences for cancer-related information (e.g., a woman may wish to avoid information on breast cancer and yet have significant others provide her with such information) (Brashers et al.; Chalmers et al.; Kilpatrick et al.). Collaborative patterns of communicating cancer-related information between patients and significant others are reported to promote positive health outcomes, while mismatched preferences for communicating information are reported to contribute to negative health outcomes (Brashers et al.; Chalmers et al.).

Researchers have begun to examine how patients and significant others manage information related to breast cancer. However, no study reviewed to date documents IM processes from the perspective of women diagnosed with breast cancer, taking into consideration the role of significant others. In the present study, women were asked to describe: (1) how they obtained the cancer-related information they needed, (2) how they reacted to the information they obtained or received, (3) how they shared breast cancer information with significant others and how significant others reacted, (4) the consequences of seeking and sharing information with significant others, and (5) the factors that influenced their IM strategies. These questions contributed to the development of a conceptual model that depicts key characteristics of IM within this particular context.

Method

A qualitative multiple-case design (interpretative analysis) was used to examine how women diagnosed with breast cancer manage cancer-related information. Participants (n = 12) were interviewed by one of the authors in the course of receiving usual nursing care (n = 9) or prior to participating in a workshop on the role of information in psychosocial adjustment to cancer (n = 3). All participants were informed by the researchers about the study and its purpose and were assured of confidentiality. All participants provided either written or verbal consent to take part in the study prior to the first interview.

Participants

Purposive sampling was employed and participants were selected based on their diagnosis of cancer, time elapsed since diagnosis, presence of a significant other, and willingness and ability to discuss their experience. Most potential participants were approached by the researchers through an inpatient oncology unit or an outpatient chemotherapy clinic in a large urban teaching hospital. Women with major concurrent physical and/or psychological illnesses were excluded.

Twelve women agreed to participate in the study. They ranged in age from 43 to 88 years and were of various ethnic backgrounds (e.g., English Canadian, East Indian, French European, French Canadian, Polish, Scottish). The women were at various stages of breast cancer: stage 1 (n = 2), stage 2 (n = 3), advanced stage 4 (n = 4), and recurrence (n = 3). Three were single, four were married, three were separated or divorced, and two were widowed.

Data Collection

Data were drawn from in-depth, face-to-face semi-structured interviews with the 12 women diagnosed with breast cancer. Semi-structured interviewing was used as a way to ensure that issues related to IM were covered while allowing participants the flexibility to elaborate on topics important to them (Morse & Field, 1995). The interviews took place between January and May 2001 and lasted approximately 90 minutes. Each participant was interviewed individually. Participants were interviewed a second time if they showed fatigue during their first interview or if they expressed an interest in discussing the issues further. The interviews were conducted either in the patient's hospital room, in the outpatient chemotherapy clinic during treatment, during home visits, or in a discreet public area (e.g., restaurant), according to the preferences of participants.

At the beginning of each interview, the researcher described the study to the participant and time was provided to address the participant's concerns or questions. The participant was informed that her anonymity would be protected and assured of confidentiality. The interview consisted of a series of open-ended questions designed to elicit perceptions of the strategies and behaviours participants used when managing cancer-related information. The participants were asked the following general questions to ascertain their personal construction of IM: "Can you describe your experience with breast cancer information so far?" "Tell me about the ways you and your significant others together handle breast cancer information" "How is your family handling breast cancer information?" They were also asked about IM-related issues, such as general IM patterns, factors that influenced their search for cancer-related information, and their reactions to the management of cancer-related information by their significant others. Additional probes were used, as needed, to clarify and expand upon participants' comments (e.g., "What do you mean by that?" "Tell me more about that") (Krefting, 1991).

Four interviews were audiotaped and transcribed verbatim. For the remaining interviews, succinct notes were taken during the interview and completed immediately afterwards to ensure optimal recall and minimal bias. The notes included observations, explicit details of situations and interactions, assumptions about what was heard or observed, and the researchers' personal narratives: what they felt before, during, and after the encounter. Data were managed using Microsoft Word.

Analysis

Data analysis for this study draws on the interpretive tradition within qualitative research, whereby portions of data are placed in categories and the categories are linked together to form a coherent model for explaining the phenomenon of interest (Sandelowski & Barroso, 2003). Although no attempt was made to develop a substantive grounded theory about IM, analytic procedures were used to capture the process of IM from initiation to outcomes. Categories within the field notes were identified through latent content analysis (Field & Morse, 1985). First, the transcript and notes for each interview were read several times to gain a sense of the overall content of the interview. Then, these were reviewed line-by-line (microanalysis), and, through inductive reasoning, words, statements, and paragraphs describing IM and IM-related issues were extracted. Through this in-depth analysis, similar excerpts were identified using the same label or code (Holloway & Wheeler, 2002). Codes were identified in the margins of the transcripts or notes. During regular meetings, codes were compared and discussed until consensus was reached. Detailed analysis and interpretation of the codes resulted in the emergence of categories. A category was construed as a grouping of codes that were similar in concept or meaning (Holloway & Wheeler; Hutchinson & Wilson, 2001; Strauss & Corbin, 1998). Categories represented the triggers to IM, reactions to the information, and outcomes of IM. Each category was subsequently defined, a process of identifying subcategories, describing the overall meaning based on a review of all the transcripts, and identifying representative quotes. Possible relationships amongst the different categories and subcategories were then discussed and mapped. Participants were recruited until the categories and subcategories were sufficiently described and additional data became redundant. This resulted in a preliminary conceptual framework illustrating links among the various categories (Figure 1). This framework contains concepts that offer the most parsimonious representation of the data.

Evaluation of Rigour

The rigour of qualitative research can be evaluated using the criteria of credibility, confirmability, and transferability (Carnevale, 2002; Chiovitti & Piran, 2003; Sandelowski, 1986; Speziale & Carpenter, 2003). Table 1 describes the strategies used to enhance the methodological rigour of this study.

Figure 1 *Information Management by Women Diagnosed with Breast Cancer*

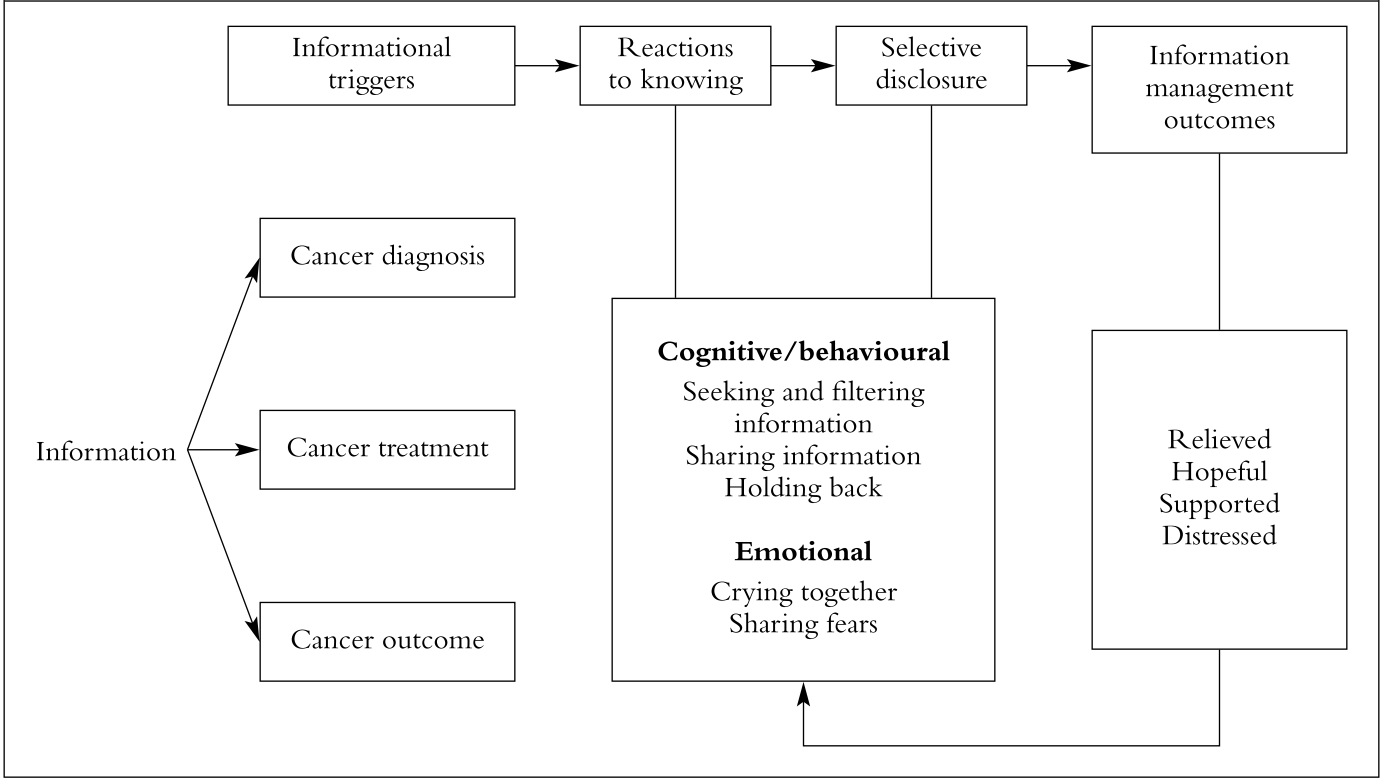

Table 1 *Evaluation of Rigour*

Criteria	**Strategies**
Credibility	Findings are discussed among the researchers for the purpose of reaching consensus (Carnevale, 2002). Prior knowledge of and experiences with the phenomenon are acknowledged; field notes are used in order to identify and document biases (Chiovitti & Piran, 2003; Sandelowski, 1986). The inquiry process is guided by participants; the point of view of participants is solicited during interviews (Chiovitti & Piran, 2003). Some labels used in the conceptual framework are the words of the participants (Chiovitti & Piran, 2003).
Confirmability	An audit trail is kept (Carnevale, 2002; Sandelowski, 1986): detailed records of data collection and analysis as well as personal notes documenting decisions made throughout the study.
Transferability	The phenomenon of IM is relevant to the target population (Chiovitti & Piran, 2003). The scope of the study, in terms of sample, setting, and proposed conceptual framework, is delineated (Chiovitti & Piran, 2003). The sample consists of individuals at different stages of the illness trajectory, so that the study will capture different experiences with IM (Sandelowski, 1986). Direct quotes are presented (Morrison-Breedy et al., 2001). The authors discuss how themes relate to the literature (Chiovitti & Piran, 2003).

Findings

Content analysis of the transcripts revealed that IM by women diagnosed with breast cancer can be conceptualized as a process consisting of four components. The first component, "informational triggers," refers to the women's initial exposure to breast cancer–related information and/or cancer-related events/situations that prompted them to react and to begin seeking or avoiding information. The second component, "reactions to knowing," can be defined as women's repertoire of emotional and behavioural responses in light of the perceived informational triggers. The participants' reactions included "information-seeking and filtering," "sharing information," "holding back," "crying together," and "sharing fears." The third component, "selective disclosure," refers to the process through which some of the women made decisions about the kinds of cancer-related information to be shared, when, and with whom. Through selective disclosure, some women readily assessed whether significant others were supportive and whether they would continue to exchange information with them. Last, four descriptors capture the range of IM outcomes reported by the women: "relieved," "hopeful," "supported," and "distressed." The IM strategies used within each dyad (i.e., woman/significant other) were found to influence the outcomes of IM and participants' reactions to further informational triggers. A conceptual framework (Figure 1) representing the findings was developed by the authors. Each category of the framework is described below.

Informational Triggers

In some instances, it was the information from health professionals that triggered participants to react and modify their behaviour regarding cancer-related information (e.g., whether to seek or avoid further cancer-related information). In other instances, informational triggers were cancer-related events or situations that incited the women to react and begin to seek or avoid information. Categories of informational triggers experienced by the women included cancer diagnosis, cancer treatment, and potential cancer-related outcomes.

Cancer diagnosis. Several participants said that their most significant emotion triggers included information they received from health professionals related to a possible (e.g., investigative test results) or actual diagnosis of breast cancer. Even though the time elapsed since diagnosis ranged from 6 months to 10 years, the moment when diagnostic information about breast cancer was provided to the women, and their reaction, stood out sharply in their memory. One woman spoke of her complete surprise when she learned of the diagnosis:

> *I went to the doctor for a check-up and she found a lump in my breast. My doctor said, "Oh, it's probably nothing, but we'll have it checked out." So even at the mammogram I was told that it looked like it was benign… So when it came time to get the biopsy results I was already convinced that I didn't have cancer.*

Another woman described seeking information about the nature of her cancer. She wanted to be more knowledgeable about her condition:

> *I did have some cancer in two of my lymph nodes, and I didn't know if this increased my chances of having a recurrence or not, if they managed to cure the cancer.*

Cancer treatment. Treatment modalities for breast cancer were important informational triggers. Several participants explained how objective information received from health professionals on the side effects of treatment incited them to react:

> *I received a sheet on side effects that I could have from the chemo. Some were serious — the chemo can damage your heart.*

Other participants were motivated to react after experiencing symptoms related to treatment (e.g., unpleasant side effects). Often, the subsequent search for information was related to management of side effects:

> *I've developed a really nasty side effect from the chemotherapy medication that I was taking most recently… [It] made me lose my taste as well as my appetite.*

Cancer outcomes. Some informational triggers were related to the outcome of having breast cancer, particularly in regard to prognosis and recurrence. For some participants, a constant concern was whether the disease was progressing and what the prognosis might be. Informational triggers often were related to physical symptoms interpreted as a sign that the disease was or was not progressing. An elderly woman had one particular question for her oncologist:

> *I wanted to know what was causing the pain. Was it because the cancer had spread? That was the question I wanted answered.*

Another participant was asked why she had been willing to share her experience of severe fatigue with women in the chemotherapy clinic but not with the oncologist:

> *Because I was scared. I was scared it was because the chemo wasn't working and the cancer was spreading.*

Several women experienced a recurrence of breast cancer. Similar to the period of diagnosis, the point at which they learned that the cancer had recurred stood out for them as a moment when they received informational triggers such as:

> *When I went to my doctor's appointment, he sent me for some tests.... He told me, "This is serious. Now the cancer has come back. We can treat it but we won't be able to cure it."*

Reactions to Knowing and Selective Disclosure

The women's range of reactions to the various informational triggers fell into two categories: cognitive/behavioural and emotional. Cognitive/behavioural reactions described by the participants included "information-seeking and filtering," "sharing information," and "holding back." Emotional reactions included "crying together" and "experiencing and sharing fears."

Cognitive/behavioural reactions

Information-seeking and filtering. Following the initial informational trigger, most participants were motivated to seek complete and objective information about breast cancer. To gain a better understanding of the illness and its treatment, these women sought information on the specific nature of their cancer and became more knowledgeable about their current status. One woman, for instance, was very inquisitive about breast cancer, stating that in addition to reading all she could about it, she prepared questions before meeting with health-care providers. Another woman said:

> *The day after my lumpectomy, I asked my husband to go to the bookstore and buy every single book that he could find on breast cancer. He came back with a half dozen, most of which were scientific and medically oriented.*

Two participants reported avoiding breast cancer information altogether. One woman had issues regarding additional information provided to her on the side effects of chemotherapy:

> *When I went for my first chemotherapy session, my nurse...handed me a four-page...document and told me to read it carefully. It contained a list of all the possible side effects I could get from chemotherapy. Without even glancing at the document, I handed it right back and told her that I didn't want to read it.*

Some women demonstrated selectivity in their search for cancer-related information. These participants did not seek all types of information but, rather, focused on information that they thought would be "positive" or comforting:

> *I was overwhelmed by fear… What I needed was "anti-fear" information — information that I could intellectually use, process, and combine, to counterbalance and reduce the fear. I needed information that would elicit hope and contribute to a positive attitude.*

Participants who sought positive information were often found to avoid the "cold, hard facts." One woman reported that she preferred to seek positive information and to avoid scientific and medical information, because "I understood too little of too vast a subject," and of what she did understand, only the negative appeared salient, causing her to be fearful.

Although information-seeking and filtering could be initiated by the woman herself, in some instances a significant other was involved in the search for and screening of information. One woman described the role her husband played in screening potentially threatening information and supplying her with more positive information:

> *I told my husband the things that I was ready to hear about breast cancer and the types of things I did not want to know…. He looked over all the pamphlets and other written documents that the nurse had given me and he told me only the things I was ready to hear. He was so helpful.*

Sharing information. Sharing information emerged as one of the most salient cognitive/behavioural reactions. All 12 women reported a desire to share cancer-related information with significant others. In the process of sharing information, they tended to disclose more information to individuals they perceived as supportive than to those they perceived as unsupportive or fragile. For example, one participant chose to discuss the potential side effects of chemotherapy with her daughter rather than with her husband:

> *I told her [about the potential side effects]. We're very close. I feel comfortable talking to her about anything. I feel she's strong and won't become depressed over hearing about what's happening to me.*

Some participants described situations in which significant others initiated information-sharing. One woman's son actively sought cancer-related information and then shared it with her:

> *It's so funny. Every time he comes home from Toronto he brings the latest piece of information that he got off the Web or from books. And we have a little family meeting, and he teaches us what he has learned.*

Significant others who had previous experience with cancer were identified as particularly important resources. One woman explained that the most recent chemotherapy drug she had taken had affected her appetite and her sense of taste. She talked to a friend who was receiving similar treatment for breast cancer at a different hospital:

> *My friend gave me some information that she had read in a pamphlet that her oncologist had given her… She also suggested that I start eating my food at room temperature or cold, and that has helped me taste it more.*

Holding back. Although seeking or avoiding information was a coping strategy used by all the participants in response to informational triggers, many reported that they withheld certain types of information from significant others, particularly if they thought it would upset or worry them. For example, after being given a pamphlet describing potential side effects of chemotherapy, one woman decided not to share the information with her husband:

> *I didn't tell him that, because I knew that then he would have double to worry about! He would worry about cancer and heart disease.*

Emotional reactions. Emotional reactions to cancer-related information included sharing and expressing emotions with significant others. The most common emotional reactions reported by the participants were crying together and experiencing and sharing fears.

Crying together. Two participants spoke of crying in the company of another person after learning about the progression of the disease. One woman spoke of calling a close friend immediately after discovering that her cancer had returned:

> *She's the first person that I called after I heard that I had cancer again. She came and picked me up at the hospital and brought me to a café, and we cried together.*

Another woman described a situation in which she cried in the chemotherapy clinic with a nurse present. This occurred after a long day at the hospital, where she had learned of a second bout of cancer in her lung:

> *I was sitting there in the chair and she asked me how I was and I just started to cry. I felt comfortable enough with her to cry with her.*

Experiencing and sharing fears. A salient emotion described by participants in reaction to cancer-related information was fear. One woman explained how the information she received induced fear:

> *The emotion of fear comes from within, from inside a person…we can readily ascertain that this fear is based on information that the patient has just been given.*

Several women spoke of the need to share their fears with people who "would understand" what they were experiencing. One participant felt comfortable talking to a friend about her fears because they were "close like sisters":

> *I talk to her about my fears, about my worries concerning who my daughter will live with… These are difficult issues that I don't necessarily want my daughter to worry about.*

Some women sought out significant others who had previous experience with cancer or who presently had breast cancer. One woman spoke of a group of four female friends who had breast cancer:

> *I don't have to explain anything to them. It's like we share the same fears, we've gone through the same things.*

Information Management Outcomes

Once they had reacted behaviourally and emotionally to cancer-related information, participants felt either "relieved," "hopeful," "supported," or "distressed." In some instances, they reported more than one IM outcome (i.e., a mixture of feelings).

Feeling relieved. Some women felt relieved when they shared information with significant others who were open to discussing issues related to breast cancer. One woman with a poor prognosis spoke to her 15-year-old daughter in order to prepare her for the eventual death. The girl was open to discussing the issue, to her mother's relief:

> *We have talked about [my death]. At first she would get upset…but recently she said to me, "You know, Mom, I am ready for the death" … I felt a sense of relief, because it means that she has been thinking about it.*

Feeling hopeful. Some women described feeling hopeful and encouraged after receiving cancer-related information from significant others or sharing it with them. Several participants felt hopeful as the "filtered" information they received from family members was "promising." One woman spoke of feeling hopeful after receiving information as a result of her son's Internet searches:

> *I'm always left with a strong feeling of hope, a feeling that I know that I am going to get better and survive this. I know I am. The information he gets is always promising. It's always positive in some way.*

Feeling supported. Participants often spoke of feeling supported by their significant others after sharing information with them. One woman described how she felt after telling a significant other about the information gathered during appointments with the oncologist:

> *The fact that she cares for me and is truly concerned about how I'm doing is so important to me. It makes me feel so supported and that I am not alone.*

Another woman described her relationship with her sister, whose husband had died of cancer the year before:

> *She would listen to me, and then convey to me that she understood what I was going through. That was reassuring. It was comforting.*

Feeling distressed. When information was disclosed to significant others who were not open to discussing issues about breast cancer, the encounter often was viewed as unhelpful and distressing:

> *When I told my husband that the cancer had come back, he didn't believe me… When I was so sick the first time, he would never acknowledge that I was sick. He would just ignore it and pretend like everything was normal.*

When asked if this relationship had helped her adjust to cancer, the woman said it had not and she had asked her husband to leave:

> *I couldn't take him any more. He was causing me more stress than anything else in my life. He could never show me any sympathy, and he was of no help.*

Subsequent to the negative interactions with her husband, this participant chose to share information about breast cancer with significant others whom she considered supportive.

Another woman was distressed by the inability of her two daughters to openly discuss cancer-related issues with her. She was obliged to "hold back" some information:

> *I've tried, trust me, but they will not talk about that. They always change the subject, as if I didn't say a thing… I think it's important to be able to talk about these things with family members. I'm not going to live forever, that's for sure.*

Discussion

The purpose of this study was to explore the experience of information management (IM) among women diagnosed with breast cancer. IM began as soon as the participants received cancer-related information, most often from health professionals at the time of diagnosis or later when they undertook treatment. These events triggered the women to react behaviourally and emotionally. Some participants focused on seeking further information, whereas others preferred to avoid or ignore subsequent information. Some reacted emotionally, such as by crying. Women's reactions and how these were subsequently managed together with significant others influenced their feelings about their situation, themselves, and others. "Informational triggers" is a term akin to "stimulus" proposed by Freimuth, Stein, and Kean (1989) and Lenz (1984). According to these authors, a discrepancy between the amount of information one possesses and the amount needed acts as a stimulus for future behaviours. In the present study, similarly, the informational triggers were found to be either internal (e.g., linked to symptoms) or external (e.g., linked to cancer information provided). Freimuth et al. and Lenz discuss two potential outcomes of triggers (information search or avoidance). The present study describes a wider range of possible reactions to informational triggers. Participants' reactions to triggers revealed nuanced patterns of information-seeking (i.e., selective information-seeking).

Most participants sought as much cancer-related information as possible, just as documented elsewhere (Jahraus et al., 2002; Rees & Bath, 2001), and a few participants avoided information altogether. Participants who gathered all available information were mainly interested in what Loiselle (1995) refers to as the "diagnosticity" of the information — that is, they were interested in information that would significantly reduce the ambiguity or uncertainty of some aspect of their situation. Interestingly, some women reported a preference for "positive" cancer-related information. This type of selectivity has not been reported elsewhere for this population, although recent studies document a positive orientation of women towards "benefit finding" pertaining to their cancer (Tomich & Helgeson, 2004). Selectivity in seeking positive information about oneself has been termed "self-enhancement," primarily in the social psychology literature (Gaertner, Sedikides, & Graetz, 1999; Sedikides, 1993; Taylor, Lerner, Sherman, Sage, & McDowell, 2003). Self-enhancement is described as a desire to promote, maintain, and defend a positive view of the self (Loiselle; Sedikides; Taylor et al.). In the present study, other participants also sought to protect themselves from aversive information about their cancer in an attempt to maintain hope or a positive outlook.

Findings from this study support the notion that women with breast cancer and their significant others are intricately involved in IM activities (see also Brashers et al., 2002; Chalmers et al., 1996; Kilpatrick et al., 1998). Participants and significant others were important sources of cancer-related information for each other. In the process of sharing information, the women were sensitive to how the disclosure of information would affect significant others, which led to selective disclosure of cancer-related information. Participants were more likely to share information unrestrictedly if they thought their significant others would be "strong enough to take it." Selective disclosure often led to decisions regarding which type of information to share, with whom, and when. Participants also were found to act as gatekeepers of cancer-related information (see also Chalmers et al.; Rees & Bath, 2000b). Some women selectively disclosed information to or withheld it from significant others because they thought it would be too upsetting or worrisome for their loved one. Such protectiveness of significant others by patients has been documented elsewhere (Hilton, 1994; Rees & Bath, 2000b). Hilton found that when sharing cancer-related issues, women diagnosed with breast cancer and their significant others were more satisfied with sensitive communication than with indiscriminate sharing.

In addition to sharing information, some participants reported sharing feelings with others in reaction to cancer-related information received or sought. Emotional reactions to breast cancer information have received less research attention than cognitive/behavioural reactions. Hilton (1994) refers to communication about fears, doubts, and emotional issues among women diagnosed with breast cancer and their significant others as "sharing meaning," an important strategy used by couples in managing illness and enhancing psychosocial adjustment.

In the present study, the experience of cancer-related IM resulted in one of four outcomes for the participants: feeling relieved, feeling hopeful, feeling supported, or feeling distressed. It became clear that the congruence (or lack thereof) between the IM strategies of participants and their significant others influenced the reported outcomes of IM. Participants were more likely to report a positive outcome (e.g., relief, support, encouragement) when significant others had similar preferences regarding the sharing of cancer-related information. Participants reported that information-sharing had little benefit or was distressing when their need for disclosure was not shared by significant others. In these instances, significant others were often seen as unsupportive. The importance of open communication about cancer among affected individuals for optimal health-related outcomes also has been discussed elsewhere. Chalmers et al. (1996) found that restricted communication about breast cancer between patients and significant others contributed to negative adjustment outcomes for significant others; however, they did not report on the consequences of different communication styles strictly from the perspective of women diagnosed with breast cancer. Hilton (1994) found that the single most critical factor in couples' adjustment to breast cancer was that they share similar views on the importance of talking about cancer-related issues. The present study supports such observations and documents the various outcomes pertaining to communication patterns from the perspective of the women themselves.

As a consequence of their interactions with significant others, the participants quickly learned whom they could share cancer-related information with and who would be most helpful in securing any required information. Participants' learning appeared to take place both during and after information-sharing. When they felt supported, the women would continue to disclose information to significant others. However, when they shared information and felt unsupported, they chose not to disclose new information and to hold back associated emotions. These findings are supported by previous research suggesting that individuals with dissimilar communication patterns disclose little information (Rees & Bath, 2000b; Rees et al., 1998). They also corroborate the theoretical proposition that IM is a process of self-regulation whereby one's IM strategies evolve and are modified until the satisfactory level of disclosure to a "coordinated" significant other is achieved (Loiselle, 1995).

Implications for Practice

The present findings highlight the need for health-care providers to more systematically assess the social networks of women with breast cancer to identify the potential IM strategies used and to address how reliance on these strategies may affect health-related outcomes. Such assessment would guide health-care providers in supporting women as they engage in IM with significant others. The findings also suggest that information provided by health professionals acts as triggers to patients, which, in turn, impact on subsequent IM strategies and outcomes.

Limitations

Findings from this study may be considered preliminary, as the sample was relatively small and homogeneous in terms of being mostly Caucasian. Additional sociodemographic data would also have been helpful in qualifying our analysis (e.g., education, number of children, family income). In addition, the audiotaping of all interviews instead of just four might have added details to certain of the comments by participants.

Conclusion

The purpose of this study was to investigate women's experience in managing cancer-related information together with significant others. A qualitative approach revealed that the process of information management (IM) is very real for this sample and includes four main components: informational triggers, ensuing behavioural and emotional reactions to knowing, selective disclosure of breast cancer information, and outcomes related to the overall IM process. The findings also highlight the importance of IM in the context of breast cancer and underscore the intricate ways that such information is managed with significant others.

To our knowledge, this is the first study on IM among women with breast cancer. Further research is needed to study potential shifts in IM strategies and behaviours as the illness experience unfolds. This would allow for comparison of IM patterns at different points on the illness trajectory. Also, the exploration of cultural and sex differences in the management of illness-related information is a promising avenue for research.

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Résumé

Essai pratique du WHOQOL-100 au Canada

Anita E. Molzahn et Ginette Pagé

L'objectif de ce projet était de mettre à l'essai le WHOQOL-100, un instrument servant à évaluer la qualité de vie (QDV) conçu pour faciliter les comparaisons interculturelles. L'instrument a été testé à partir d'un échantillon de commodité de 144 personnes. L'âge moyen des participants était de 58 ans, et 41 % d'entre eux étaient des femmes. La fidélité de test-retest était de 0,86 pour le domaine physique, 0,78 pour le domaine psychologique, 0,91 pour l'indépendance, 0,87 pour les relations sociales, 0,77 pour l'environnement et 0,60 pour la spiritualité. La cohérence interne était de 0,77 pour le domaine physique, 0,79 pour le domaine psychologique, 0,89 pour l'indépendance, 0,71 pour les relations sociales, 0,80 pour l'environnement et 0,89 pour la spiritualité/les croyances personnelles. Les corrélations entre les divers domaines et les mesures correspondantes effectuées par d'autres instruments, notamment le SF-36, la Self-Anchoring Striving Scale et la Visual Analogue Scale for Pain, ont étayé la validité convergente de l'instrument. Celui-ci a permis de différencier les populations saines des populations malsaines, ce qui vient étayer sa validité conceptuelle.

Mots clés : Qualité de vie, mesure

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Field Testing the WHOQOL-100 in Canada

Anita E. Molzahn and Ginette Pagé

The purpose of this project was to test the WHOQOL-100, an instrument for assessing quality of life (QOL), developed to facilitate cross-cultural comparison. The instrument was tested with a convenience sample of 144 people. The mean age of participants was 58 years and 41% were female. Test-retest reliability was .86 for the physical domain, .78 for the psychological domain, .91 for independence, .87 for social relationships, .77 for environment, and .60 for spirituality. Consistency reliability was .77 for physical, .79 for psychological, .89 for independence, .71 for social relationships, .80 for environment, and .89 for spirituality/personal beliefs. Correlations of the various domains with other instruments, including the SF-36, the Self-Anchoring Striving Scale, and the Visual Analogue Scale for Pain, supported the convergent validity of the instrument. The instrument was able to discriminate between healthy and ill populations, providing support for construct validity.

Keywords: Quality of life, measurement

Introduction

The concept of quality of life (QOL) has received considerable attention around the world in both the lay and the professional literature. However, measurement of the concept is complex. Although many instruments have been developed, they have numerous deficiencies, including excessive focus on disease symptoms, lack of responsiveness to change, and lack of reliability and validity (Carver, Chapman, Salazar, Stadnyk, & Rockwood, 1999; Harrison, Juniper, & Mitchell-DiCenso, 1996). These limitations have made it difficult if not impossible to compare research findings across settings and countries. Further, comparison across countries can be problematic because translation of instruments may not take cultural differences into account (Bowden & Fox-Rushby, 2003). We need a reliable and valid instrument for making accurate cross-cultural comparisons of QOL. The purpose of this project was to test an instrument for assessing QOL, the WHOQOL-100, which was developed as part of a multi-country consortium and the World Health Organization. The Canadian research team joined the international research group at a later time, after pilot testing of the WHOQOL-100 had been completed. As a result, our findings have not been previously reported and have not been compiled with the data from the other international centres.

Literature Review

Conceptualization and Measurement of QOL

QOL has been defined and measured in many different ways. The question of what constitutes QOL has been a focus of exploration and investigation since the days of the early philosophers. Aristotle and Aquinas wrote extensively about "the good life" (Adler, 1970, 1971; Molzahn & Kikuchi, 1998). The introduction of the concept into health research came at a time when the predominance of traditional medical outcomes such as mortality and morbidity was criticized because these outcomes did not represent the full range of potential outcomes of interventions. Recent years have seen the publication of numerous empirical studies (Fry, 2000; Spilker, 1996) addressing QOL in various health and illness contexts.

While some researchers have described QOL in terms of different indicators, such as social indicators, societal resources, infant mortality, economic situation, and community QOL, there is widespread agreement among researchers that the concept of QOL relates to the individual and must be based on individuals' subjective assessment of their own lives (Harrison et al., 1996). Further, it is generally agreed that QOL is a multidimensional construct (Fayers, 2000; Fry, 2000; Spilker, 1996).

Most researchers include physical, psychological, and social domains in their conceptualizations and instruments. Williams (1999) argues that the ideal assessment of QOL would include indicators of the person's physical health, social well-being, psychological functioning, environment, and spiritual well-being. Some researchers have chosen to simply use a set of independent scales that reflect one or more QOL domains. For example, in their study of QOL in assisted living settings, Mitchell and Kemp (2000) elected to use life satisfaction, depression, and satisfaction with the facility as indicators of QOL. Other researchers have used measures of depression, self-esteem, life satisfaction, functional status, and health status.

There is no single ideal measure of QOL. One of the well-known early measures, the Karnofsky scale, actually measures functional status (Karnofsky & Borchenal, 1949). The Karnofsky scale also involves ratings by health professionals, which are known to differ from ratings by the individuals themselves (McPherson & Addington-Hall, 2003; Molzahn, Northcott, & Dossetor, 1997). One of the best known and most popular measures used in QOL studies, the SF-36 (Ware & Sherbourne, 1992), is described by the authors as a measure of health and functional status. Many researchers mislabel these measures; it is important that the concept under study be clarified. QOL is broader than health and functional status; it is inherently subjective and pertains to all aspects of life that are important to the person. Health status typically refers to well-being in relation to the physical, psychological, and social aspects of one's life, while functional status pertains to what one is and is not able to do for oneself.

The creation, adaptation, and testing of measures have increased exponentially over the past 20 years in Europe and North America. Spilker (1996) describes 215 measures. Bowling (1995, 1997) and McDowell and Newell (1996) provide guides for the selection and use of some of these. The journal *Quality of Life Research* is filled with papers addressing the psychometric properties of various instruments. A number of Web sites list various QOL instruments and their properties (see American Thoracic Society, 2004; MAPI Research Institute, 2004). The MAPI Research Institute Web site includes reviews of 454 measures (not all of which actually measure QOL).

There remains a need to address cross-cultural measurement of QOL. It has been difficult to compare results across studies and countries when such a wide variety of instruments are used. Further, it has been difficult for researchers to use the same measure, because many measures are not appropriate for a variety of cultural groups. In recent years several international consortia of researchers have come together to address measurement of QOL in a cross-cultural context (e.g., Bonomi et al., 1996; Ware, Gandek, & IQOLA Project Group, 1994). The WHOQOL Group is one of these. Bowden and Fox-Rushby (2003) evaluated the processes used to translate and adapt nine generic health-related QOL instruments for use in Africa, Asia, Eastern Europe, the Middle East, and South America. They argue that many of the measures focus on the scales rather than on the concept and note that the WHOQOL approach is more likely to establish equivalence of the instrument across countries.

Development of the WHOQOL-100

The rationale for the development of the WHOQOL-100 — its conceptual background and proposed uses and the steps taken to develop the pilot version — has been described in detail in a number of publications (Power, Harper, Bullinger, & WHOQOL Group, 1999; World Health Organization Quality of Life [WHOQOL] Group, 1996, 1998a, 1998b). An agreed definition of QOL provided the starting point: "Quality of life is the individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment" (Szabo, 1996, p.

356). This definition drew on the World Health Organization's comprehensive approach to health and health care and was further supported by the focus group work that was used to inductively identify the components of QOL (Skevington, Sartorius, Amir, & WHOQOL Group, 2004).

The WHOQOL-100 was initially developed in 15 different countries (WHOQOL Group, 1995, 1996, 1998a, 1998b) and more than 30 centres are now involved in the project. Development of the pilot WHOQOL-100 included input at a conceptual level by culturally diverse centres. Thus, the base instrument was not provided by any one centre and then merely translated into other languages. Rather, a general instrument was produced through an iterative process that included the development of an agreed definition of QOL, agreed definitions of facets or particular characteristics of QOL and a large item pool reflecting those definitions, and, finally, an agreed set of items for the pilot version. Translation and back-translation methodology was used at all stages to ensure the applicability of different items and facets across different cultural groups. Response scales appropriate for each culture, rather than being merely translations from English, were also constructed (Sartorius & Kuyken, 1994). The net effect of this approach was the production of a subjectively defined measure of QOL.

The resulting instrument, the WHOQOL-100, consists of 100 items and six domains: physical health; psychological well-being; level of independence; social relationships; environment; and spirituality, religion, and personal beliefs. It has 24 facets or subdomains and four questions per facet. The factor structure was confirmed using confirmatory factor analysis, and the instrument was found to discriminate between healthy and ill populations (WHOQOL Group, 1998a). Some countries have developed supplementary national items for their language version of the instrument. No significant differences have been found in the performance of the scales when national items are added (Skevington, 1999). The instrument is available free of charge, in more than 40 languages, with the permission of the investigators from the respective collaborating centre (see World Health Organization, 2004).

Method

Sample

Convenience sampling was used for this study. The inclusion criteria were that participants be at least 19 years of age, able to read English, and willing to complete the questionnaire. A total of 144 people took part. All participants resided on Vancouver Island in the Canadian province of British Columbia. Most participants were recruited through a hospital outpatient clinic. They included people on dialysis (*n* = 32), people awaiting joint replacement surgery (*n* = 52), and people with various other health problems. A "healthy" population was recruited through a university and through snowball sampling. Posters were placed on university bulletin boards inviting individuals to complete a questionnaire. Of these people, 30 (20.6%) considered themselves to be "healthy," did not report health problems, and were not receiving ongoing medical or hospital care. For the purposes of the study, "health" was self-defined, but the sample excluded people with medical problems for which they were attending an outpatient clinic. No remuneration was offered to participants.

The participants ranged in age from 19 to 89 years with a mean age of 58 years (*SD* = 17.93); the sample tended to be older, consisting of 92 individuals over the age of 50 (64%) and 52 over the age of 70 (36%). Sixty-eight percent were married or living with a partner. Sixty-two of the participants (43.1%) were female, 73 were male (50.7%), and six (4.2%) did not identify their gender. The sample was well educated, with 52.1% reporting postsecondary education. Fourteen participants (7.2%) resided in a hospital or other medical-care facility.

Procedure

Permission was obtained from the ethics review committee of the hospital to seek participants through its outpatient clinics. In the case of the joint replacement clinics, the research assistant attended a preoperative teaching session, described the study, and invited participation. She also visited other clinics and the dialysis unit and left letters inviting participation. She was then contacted by individuals expressing an interest in completing the questionnaire. Healthy participants were recruited via notices posted at the university. Telephone follow-up was used for outpatients who had indicated an interest in participating but had not returned the questionnaire. Participants were also asked if they were willing to complete a second questionnaire 2 to 4 weeks after the first for the purpose of assessing test-retest reliability.

All participants completed a demographic data sheet, the *World Health Organization Quality of Life–100 Inventory* (WHOQOL-100), the SF-36 (McHorney, Ware, Lu, & Sherbourne, 1994), Cantril's (1965) Self-Anchoring Striving Scale (SASS), and a Visual Analogue Scale (VAS) for pain. Completed inventories, along with the form for collecting demographic data and the signed consent forms, were returned to the investigator in self-addressed stamped envelopes.

Instruments

WHOQOL-100. The WHOQOL-100 is an inventory designed to assess the perceptions of QOL in an individual. For this study, it was scored according to the guidelines of the developers (Harper & Power, n.d.). The WHOQOL provides 24 individual facet scores and one additional facet describing the person's overall rating of his or her QOL. It does not support aggregating facet and/or domain scores to obtain a total QOL score. The facets include pain and discomfort; energy and fatigue; and sleep and rest (in the physical health domain); positive feelings; thinking, learning, memory, and concentration; self-esteem; body image and appearance; and negative feelings (in the psychological well-being domain); mobility; activities of daily living; dependence on medicinal substances and medical aids; and work capacity (in the level of independence domain); personal relationships; social support; and sexual activity (in the social relationships domain); physical safety and security; home environment; financial resources; accessibility and quality of health and social care; opportunities for acquiring new information and skills; participation in and opportunities for recreation/leisure activities; physical environment; and transport (in the environment domain); and spirituality and personal beliefs (in the spirituality domain). The instrument was not modified for use in Canada and no new items or national items were added. Response scales were on a five-point Likert scale from lowest to highest possible scores. Higher scores denote perceptions of better QOL. Three facet scores that are negatively framed — pain, negative feelings, and dependence on medicinal substances and medical aids — were recoded to calculate domain scores that reflect higher QOL with higher scores. The 24-facet scores are combined to provide six domain scores. Each facet score is calculated by taking an average of the ratings for the four items within that facet. Within each domain, the facets that contribute to the domain score are summed and an average is taken, to yield a domain score. The facet score for spirituality is also taken as the domain score for spirituality. Scores on the WHOQOL-100 can be transformed to a 0–100 scale if necessary (Harper & Power).

Demographics

The participants completed a brief sociodemographic questionnaire: gender, date of birth, age, education level, and marital status. They also rated their health as good or poor. They were presented with a list of common health conditions (e.g., diabetes, hypertension, heart disease, kidney disease) and asked to indicate those that were a concern for them.

SF-36. The SF-36 was developed for the Medical Outcomes Study (McHorney et al., 1994) and has been used extensively over the last 10 years. The scale measures subjective health and functional status in eight domains: limitations in physical activities, limitations in usual role activities because of physical health problems, limitations in social activities, bodily pain, general mental health, limitations in usual role activities because of emotional problems, vitality, and general health perceptions. The reliability and validity of this scale have been demonstrated in numerous studies with various populations. Across patient groups, all subscales were found to be internally consistent (most with Cronbach's alpha above .8) and had satisfactory item-discriminant validity (McHorney et al.).

Cantril's Self-Anchoring Striving Scale, a measure of life satisfaction, has been used extensively with normal and patient populations (Cantril, 1965) in at least 12 countries, including Canada and the United States. It consists of a ladder with rungs that depict the best to worst possible life. Individuals indicate where they are on the ladder. Test-retest reliability of this scale was .79 after 6 weeks. Concurrent validity was demonstrated by correlations of .50 to .74 with the Index of Well-Being (Molzahn, 1989).

Visual Analogue Scale for Pain. All participants were asked to complete a visual analogue scale for pain. They were asked to rate their pain, on a 100 mm line, from no pain to extreme pain. Visual analogue scales have been shown to measure pain reliably and validly (Jensen, 2003).

Data Analysis

SPSS version 10 was used to conduct the data analysis. Frequencies and appropriate descriptive statistics were calculated for all variables. Spearman's rho was used to calculate correlations between variables. One-way analyses of variance were used to determine whether there were differences between the healthy group and the group with one or more health problems. These were confirmed using Bonferroni adjustments at $p < .05$.

Ethical Considerations

The study was approved by a university Human Ethics Review Committee and by a hospital Ethics Review Committee. Participants were asked to complete a consent form and return it with their questionnaire. The questionnaires were coded with a number to ensure confidentiality. Consent forms and inventories were labelled with participant identification codes and stored separately, under lock and key.

Findings

Stability (Test-Retest) Reliability

To test stability reliability, participants who volunteered to complete the instruments on a second occasion 2 to 4 weeks after the first administration were given a second questionnaire and asked to mail it back; 23

participants agreed to do so. The WHOQOL-100 was found to be relatively stable. Test-retest reliability ranged from .60 to .91 on the various domains, with the low of .60 for spirituality/personal beliefs. For the facets, test-retest reliability ranged from .61 to .94, with three exceptions: opportunities for new information and skills (*r* = .33), transportation (*r* = .42), and physical safety and security (*r* = .54) (see Table 1).

Table 1 ***Reliability of WHOQOL-100 Domains and Facets***

DOMAIN/Facet	***r*** **(*n* = 23)**	**α** **(*n* = 140)**
Physical health	.86**	.77
Pain and discomfort	.86**	.81
Energy and fatigue	.84**	.88
Sleep and rest	.89**	.94
Psychological	.78**	.79
Positive feelings	.64**	.82
Thinking, learning, memory, and concentration	.74**	.85
Self-esteem	.74**	.80
Body image	.76**	.84
Negative feelings	.81**	.90
Independence	.91**	.89
Mobility	.87**	.91
Adl	.79**	.89
Medications	.94**	.94
Work capacity	.73**	.95
Social relationships	.87**	.71
Personal relationships	.61**	.65
Social support	.77**	.84
Sexual activity	.86**	.84
Environment	.77**	.80
Physical safety and security	.54**	.83
Home environment	.67**	.84
Financial resources	.85**	.91
Health and social services	.77**	.82
Opportunities for new information	.33	.79
Leisure	.68**	.82
Physical environment	.57**	.61
Transportation	.42*	.89
Spirituality/personal beliefs	.60**	.89

Consistency Reliability

Cronbach's alpha was used to determine the internal consistency of the facets and domains. For the various facets, internal consistency ranged from a low of .61 for physical environment to a high of .95 for work capacity. For the domains, internal consistency ranged from .71 for social relationships to .89 for independence (see Table 1).

Concurrent Validity

Although there is no "gold standard" for the measurement of QOL, we examined correlations of the WHOQOL-100 with other measures, including the SASS, the SF-36, and the VAS for pain. There were moderately large and statistically significant correlations between the SASS and the various domains of the WHOQOL-100, with correlations of $r = .41$ ($p < .001$) between the SASS and the overall QOL item on the WHOQOL-100, $r = .66$ ($p < .001$) for the social relationships domain with the SASS, and $r = .62$ ($p < .001$) for the correlations between both physical health and psychological well-being domains with the SASS.

The WHOQOL-100 "overall" facet was correlated with the eight domains of the SF-36 ($r = .30$–63). In the area of physical functioning, comparisons between the WHOQOL-100 facets and domains with those of the SF-36 revealed strong correlations between related scales. The WHOQOL-100 physical functioning domain scores were highly correlated with scores on the SF-36 physical functioning scale ($r = .54$; $p < .001$), the SF-36 bodily pain scale ($r = .72$, $p < .001$), and the SF-36 vitality scale ($r = .75$, $p < .001$). The WHOQOL-100 facet for pain was correlated with the SF-36 vitality scale ($r = .82$, $p < .001$) and the SF-36 bodily pain scale ($r = .72$, $p < .001$). The WHOQOL-100 facets of energy ($r = .84$, $p < .001$), sleep ($r = .48$, $p < .001$), and participation/opportunity for recreation and leisure ($r = .53$, $p < .001$) were also correlated with the SF-36 vitality scale. As might be expected, the WHOQOL-100 facets of work capacity ($r = .63$, $p < .001$) and participation/opportunity for recreation/leisure ($r = .29$, $p < .001$) were correlated with the SF-36 role-physical scale.

In the psychosocial areas thought to contribute to QOL measured by the WHOQOL-100 and SF-36, significant correlations between responses were also found. The WHOQOL-100 facet, personal relationships, and WHOQOL-100 domain, social relationships, correlated with the SF-36 social functioning scale ($r = .32$ and .31, respectively; $p < .001$). The SF-36 role-emotional scale was correlated with the WHOQOL-100 facets participation/opportunity for recreation and leisure ($r = .26$, $p < .01$), work capacity ($r = .30$, $p < .001$) and WHOQOL-100 domain psychological functioning ($r = .45$, $p < .001$) with SF-36 role-emotional scale. The following WHOQOL-100 facets were found to be significantly correlated with the SF-36 mental health scale: positive feelings ($r = .55$, $p < .001$); negative feelings ($r = .55$, $p < .001$); thinking, learning, memory, and concentration ($r = .44$, $p < .001$); self-esteem ($r = .49$, $p < .001$); and the entire WHOQOL-100 psychological domain ($r = .67$, $p < .001$).

As predicted, there were negative correlations between the VAS for pain and the various domains of the WHOQOL-100, ranging from -.25 for the relationship between social relationships on the WHOQOL-100 with the VAS for pain and -.57 for physical health on the WHOQOL-100 with VAS for pain.

Discriminatory Power

It was important for us to determine whether QOL scores reflected differences in health status. It was predicted that people who considered themselves to be healthy would have higher QOL scores than those who reported one or more health problems. We examined QOL scores for statistically significant differences between the two groups. The healthy group consisted of healthy volunteers from the university. One-way ANOVA was used to compare the mean scores of respondents who reported no health problems and those who reported one or more problems. As predicted, the instrument was able to discriminate between the two groups on overall assessment of QOL and three of the domains — physical health, psychological well-being, and level of independence — that are most likely to be affected by illness. People who reported no health problems had a higher QOL than those with one or more health problems on the overall ($F = 7.10$; $p < .01$) physical ($F = 12.75$; $p < .01$), psychological ($F = 5.95$; $p < .05$), social ($F < 1.0$; ns), environment ($F < 1.0$; ns), and spirituality domains ($F = 2.25$; ns). As one might expect, there were no statistically significant differences between the groups on social relationships, environment, and spirituality/personal beliefs.

Discussion

The WHOQOL-100 was field-tested with a sample of 144 people on Vancouver Island, British Columbia, Canada. While this is not a representative sample, the findings are similar to those of other field tests of the instrument with English-speaking people (Bonomi, Patrick, Bushnell, & Martin, 2000; Skevington, 1999; WHOQOL Group, 1998a).

Stability reliability for the domains was generally good, with correlations ranging from .6 on the spiritual domain to .91 on the independence domain. Bonomi et al. (2000) report similar stability reliability of the domains using an intraclass correlation coefficient; they found that reliability ranged from .83 on the physical domain to .96 on the independence domain in 64 healthy people completing the instruments 2 weeks apart in the absence of life-altering events. It is not clear why test-retest reliability for the facets "transportation" and "opportunities for new information" was low in this study. It is possible that something occurred in the community to change individuals' perceptions about these areas or that the wording of the items was unclear. Also, the reason for the modest stability reliability coefficient (.6) for the domain of personal beliefs/spirituality is not clear. It is unlikely that there would be a change in personal beliefs over the period between the two administrations of the questionnaire when the scores on the other domains remained fairly constant. Otherwise, test-retest reliability was acceptable for the various domains. It is interesting to note that few researchers have actually assessed stability reliability and that those who have assessed it report scores for the domains and not the facets.

In this study, the consistency reliabilities for the various domains were in the acceptable range, from .71 for the social domain to .89 for the independence domain. However, for the facets, the reliability for physical environment was lower (.61), followed by personal relationships (.65). The lower number of questions in the facets partially explains the lower consistency reliability. Even though accepted minimum standards for alpha coefficients are .7 for group comparisons, it is not uncommon to observe an alpha of less than .7 with subscales in some instruments (Bonomi et al., 2000). Other investigators report similar Cronbach's alphas for internal consistency of the domains but do not report findings for the facets, which makes it difficult to compare these findings (Bonomi et al, 2000; Power et al., 1999; Skevington, 1999; WHOQOL Group, 1998a).

Although all correlations between the WHOQOL-100 and other measures examined were statistically significant, some of the correlations were less than the range of 0.40 to 0.80 reflecting good criterion validity. In particular, we expected a higher correlation between the SASS and the overall QOL item on the WHOQOL-100 (0.41); this may be explained, at least in part, by the observation that QOL and life satisfaction are different but related concepts. The correlations between the SASS and the various domains of the WHOQOL-100 were moderately large, and there were strong correlations between the WHOQOL-100 domain scores with similar SF-36 domains. There were lower correlations between the WHOQOL-100 facets participation/ opportunity for recreation/leisure ($r = .29$, $p < .001$) and the SF-36 role-physical scale, but this might be explained by the differences between the concepts. In the WHOQOL-100 social domain, moderately low ($r = .32$) relationships were found with the social functioning scale of the SF-36; this might be explained by the fact that the latter instrument focuses on function rather than satisfaction. Bonomi et al. (2000), in the United States, note that while 77% of their predicted correlations for the WHOQOL-100 domains were upheld for the SF-36, convergent validity was not consistently supported.

In relation to discriminatory power, in most domains healthy people had better QOL than those with one or more health problems, but it is worth noting that healthy people did not consistently rate QOL higher than people with multiple health problems, especially in the social, environmental, and spiritual domains. Similar findings are reported from Britain in relation to spiritual and psychological domains (Skevington, 1999). This raises questions regarding how illness impacts on QOL. We typically assume that illness affects all areas of QOL, but that is not necessarily the case; the effects may differ depending on the nature of the illness and on the individual. For instance, a life-threatening illness such as cancer may have a greater negative impact on the spiritual domain of QOL than a well-controlled chronic illness such as asthma or arthritis.

Suggestions for Future Research

At this time, we are not recommending any changes to the items or the overall structure of the instrument. While reliability and validity could have been better in a few areas, confirmatory factor analyses support the factor structure of the instrument (Power et al., 1999; WHOQOL Group, 1998a). We recommend use and testing of the instrument with a wider range of samples to ensure that the noted effects were not spurious.

Further examination of the reliability of these items with a larger, more representative sample is recommended. Assessing criterion validity with another multidimensional global QOL measure, such as Ferrans and Powers's (1992) Quality of Life Index or Flanagan's Quality of Life Scale (Burkhart, Anderson, Archenholtz, & Hagg, 2003), in addition to the SF-36 and the SASS, would be advisable. Little research has actually examined the stability or reproducibility reliability of the instrument, and this should be the focus of further research.

Further evaluation of the instrument with other samples and populations is advisable before it is used with special populations. Research is also needed to clarify whether the instrument is appropriate for all age groups; it has not been tested with children or adolescents, and it may be that some of the items need modification for older adults.

While the WHOQOL-100 has been used in many studies and is often employed in cross-national cross-cultural studies, its use in the Canadian context has been limited. Given Canada's cultural diversity, further work should be done to examine the appropriateness of various language versions for the study of cultural and minority communities.

Potential Applications of the Instrument

While there is still no perfect QOL instrument, the WHOQOL-100 is a reasonable choice for the comprehensive measurement of QOL in health-care settings, particularly with young and middle-aged adults. Because this instrument measures QOL from the perspective of the individual across important domains, it is more useful for a wide range of health-care settings than many other QOL measures that focus on specific diseases.

The instrument has numerous potential applications in mental health settings, among people with depression, schizophrenia, and other disorders. Orsel, Akdemir, and Dag (2004) examined the reliability of the WHOQOL among 54 stabilized patients diagnosed with schizophrenia and 49 healthy matched subjects in Turkey. They report that it is "a reliable subjective QOL scale for patients diagnosed with schizophrenia" but recommend further testing in large follow-up studies to assess its clinical sensitivity. The WHOQOL has also been validated with people receiving antidepressant medications (Skevington & Wright, 2001) and people with chronic pain (Skevington, Carse, & Williams, 2001).

For some clinical applications, a shorter version of the instrument, the WHOQOL-BREF, may be more appropriate (WHOQOL Group, 1998b). The BREF consists of 26 items and four facets and is useful with clinical samples where fatigue is likely to be an issue or when multiple measures are planned. It may be useful to augment it with disease-specific measures in clinical trials assessing the efficacy of specific interventions. The factor structure of the BREF is somewhat different; the spirituality domain is combined with the psychological well-being domain and the physical health domain is combined with level of independence. It has also undergone considerable testing (WHOQOL Group, 1998b).

Further work is being done on the development of supplementary modules for people with HIV/AIDS (O'Connell, Skevington, Saxena, & WHOQOL-HIV Group, 2003), for older adults (Power, Quinn, Schmdt, & WHOQOL-OLD Group, 2005; World Health Organization Regional Office for Europe, 2005), and for people with developmental disabilities (M. Power, personal communication, October 5, 2004). In addition, a group has developed a module on spirituality (WHOQOL SRPB Group, 2006).

Limitations

The study has a number of limitations. The sample was a convenience sample and not representative of any wider population. There may have been some biases in sampling by virtue of self-selection of the participants. The size of the sample was also limited, particularly for the assessment of test-retest reliability.

Summary and Conclusions

Overall, the WHOQOL-100 performed fairly well in this sample. There was evidence of test-retest reliability, consistency reliability, and concurrent validity. As well, it appears that the instrument was able to discriminate on the physical, psychological, and independence domains between people who considered themselves to be healthy and those with health concerns. QOL is an important health outcome and nurse researchers may wish to consider use of the WHOQOL-100 measure in their studies. Further testing is recommended with diverse populations.

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Résumé

Les soins auto-administrés du point de vue des personnes vivant avec le diabète

Shannon M. Spenceley et Beverly A. Williams

Cette étude présente les résultats d'une importante revue intégrative de la recherche sur les obstacles et les facilitateurs des soins auto-administrés selon le point de vue des personnes atteintes de diabète. La réalisation de l'étude a été motivée par un besoin de comprendre les soins auto-administrés selon la perspective des personnes vivant avec cette maladie chronique et d'explorer les implications de cette compréhension sur les politiques de santé au Canada. Des articles et des dissertations explorant les soins auto-administrés du point de vue d'adultes souffrant de diabète de type I ou II et publiés en anglais entre 1993 et 2003 ont été analysés, et des études tant quantitatives que qualitatives ont été considérées. Comme les études s'appuyaient sur différentes définitions des soins auto-administrés, les facilitateurs et obstacles ont été définis en conséquence. Une tension thématique globale était évidente, causée par une vision des soins auto-administrés comme soit tournant autour de la maladie, soit évoluant dans la vie des personnes atteintes de diabète. Cette tension a des implications pour les professionnels de la santé et pour les personnes prenant part à l'élaboration des politiques liées aux soins auto-administrés.

Mots clés : Soins auto-administrés, gestion de la maladie, diabète, revue intégrative de la littérature

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Self-Care from the Perspective of People Living with Diabetes

Shannon M. Spenceley and Beverly A. Williams

This review presents findings from a critical integrative review of research into barriers to and facilitators of self-care from the perspective of people with diabetes. The review was motivated by a perceived need to understand self-care from the perspective of those living with this chronic disease and to explore the implications of this understanding for health-care policy in Canada. Journal manuscripts and dissertations exploring self-care from the perspective of adults with type I or type II diabetes and published in English between 1993 and 2003 were reviewed. Both quantitative and qualitative studies were included. Studies were informed by varying definitions of self-care and facilitators and barriers emerged accordingly. An overarching thematic tension was evident, based on a view of self-care as revolving around the disease or evolving in the lives of people with diabetes. This tension has implications for health professionals and for those involved in policy development related to self-care.

Keywords: Self-care, disease management, diabetes, integrative literature review

The World Health Organization (2005) describes the global rise in diabetes prevalence since 1985 as "epidemic" in proportions. Diabetes is a significant and growing health concern in Canada, with more than two million people estimated to be living with the disease (Canadian Diabetes Association, 2005a). With self-care an essential feature of diabetes management, effective health care and health policy must be sensitive to the self-care needs of these individuals. This paper presents findings from a critical integrative review of research into barriers to and facilitators of self-care from the perspective of people living with diabetes. It focuses on all research that examines self-care from the perspective of adults with either type I or type II diabetes, and concludes with a discussion of implications for health-related public policy, particularly in the Canadian context.

Methods

An integrative literature review examines empirical or theoretical work around a particular topic. It may be narrow or broad in focus, and may employ a broad sampling frame that includes qualitative, quantitative, or purely theoretic literature (Whittemore, 2005). While less focused than other types of synthesis such as meta-analyses or systematic reviews, an integrative review should follow a research protocol that is set up in advance of the literature search. The review is guided by a specific question, terms and variables are defined, search terms and strategies employed are described, criteria for study selection are provided, and the quality of the primary studies is appraised (Whittemore). These elements will now be described as they were implemented in the present review.

Search Protocol

The review protocol addressed the following question: *What are the barriers to and facilitators of successful self-care from the perspective of adults living with diabetes?* Self-care was defined as all health/illness-related decisions and activities carried out by individuals or families related to managing and/or coping with diabetes and/or improving health while living with diabetes. Barriers to self-care were defined as factors that made self-care more difficult and facilitators as factors that made it easier, from the ill person's point of view. Studies had to include a specific exploration of the ill person's perspective. Journal manuscripts and dissertations that explored self-care from the perspective of adults living with diabetes and published in English between 1993 and 2003 were included. There were no restrictions placed on research design, as the aim was to gain an inclusive view of the knowledge about self-care and living with diabetes. The value of exploring the "contradiction and tension between findings generated by different methods" in self-care research, in order to gain a multi-dimensional view of the phenomenon under study, has been noted by others (Meetoo & Temple, 2003, p. 7) and is consistent with the integrative review approach.

In consultation with a University of Alberta health sciences librarian, nine databases were selected and specific search strategies were developed. Databases searched included the Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBASE, Medline, HealthStar, and PsycINFO. These databases support controlled search vocabularies, and a strategy was designed to capture published research of all types that focused on self-care, self-management, or self-help in the target period. Keyword searches (self care or self manage or self help) were also conducted in non-periodical databases: the Database of Abstracts of Reviews of Effects (DARE), the Cochrane Database of Systematic Reviews, Medline in Process (current), and Allied and Complementary Medicine (AMED). The online search strategy was supplemented by a manual search of reference lists of articles selected for complete review. Data were managed using Procite™ bibliographic software (version 5) and the outcomes of decision processes were captured using Excel™ (2002 version).

Search Results and Selection Criteria

A review of 461 abstracts against predetermined exclusion criteria (see Table 1) resulted in the selection of 42 papers that explored self-care in diabetes. The majority of the papers focused on type II diabetes, surely reflecting the much greater prevalence of this form of the disease worldwide (World Health Organization, 2005). At this stage of the review, the decision was made to include studies of self-care in both types of chronic diabetes. This decision was premised on our having chosen to

Table 1 *Criteria and Questions*

Exclusion criteria

- non-research items, including editorials, commentary, letters, descriptive articles
- work that relates only to diabetes or health care for diabetes in general or that mentions but does not explore self-care
- work that investigates associations between particular factors or characteristics and the incidence or frequency of self-care behaviours without any exploration of the person's perspective on what made self-care easier or more difficult
- research focused on tool development only
- research focused on gestational diabetes
- program evaluation research that does not specifically explore the impact of the program on perceived barriers to or facilitators of self-care

Questions used to interrogate reviewed papers

- Is the research specifically about barriers/challenges to self-care as related to diabetes management (i.e., self-care or components of self-care as dependent variable or outcome of interest, with research focused on impacts of barriers, facilitators)?
- Do the researchers specifically seek the perspective of participants living with diabetes?
- Is the research about effective strategies for promoting self-care in diabetes (i.e., intervention research with self-care or components of self-care as outcome of interest, with research focused on ways of facilitating self-care)?
- Does the research explore self-care facilitation or impedance as related to outcome measures of related concepts: coping, self-management, self-efficacy, mastery, self-help, empowerment?

focus the review on self-care as well as the observation that the elements of self-care are very similar in type I and type II diabetes (Canadian Diabetes Association 2005a). We believed that we could learn valuable lessons by keeping the focus upon self-care while remaining sensitive to any differences that emerged in terms of the processes of self-care in the two chronic forms of the disease.

All 42 papers were reviewed against a series of questions developed by the authors (see Table 1). We were clear about what we would accept as evidence that self-care is indeed "easier" as a result of particular factors. It was decided that "easier" self-care would be evidenced by an expressed (a) perception of increased ability to assume responsibility for and to direct self-care; (b) feeling of comfort, confidence, or "success" in self-care; or (c) feeling of being supported or reinforced in self-care efforts as a result of particular factors. We excluded studies that simply reported increased incidence or frequency of self-care activity as an outcome, unless a specific attempt had been made to seek the patient/client's point of view about the role of particular factors in increasing personal self-care ability. Any systematic attempt to gain the patient/client's perspective was deemed eligible, including a survey, interview, or questionnaire. At this stage we reached consensus on 22 studies: 13 qualitative, seven quantitative, and two mixed method. These 22 studies were accepted into the next phase of the review process. Manual searching of the reference lists resulted in the selection of eight additional works for review; none of these satisfied all inclusion criteria and all were excluded from the review.

Quality appraisal of primary research is difficult and complex; there is no "gold standard" for assessing quality, particularly when different designs are included (Whittemore, 2005). Such concerns notwithstanding, a consistent method of quality assessment that includes independent appraisal is an important aspect of any integrative review (Whittemore). The 13 qualitative studies were assessed by the first author and an independent rater using a modified research appraisal tool based upon the work of Duffy (1985), Eakin and Mykhalovskiy (2003), and Mays and Pope (2000). The modified instrument was reviewed for content validity by an expert in qualitative health research, and the process of appraisal was guided by the following assumptions: (a) qualitative and quantitative research are methodologically and epistemologically distinct; (b) qualitative research reports must, at a minimum, accurately and completely describe the procedures followed in the research process; (c) procedural correctness alone is insufficient; and (d) a key consideration in appraisal is how the author enables the reader to access the substantive contribution of a study to new or existing knowledge about the topic of inquiry. Therefore, the tool was constructed to assess procedural rigour as well as the study's substantive contribution to our understanding of self-care in diabetes. This approach also facilitated analysis, in that it allowed for the capture of analytic thoughts/questions in the form of memos. This provided the basis for an iterative process of moving back and forth among studies, informing analytic discussions between the two authors, connecting substantive findings, and comparing key assumptions and definitions. This activity also supported the selection of key elements for subsequent data extraction.

The seven quantitative studies were assessed using a modified appraisal tool developed by Cummings and Estabrooks (2003) and Estabrooks, Floyd, Scott-Findlay, O'Leary, and Gushta (2003). Modifications to the quantitative instrument were reviewed in detail with one of its primary authors (G. Cummings, personal communication, July 8, 2004). In order to extend the memoing process to the assessment of the quantitative studies, a further modification of this instrument evolved as the review progressed. Both tools were used to appraise two mixed-method studies. Six studies (three qualitative, three quantitative) were excluded on grounds of quality. This review ultimately included 16 studies (Table 2), 10 exploring self-care in type II diabetes, five focusing on type I, and one that included participants with both forms of the disease (see Table 3).

Findings

The key elements extracted from the studies included the research aim(s), theoretical framework, study design, instruments and sampling procedures, participants, setting, analytic procedures, and identified barriers to or facilitators of self-care. The studies were then carefully reviewed in order to capture key underlying assumptions and explicit or implicit definitions of self-care. To better understand the underlying structure of the existing knowledge, barriers to and facilitators of self-care were coded and thematically grouped by definition of self-care and related self-care assumptions.

Barriers to Self-Care

The most common studies were those informed by a definition of self-care as disease self-management and symptom control based on adherence to the advice of health-care experts. Of the seven studies, five dealt with type II diabetes and two with type I (see Table 3). Barriers described across these studies were similar. The only notable difference was that the studies of type I noted the burdensome nature of frequent injections (Mollem, Snoek, & Heine, 1996) and of monitoring and controlling symptoms related to blood sugar levels (Mollem et al.; Wdowik, Kendall, & Harris, 1997). All seven studies described barriers to

Table 2 ***Studies Included in the Review***

First Author (Year)	**Country**	**Publication**	**Design**
Cagle (2002)	United States	*Ethnicity and Disease*	Qualitative
Cooper (2003)	United Kingdom	*Health Education and Research*	Qualitative
Greenhalgh (1998)	United Kingdom	*British Medical Journal*	Qualitative
Hunt (1998)	United States	*Journal of Family Practice*	Qualitative
Jayne (1993)	United States	Doctoral dissertation	Qualitative
Maillet (1996)	United States	*Diabetes Educator*	Qualitative
Mollem (1996)	Canada	*Patient Education and Counseling*	Quantitative survey
Paterson (2000)	Canada	*Clinical Nursing Research*	Qualitative
Schoenberg (2001)	United States	*Journal of Aging and Health*	Mixed method
Shultz (2001)	United States	*Journal of Health Communication*	Quantitative survey
Simmons (1998)	New Zealand	*Diabetic Medicine*	Mixed method
Thorne (2001)	Canada	*Patient Education and Counseling*	Qualitative
Tu (1993)	United States	*Journal of Community Health Nursing*	Quantitative survey
von Goeler (2003)	United States	*Diabetes Educator*	Quantitative survey
Wdowik (1997)	United States	*Diabetes Educator*	Qualitative
Weiss (1997)	United States	Doctoral dissertation	Qualitative

self-care inherent in the rigidity and burdensome nature of diabetes management regimes (particularly dietary restrictions and exercise expectations) within the constraints of time, resources, and physical capacity, with motivation to follow restrictions reported as difficult to maintain. Self-care was hindered by challenges arising out of anxiety or social expectations (Maillet, Melkus, & Spollet, 1996; Mollem et al.; Schultz, Sprague, Branen, & Lambeth, 2001; von Goeler, Rosal, Ockene, Scavron, & DeTorrijos, 2003) and the demands of managing multiple chronic disease regimens (Simmons et al., 1998) or chronic pain (von Goeler et al.). Also described were a lack of understanding and inadequate education related to the knowledge and skills required to manage diabetes or prevent complications (Maillet et al.; Simmons et al.; von Goeler et al.) and a lack of confidence in using the tools of self-monitoring (Simmons et al.; Tu & Barchard, 1993; von Goeler et al.). Also noted were a fear of frequent injections and uncertainty about the future (von Goeler et al.). Barriers to compliance were the financial costs of diabetes self-care (Tu & Barchard; von Goeler et al.; Wdowik et al.) and poor or unsafe living conditions (Maillet et al.). This form of self-care was hindered by conflicting social roles, social pressures, and family expectations that the needs of others be put first (Maillet et al.; Schultz et al.). Competing life priorities and stress also created barriers to one's ability to manage diabetes as directed (Mollem et al.; von Goeler et al.; Wdowik et al.). Other barriers to self-care were inadequate family and community support, perceived language or communication barriers, and unrealistic expectations by health professionals (Maillet et al.; Simmons et al., 1998; von Goeler et al.). Also noted were structural or cultural barriers in the design and accessibility of services (Simmons et al.).

Two studies focused on self-care as a personal responsibility and as the outcome of lay-initiated choices about health; one study focused on older women with type II diabetes (Schoenberg & Drungle, 2001), the other on adults with hypertension and either type I or type II (Weiss, 1997). Adherence to health-care advice was identified as an important component of diabetes self-care, but personal factors were also acknowledged as influencing one's ability to make positive choices related to diabetes management. Barriers to making positive choices noted in both studies included a lack of resources such as money, knowledge, skills, time, energy, and physical ability to engage in what were perceived as complex planning and diabetes management activities. A lack of family understanding and support, along with social pressures to put the needs of others first, contributed to feelings of social isolation and created barriers to positive self-care (Weiss). Other barriers were fear and uncertainty about a future life with diabetes and lack of confidence in ability to self-monitor and manage the disease (Weiss). Self-care was also

Table 3 *Definitions of Self-Care and Related Barriers and Facilitators*

First Author (Year)	Definitions of Self-Care	Barriers	Facilitators
‡ Schoenberg (2001) ♓ Weiss (1997)	An individual's responsibility and a result of lay decisions about appropriate behaviour to benefit health, prevent further illness, limit illness, restore health, and maintain independence; based on rules of adherence and on factors arising from a personal perspective	Lack of money, knowledge, skills, time, energy, physical capacity, support; social isolation; lack of access to health care; lack of continuity of care; overwhelming needs of others; stress	Realizing benefits of self-care; mutual trust, respect, collegiality in health-care relationships; support of a self-care partner; timely self-care information; connecting past choices with present health and future risks; comparing self with positive and negative self-care examples in others
‡ Maillet (1996) † Mollem (1996) ‡ Schultz (2001) ‡ Simmons (1998) ‡ Tu (1993) ‡ von Goeler (2003) † Wdowik (1997)	Self-management of diabetes by self-administration of medical therapies; synonymous with symptom control and disease management	Costs; rigid, burdensome regimens conflicting with life priorities and with other regimens; unrealistic provider goals; lack of community support; little or no access to services; sociocultural pressures; belief that cause and cure are non-medical; communication barriers; lack of instruction; inability to use tools; lack of confidence in self or in therapy; environmental or personal barriers to exercise; situational challenges to blood sugar control	Supportive self-care partners or networks of social support; family support Fear of complications

‡ Cooper (2003) † Jayne (1993) † Paterson (2000) † Thorne (2001)	An evolutionary process of developing knowledge by learning to live with the complexity of diabetes in a social context	Discomfort with public exposure; fear of stigmatization; low self-esteem; standardized, reactive compliance advice; lack of ongoing education in regimen modification; health professionals "enamoured of the science" and resistant to partnership	Experiencing and confronting barriers to compliance; losing faith in health professional's ability to manage the disease; support in learning to live with unpredictability and accepting that perfect control is unrealistic; recruiting trusted self-care partners; providers who acknowledge that science is limited, that patients are as knowledgeable, and that self-care is complex; education that supports the evolution of client expertise and "real world" self-care; opportunities to share and reflect with supportive peers; "routinization" of self-care; vigilant body-listening, monitoring, and tracking
‡ Cagle (2002) ‡ Hunt (1998) ‡ Greenhalgh (1998)	Decisions made to manage illness in a sociocultural context based upon sociocultural belief systems; balancing disease with fulfilling expected roles	Cultural beliefs; advice in conflict with cultural values, rituals, and social roles; social isolation; stigma; discrimination; financial hardship; confusion about insurance coverage; language barriers	Strong connections to social networks; role-preserving assistance of caregivers

‡ Type II diabetes † Type I diabetes ϰ Both types I and II diabetes

hampered by a lack of both access to quality health services and continuity in health-care relationships (Schoenberg & Drungle).

Self-care as a complex balancing act regarding decisions about managing diabetes and fulfilling expected social roles was the basis of three studies, all on type II (Table 3). Barriers emerged when cultural beliefs, ethnicity, and the demands of social roles clashed with the expectations of the medical culture or of society. The cultural belief that a person with diabetes should take a passive role in health-care relationships caused people to avoid asking for information about self-care (Greenhalgh, Helman, & Chowdhury, 1998). Differing beliefs about illness causation, appropriate therapies, and the meaning of symptoms also caused conflict within health-care relationships (Greenhalgh et al.; Hunt, Pugh, & Valenzuela, 1998). A belief that taking medication represents worsening disease or weakness caused a sense of stigmatization and social isolation, and perceived negative judgement by others brought reluctance to engage in visible self-care activities (Cagle, Appel, Skelly, & Carter-Edwards, 2002). The belief that diabetes is not really a health threat led to a reluctance to follow medical advice; this was particularly evident when following medical advice conflicted with the demands of social roles or one's ability to participate in cherished rituals (Cagle et al.; Hunt et al.). Persistent symptoms and physical limitations further impaired self-care ability and functioning in social roles (Cagle et al.; Hunt et al.). Financial constraints and living in impoverished, unsafe neighbourhoods made it difficult for people to access diabetes management supplies and to engage in recommended exercise (Greenhalgh et al.; Hunt et al.). Because of language barriers, some people had difficulty understanding written or verbal communication from providers (Greenhalgh et al.); some people also experienced difficulty understanding health-care benefit plans (Cagle et al.; Greenhalgh et al.). Individuals also reported discrimination in employment settings and in access to health services (Cagle et al.).

Finally, four studies were founded on a definition of self-care as an evolutionary process whereby self-care knowledge develops over time as the individual lives with this complex disease; three of these studies focused on people with type I diabetes, one on those with type II (see Table 3). Barriers to self-care from this point of view included health professionals being resistant to working in partnership (Cooper, Booth, & Gill, 2003) or being too "enamoured of the science" (Thorne & Paterson, 2001, p. 87) to see other sources of self-care knowledge as legitimate. A related barrier was the propensity for health professionals to provide standardized advice and static rules of self-care, when what was needed was dynamic problem-solving assistance with regimen modification (Cooper et al.; Jayne, 1993; Thorne & Paterson, 2001). Also noted were barriers associated with low self-esteem (Jayne) and with unsupportive social contexts, where visible disease-management behaviour caused a fear of stigmatization (Jayne).

Facilitators of Self-Care

Among the seven studies that emphasized diabetes management and symptom control based on adherence to medical advice (Table 3), five did not describe any facilitating factors. Self-care assistance and support from family members was identified as facilitative in one study (Maillett et al., 1996) and assistance from social networks was identified as facilitative in another (Wdowik et al., 1997). Fear of diabetes complications was also described as a strong motivator of compliance (Maillet et al.). Facilitators were discussed in one of the two studies that emphasized individual responsibility for positive choices (Table 3). These included health-care relationships characterized by trust, respect, collegiality, and the sharing of timely, relevant self-care information (Weiss, 1997). Examining one's present health in light of past choices and future risks and comparing one's self-care behaviour, both positive and negative, with that of others were identified as helpful to the achievement of effective self-care. The facilitative impact of achieving health benefits from positive self-care choices was also noted (Weiss).

In the studies conceptualizing self-care within a sociocultural context (Table 3), decisions about managing diabetes were based on a cultural understanding of diabetes self-care. Strong connections to community social networks, church, and close friends (Cagle et al., 2002) and self-care assistance from a spouse were identified as helpful in maintaining an expected social role or image (Hunt et al., 1998).

The final group of studies (Table 3) focused on the importance of health-care partnerships characterized by trust, respect, empathy, and shared decision-making in the development and evolution of diabetes self-care knowledge (Cooper et al., 2003; Paterson & Thorne, 2000; Thorne & Paterson, 2001). Facilitating factors in the health-care relationship included acknowledgement of the complexity of diabetes self-care and the value of the knowledge gained from living with a chronic condition (Cooper et al.; Thorne & Paterson, 2001). The importance of creating opportunities for self-care knowledge to evolve and integrate with life experience was emphasized (Cooper et al.; Jayne, 1993). Shared reflection with health professionals and other self-care partners or peers on what self-care is like in the real world was of great benefit (Cooper et al.; Paterson & Thorne). Assistance from supportive others in building diabetes self-care routines was essential, and developing skills in listening to one's own body, monitoring responses to particular situations, and tracking trends was critical to diabetes self-care (Thorne & Paterson, 2001.

Barriers as Facilitators of Self-Care Evolution

An interesting observation emerged from the thematic grouping of the barriers and facilitators by definition of self-care. Factors that emerged as barriers to diabetes self-care according to one definition were identified as facilitators of self-care evolution according to another. In the majority of studies, self-care was understood to be disease management and symptom control based upon compliance with medical advice (Table 3). In these studies, self-care entailed following rigid regimens, meeting provider expectations, and complying with static rules. In the face of life's complexities, the burdensome nature of prescribed self-care and the unrealistic expectations of providers emerged as strong barriers to compliance, making it very difficult to achieve self-care (according to the definition of self-care operant in these studies). These studies described disillusionment with advice that did not work very well and anger at having to abandon cherished activities or traditions. In contrast, in studies that defined self-care as an evolutionary, developmental process (Table 3) these same barriers to compliance were framed as facilitators of learning. The acknowledgement and confrontation of these very barriers to compliance facilitated an evolution towards an ability to live with unpredictability and to respond knowledgably and flexibly to challenges as they arose (Jayne, 1993; Paterson & Thorne, 2000). Indeed, barriers to self-care that emerged from within this definition included the standard educational approaches that are the hallmark of most disease-management programs; such approaches were identified as offering no creative solutions for self-care puzzles encountered in the course of living life with diabetes.

Discussion

Extending knowledge in an area of scholarly endeavour requires sensitivity to assumptions underpinning the existing research (Paterson, Canam, Joachim, & Thorne, 2003; Shadish, 1993) and an awareness of the assumptions and biases brought to the synthesis of that research. We surfaced and questioned our own assumptions in approaching this review, including our underlying belief that self-care is a desirable outcome of health-care relationships with people living with chronic illness, and that patients/clients would ultimately favour being self-care experts. These assumptions most certainly influenced our interpretation of the findings. As Paterson and Thorne (2000) note, however, until much more is known about the evolution of self-care expertise and the outcomes of assuming the expert role, blanket assumptions about patients/clients wishing to take on that role are untenable. Underlying assumptions in the studies were also examined. These were coded, extracted as data, and then recoded by definition of self-care. While it is obvious that the barriers to or facilitators of self-care would be viewed according to what the researchers perceived self-care to be, we noted that with few exceptions (Paterson & Thorne; Thorne & Paterson, 2001) the assumptions about self-care underpinning much of the literature were not surfaced or questioned. We therefore believed it would be useful to stand back from the synthesis and identify any overall patterns in these assumptions. We identified an overarching thematic tension in the synthesized literature between a disease-centred and a life-centred conceptualization of diabetes self-care (Figure 1).

In a disease-centred approach to diabetes self-care, there was a focus on laboratory markers as a measure of adherence to medical advice. Individual choice was limited to a list of rules and restrictions and self-care was considered a solitary activity. Practitioners were considered the self-care experts, emphasizing compliance and control. Self-care education was standardized and based on rigorous scientific evidence. Clearly, self-care was about managing diabetes.

In a life-centred approach to diabetes self-care, individuals were encouraged to listen to and gradually develop trust in what their bodies were telling them. Self-care adjustments might be made simultaneously in various aspects of diabetes care, and were made according to individually relevant guidelines. Diabetes self-care was considered evolutionary, calling for constant readjustment based on individual requirements. Practitioners acknowledged self-care as a personal journey, and were often considered trusted partners on this journey. Self-care education was anticipatory, and the health practitioner helped to mobilize both internal and external resources with the individual and significant others. The person with diabetes was considered the expert on his or her own care. It was evident in studies focusing on the individual and personally meaningful nature of self-care, however, that self-care was about learning to live a unique life well with diabetes.

We suggest that the tension between these two perspectives is an important factor in the development of self-care ability. Over time, the nature of diabetes self-care changed. Paterson and Thorne (2000) identified elements or phases of the evolution of self-care ability, which varied from person to person in sequence and occurrence but seemed to arise out of the tension between the disease taking control of life and taking control of the disease within life as lived. However, this tension may go unrecognized within the dominant view of disease-centred self-care. Indeed, if surfaced at all, such tension is likely to be dismissed as the

Figure 1 *Thematic Tensions Identified in Reviewed Literature*

Underlying Assumptions about Diabetes Self-Care

	Disease-Centred	**Life-Centred** →
People living with chronic disease	Individual concept	Relational concept
	Focus on signs, laboratory markers	Focus on tuning in to body
	Adherence to advice	Making sense of advice
	Restrictions, rules imposed on life	Seeking normality in complexity of life
	A list of discrete choices	Self-care as a dynamic, fluid process
	Self-care is about disease management	Self-care is about living life
Health professionals	Self-care is about the health-care system	Self-care is a personal journey
	The health professional role is about stewardship	Health professional is part of a trusting partnership
	Providing resources	Working with people to mobilize resources
	Relying on measuring the body, illness	Trusting person to know the lived body
	Standardized advice/scientific evidence	Reciprocity of information and lived experience
	Self-care is uniform, static	Self-care is learned, evolutionary
	Compliance/control priorities	Adjusting, tailoring care to life priorities
	Certainty	Living well with uncertainty
	The health professional is the expert	Ill person is the best expert on self
	Sick role is dominant	Multiple life roles take priority
	Disease as malfunction	Illness as part of life
	Disease management is foreground	Managing the disease is background

persistent challenge of non-compliance. Much of the diabetes self-care literature continues to reflect notions of self-care as a static achievement, a compendium of discrete choices focused on restriction, control, and adherence achieved through educative means. It is worth noting that most of the factors identified as facilitative of self-care from the perspective of people with diabetes were relational in nature, founded upon sensitivity to and knowledge of the unique life circumstances of people living with diabetes (Table 3).

The emerging role of health professionals as participants in evolving self-care partnerships with people learning to live with diabetes calls for close examination of the assumptions that inform current patterns of practice. It is essential that this become an element of nursing advocacy at the level of individual health-care relationships. In the area of diabetes self-care, nurses practise at the interface between self-care as taught and self-care as lived. Supporting self-care for people with diabetes should reflect the philosophical, theoretical, and practical essence of nursing as a discipline. Whether theoretical perspectives on practice guide a nurse to support, facilitate, assist, monitor, or teach self-care, or simply to "be present" during the self-care experience, the core value of commitment to use nursing knowledge to assist another in meaningful care transects all current worldviews in nursing. At the level of the individual health-care relationship, there is increasing acknowledgement that self-care support must start where the client is and be framed from the perspective of the individual's life experience and meaning (Cicutto, Brooks, & Henderson, 2004). The idea that the chronically ill person brings expert knowledge about living with chronic disease to the health-care relationship began to appear in the nursing literature in the early 1990s (Thorne, 1993; Thorne & Paterson, 1998) and was an important step forward in reframing health-care relationships. While we must not assume that all people with diabetes are willing and able to take on the expert self-care role all of the time, some of the findings in this review indicate that there is merit in challenging the assumptions that inform the traditional insistence that people with diabetes must paradoxically and simultaneously achieve compliance and self-reliance (Wilson, 2001). This recognition, we believe, presents interesting implications for those working at the policy level.

Health policy frames what self-care choices are considered appropriate and are supported for those living with diabetes. Supporting self-care in practice requires an awareness of health policy structures that serve to define what constitutes appropriate self-care and appropriate support from the health-care system as well as the limits on access to services or treatments. The focus on individually meaningful and useful self-care is even more complex at the policy level. Although self-care is described as a "pillar" of health-care reform in Canada, discussions of self-care truncate quickly as they move to the level of "policy implications" (Health Canada, 1997, 1998, 2002). We have attempted to surface some of the pervasive assumptions underlying our understanding of diabetes self-care from the perspective of people living with the disease. We believe that similarly pervasive assumptions frame any discussion of self-care at the policy level. These include the assumptions that health policy relating to living with diabetes is mainly about the health-care system, that diabetes is largely preventable, that self-care is a resource-saving device for the system, and that the most relevant evidence to support health policy is generated from a medical-scientific perspective. In the Canadian context, policy core values increasingly reflect a belief in individual responsibility for health and collective responsibility for economic competitiveness driven by the globalization agenda (Chambers & Smith, 2002). Attention has focused broadly on disease prevention through education about healthy choices. Prevention is an extremely important policy focus, but in terms of meeting the needs of those already living with diabetes it seems that policy-makers have proceeded based on a very static, disease-oriented understanding of self-care. Policy has *encouraged* self-care by placing disease in the foreground, yet it has marginally and inconsistently supported only the most basic requirements for diabetes self-care. In Canada, provincial jurisdiction over health care has resulted in a patchwork of support; indeed, access to and coverage of the medications and supplies needed for basic self-care in diabetes are highly variable and uneven across the country (Canadian Diabetes Association, 2005b). There is currently little discussion at a national policy level about how such an approach affects diabetes self-care in Canada. The impact of such policy frames upon the development of self-care capacity needs to be more closely examined.

How might policy differ if it is founded upon a commitment to supporting diabetes self-care as an evolving, life-centred process facilitated within knowledgeable, mutually respectful primary care partnerships? Policy-makers would need to access and act upon the input and expertise of people living with diabetes and to create space in policy dialogue for the discussion of how policy impacts upon self-care and how it might more effectively and consistently support self-care efforts. For example, new team-based approaches to chronic disease management are being enthusiastically undertaken across the country (Calgary Health Region, 2002; Chinook Health Region, n.d.; Government of British Columbia, 2005; Health Quality Council, n.d.; Wong, Gilbert, & Kilburn, 2004). The results of this review indicate that the impact of such reform on the establishment and development of consistent health-care relationships with trusted providers should be carefully considered.

Limitations of the Review

Learning to self-care is a complex human health experience that has been researched from a variety of perspectives. We have attempted to be systematic, thorough, and inclusive in our approach to examining the perspective of people with diabetes learning to self-care, but we are aware that this approach has introduced into the review a number of limitations. Firstly, we have included studies from both qualitative and quantitative research traditions, along with their different epistemological assumptions. For this reason the approach taken was that of the integrative review (Whittemore, 2005). This is a synthesis approach aimed at discovering the broad landscape of an area of inquiry, with a purposefully broad sampling frame intended to capture "a comprehensive portrayal" of the topic (Whittemore, p. 57). Such an approach, however, limits the analysis to a narrative synthesis of broad themes and limits the depth of the conclusions that can be drawn from the work. While we did closely examine the assumptions made about self-care in each of the studies, we acknowledge that many of these assumptions likely had their origins in the research approach chosen to study the phenomenon in the first place.

Further, the search strategies and exclusion criteria employed have limited the international relevance of the work, given that, with the exception of two studies from the United Kingdom and one from New Zealand, all studies were from North America. We have, however, attempted to focus the discussion on the Canadian context.

Finally, extending the review to both chronic forms of diabetes may be considered a limitation, as they are quite different in clinical course, etiology, and pathophysiology. Limiting the synthesis based upon these medical criteria, however, would be inconsistent with our goal of gaining a broad understanding self-care in chronic diabetes and would be incongruent with a focus on seeking the perspective of people living with diabetes (Campbell et al., 2003). Further, this inclusive approach did not appear to generate different descriptions of barriers to and facilitators of self-care. However, most of the studies emphasizing the evolution of self-care knowledge were grounded in research with adults living with longstanding type I diabetes. This suggests the need for further research on the factors that facilitate self-care over time and how this evolutionary process might be supported in the context of other chronic diseases.

Conclusion

An important focus of nursing research is the search for understanding health as lived. The goal of this review was to examine the state of the science in self-care from the perspective of those living with diabetes and to attempt to determine the implications of this understanding for health-care policy development. Knowledge arising from the review may be valuable in practice and in extending policy discussions beyond the limits currently placed upon them by largely unchallenged assumptions related to chronic disease management. Public policy discussions in Canada would be fruitfully informed by evidence on how diabetes self-care evolves and how it can best be supported. In partnership with those living with diabetes, nurses have an important role to play in bringing to the policy table an understanding of the implications of health policy for how self-care is lived and of how rigid policy or service structures may inadvertently create barriers to effective diabetes self-care.

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Happenings

Canadian Academy of Health Sciences

Celeste Johnston

The Canadian Academy of Health Sciences (CAHS) is a unique group of multidisciplinary health scientists, all working together under one umbrella to provide assessments of health-related issues for the government and possibly industry. While such groups are an integral part of health-care policies in the United Kingdom and the United States, until 2005 there was no such entity in Canada.

The CAHS is one of three academies that together make up the Canadian Academy of Science, the other two being the Royal Society of Canada and the Engineering Society of Canada. The goals of the CAHS are to

- serve as a credible, expert, independent assessor of science and technology issues relevant to the health of Canadians
- support the development of timely, informed, strategic advice on urgent health issues
- support the development of sound and informed public policy related to these issues
- enhance understanding of science and technology issues affecting the public good by publicizing the results of its assessments and providing opportunities for public discussion of such matters
- provide a single authoritative and informed voice for Canadian health science communities
- monitor global health-related events to enhance Canada's state of readiness for the future
- represent Canadian health sciences internationally and liaise with like international academies to enhance understanding and collaboration on matters of mutual interest.

These goals are achieved by means of expert, arm's-length, credible assessments. Members of the CAHS receive no monetary remuneration for their work, and their academic independence ensures that CAHS assessments are free of conflict of interest.

Examples of assessments conducted in the United States that had significant input from nurses include *To Err Is Human: Building a Safer*

Health Care System and *Who Will Keep the Public Healthy? Educating Health Professionals for the 21st Century*.

Fellows of the CAHS are internationally recognized leaders with a strong research track record in health disciplines. Candidates are subjected to a nominating procedure and peer review before being admitted to the Academy. In 2005 the CAHS comprised approximately 200 fellows, 12 of whom were nurses; more nurses were to be inducted as fellows in September 2006. Dr. Dorothy Pringle sits on the CAHS Advisory Board and has taken an active leadership role in planning its future directions.

For more information, please consult http://www.cahs-acss.ca

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Book Reviews

Women's Health in Canada: Critical Theory and Policy

Edited by Marina Morrow,
Olena Hankivsky, and Colleen Varcoe
Toronto: University of Toronto Press, 2006

Reviewed by Joan Bassett-Smith

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

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

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

Chapter 1, written jointly by the three editors, clearly sets out the purpose and goals of *Women's Health in Canada* and provides a useful link between topics discussed in the book and relevant chapters. It then discusses the stated goals of the book. For the most part there is a sense of coherency among the chapters.

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

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

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

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Introduction to Evidence-Based Practice in Nursing and Health Care

Edited by Kathy Malloch and Tim Porter-O'Grady
Sudbury, MA: Jones & Bartlett, 2006. 278 pp.
ISBN 0-7637-2913-2

Reviewed by Judith A. Ritchie

The editors of this book have taken an unusual and diversified perspective on evidence-based practice. Readers seeking an introduction to the topic of using evidence in clinical nursing practice will not find it here. Malloch and Porter-O'Grady state that the premise of the collection is that health-care workers, and nurses in particular, must move quickly to "fully identify and articulate the value consumers receive for the time and energy that nurses expend, the fiscal support provided by the marketplace for those services, and the specific relationships between those resources expended and value received." They argue that creating evidence will serve this agenda and that they have set out to provide "an overview of the world of evidence for nursing practice." To do the latter they have invited authors with very different perspectives to discuss the "application of the EBP principles" in their frame of reference. It is not clear what "the EBP principles" are and which ones are to be applied.

The 10 chapters in *Introduction to Evidence-Based Practice in Nursing and Health Care* are independent and diverse essays that address a very broad array of topics. They vary widely in their depth and in their view of evidence and evidence-based practice. Very little attempt has been made to create linkage between the chapters. The definition of evidence-based practice varies from one chapter to the next. Often the "evidence" that is presented is not strong research-based evidence. The dual intent of the book comes through clearly but is confusing — for example, the subtitle of chapter 1 is "Creating the Framework for Evidence," but it is not clear in the subtitle or in the text whether the intention here is a framework for evidence-based practice or a framework for creating the evidence.

Clinical practice is a relatively minor focus of the various chapters. In this book, the term "evidence-based practice" refers mainly to managers or educators using evidence to create systems that support nurses and nursing practice — education, architectural design, information systems, managing variance in high-risk systems, workload management systems, and policy and workplaces that exhibit the Forces of Magnetism.

Chapter 4, "Linking Structure and Healing: Building Architecture for Evidence Based Practice," is concerned with the practice of the architect or design engineer.

Some chapters are clearly written, present strong arguments, and make a contribution to the topic. They address the available research evidence regarding some personal and contextual issues that are relevant to evidence-based clinical practice. Other chapters are almost incomprehensible because of a complex and dense writing style and the use of obtuse language, such as "tenure of life" instead of "lifespan." Some chapters consist largely of idealistic rhetoric about the need for change, presenting very little evidence. The overall conclusion seems to be that evidence-based practice is not possible without a revolution in the structure and culture of nursing.

A distraction for the reader throughout the book are numerous spelling and grammatical errors, typesetting errors such as repetition of phrases, inconsistency in citations, citations without matching references, citing of resources or programs that no longer exist, and, particularly in the early chapters, tables and graphs that are either referred to incorrectly in the text or not referred to at all.

Some chapters are difficult to follow and lack direction and purpose. The lack of organization and clarity and the rhetorical nature of the ideas presented pose many challenges for the reader. One is left with a wealth of ideas but no clear framework and no sense of how any of this rhetorical vision might be realized. Chapter 9, "Evidence-Based Practice and Health Policy: A Match or a Mismatch?," is particularly disappointing. The authors shamefully conclude that, because it is difficult to do, policymakers should not attempt to reach decisions about policy based on research evidence. This is a surprising conclusion as well as a shameful one, given the wealth of information now available about the roles of various types of information in creating policy and the advocacy for "evidence-informed policy." On the other hand, chapter 7, "Managing Variance through an Evidence-Based Framework for Safe and Reliable Health Care," is cogent and crisply written and provides a wealth of interesting and well-documented information. This chapter includes comments acknowledging the reality of the nursing context and introduces much evidence and opinion from other disciplines, the Institute for Healthcare Improvement, and the author's own research.

The issues presented in this book could be highly relevant for those interested in evidence-based practice from a research, educational, or management perspective. The topics could be appropriate for those readers who are beyond the introductory level. The strength of the collection is that it discusses contextual factors not usually addressed in the discourse on evidence-based practice. However, the book's intended audience is not clear, and it is a disappointing attempt to broaden the discussion of evidence and evidence-based practice.

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