CJNR 2005, Vol. 37 Nº 3, 5–9

EDITORIAL

Advice to Authors: The "Big 4" Reasons Behind Manuscript Rejection

For everyone involved, publication is a big step — sometimes a hurdle — in the research process. Much is at stake. Continued funding, scholarships, positive annual reviews, and even promotions can be contingent on having the right number and mix of publications on one's CV. No wonder publishing causes so much anxiety. In my role as Associate Editor and as a peer reviewer for *CJNR* and a number of other journals over the years, I've noticed a few patterns in what influences whether a manuscript gets accepted. Indeed the process of getting a paper into print isn't as secretive or obscure as it might seem. I'd like to offer a few thoughts and suggestions for authors based what I've learned so far. Understanding why papers get rejected and intervening appropriately ahead of time can reduce frustration for everyone concerned; editors and reviewers can concentrate on manuscripts that are truly publishable, and authors can be spared the pain of delays in publication or flat-out rejection. None of the problems and none of the suggestions I'll offer is especially obscure, but all are time-tested and most also apply to journals other than *CJNR*.

"Not Our Cup of Tea"

One of the most preventable forms of rejection could be called "not our cup of tea," and it occurs when a manuscript is just inappropriate for the journal to which it has been submitted. Either the subject matter or the approach to it (research or scholarly analytic techniques) strays too far from the journal's focus. The solution in this case is obvious: know the mission of the journal you are approaching.

Obtaining a journal's up-to-date guidelines for authors and reading them carefully is fundamental to a successful submission. And if you are not a regular reader of the journal, make a point of picking up a year's worth of issues (or scanning online versions) in order to examine the journal's emphasis, tone, presentation, and style.

Ask yourself, Why this particular journal? How does my contribution fit? Seek the advice of colleagues about slants and preferences of particular journals. While such unofficial information must be taken with a grain of salt, it can be quite useful. The "impact factor" may enter into the choice of one journal over another. No academic can afford to ignore the fact that institutions differ in relation to the publications that hold value in terms of hiring, tenure, and promotion. (The premises underlying journal scoring systems and their ultimate effects are certainly open to debate. This is a subject we will take up in a future editorial.) Your mentors or collaborators may have very specific publications where they would like to see your work appear, likely based on solid rationale. Once you choose a particular journal for your submission, for whatever reason or reasons, make a point of familiarizing yourself with its publishing priorities. Know, for instance, that original research in the major methodological streams is the "meat and potatoes" of *CJNR*. We do not publish clinically oriented reviews or case studies, for instance — but other journals do.

Know also that each of our issues has a focus or theme, whereby a guest editor collects a cluster of articles in a broad area of research (consult the back pages of each issue for upcoming submission deadlines). If the timing is right, this can be a wonderful opportunity to have your manuscript carefully read by reviewers and editors. Each issue also includes contributions that fall outside the focus, so the theme concept offers special opportunities without putting any research articles at a disadvantage.

Another way to strike pre-emptively against a flat-out "not our cup of tea" rejection is to send a query letter or e-mail to the editorial staff to determine whether your topic and slant are appropriate. In some cases you should do this even before drafting your manuscript. Editors and editorial staff members will gladly suggest other journals that may be more suitable choices for your work.

"Too Much Development Required"

The second form of rejection might be called "too much development required" (or, less charitably, "not even close"). Editors are generally looking for work that can be brought up to an acceptable level of quality with one rewrite, followed perhaps by one set of revisions. Once writing issues and even resolvable issues of clarity and scientific accuracy reach a critical mass, the editors and reviewers may harbour grave doubts that the author is able to generate an acceptable manuscript within one resubmission. There are exceptions. A manuscript that has a bold or important message may get special treatment in this respect, with the editorial office or board providing direct assistance in redrafting the manuscript (beyond the copy editing that all manuscripts undergo). At *CJNR* we rarely if ever have the resources to do that, and you cannot count on being allowed to submit multiple drafts. The message: get it close enough on the first round or face rejection.

The prevention of "not even close" rejection entails careful reading and rewriting prior to submission. Every serious author needs at least one friendly reader/editor, preferably a colleague who publishes in journals of a similar type. Busy reviewers become offended when asked to read hastily written, poorly edited work. Reviewers are usually reading someone else's manuscript at the expense of preparing a manuscript of their own. Of the half dozen papers they may be asked to review each year, some are difficult to read and evaluate, as though they have been thrown into the wind to see if they will stick. No reviewer should have to slog through unreadable prose, or to play detective in order to draw connections across the sections of a manuscript. It is crucial that you make the reviewer's job easier by expressing yourself clearly. Check and double-check writing mechanics and flow after a day's gap between sittings, and have friendly readers check your work for grammatical, spelling, and typographical errors.

The sequencing of ideas in sentences within paragraphs and paragraphs within sections should be easy to follow. Lack of flow makes reading a chore. In terms of formal structure, the introduction should lead logically to the research questions or, in the case of an essay, should clearly indicate the territory the author intends to cover in the paper. Details about methods belong in the methods section and results are reported in the results section — not vice versa — and the discussion should never refer to findings that are not described in the results section. The discussion should nearly always refer, at some point, to limitations of the study design and should conclude by pulling the reader back to the overall significance of the paper.

You would be shocked at how often these conventions are ignored and at how much the stock of your manuscript is raised if you respect them. I have no scientific data to back up this contention, but I know that if two papers of similar substance are submitted, the one that is free of writing and structural problems will get a much more favourable review. Submit the best, most smoothly written manuscript you can manage. There is a counterpoint to this, however: know when to stop revising. If the manuscript is readable, you and your readers can find no gaping holes, and your colleagues tell you they can follow your line of thinking and know what it is you are trying to express, it's time to submit.

“Fatally Flawed”

“Fatally flawed” is the third type of rejection. This category includes submissions that are turned down because of fundamental problems in study design that weaken or invalidate the conclusions. Such a criticism may take you and your colleagues by surprise, because we tend to become blind to a study’s flaws after working on it at length. Most of the methodological problems in general-interest nursing research fall into five categories: sampling problems, instrumentation (measurement tool) flaws, biased data-collection design, poor analysis strategies, and inappropriate or insufficiently guarded conclusions. Ensure that your analysis is correctly done by clearing it with senior colleagues and/or statistical consultants. Do not make your reader hunt for other methodological problems, and be forthright about limitations in your design; no study design is flawless and the odds are very good that you still have something important to say about the phenomenon you studied in spite of any inevitable imperfections.

Rejection on the basis of flawed design or analysis sometimes results from a misunderstanding on the part of reviewers about what you actually did in your study. You can attempt to address such impressions in a revision of the manuscript. You could also reanalyze data and present the new analyses (or show that reanalysis of your data does not change the conclusions you originally reached). It may well be, however, that data were collected using flawed techniques and little can be done about it. If this is the case, carefully explain, in your discussion section, why, despite irresolvable problems, the results are still significant and are worthy of further exploration.

Essays, reviews, and commentaries that are fatally flawed often have the basic facts wrong. The rejection of narrative pieces and reviews may also be grounded in unclear purpose or in writing problems, particularly with regard to clarity and organization.

“And So?”

The most discouraging reason why manuscripts are turned down might be called “and so?” (or, less politely, “so what?”). Bottom line: the “message” is unclear. What can be done about this? The purpose of scholarly writing is, of course, to inform, but it’s also to stimulate discussion, debate, and deeper investigation of various issues and questions. Contributions to the literature should move beyond what is already in print. They should expand or extend findings (confirming, qualifying, or refuting them), or, in some instances, synthesize, re-synthesize, or recast ideas that have already been published. Avoid finding out down the line that you failed to identify other authors who have demonstrated the same or similar findings by doing a thorough literature search. Know how your paper will contribute to the literature.

Make sure your paper indicates to the reader the relevance of your work for the field. Needless to say, even under pressure to publish we strongly advise against overstating results or exaggerating the overall contribution or originality of your work. (You never know whom you might offend.) If you have nothing new to say, there's really no reason to publish. However, the odds are very good that even if your results look "old" you have something new to say about them. And sometimes there's a reason to present something "old" (an idea discussed or researched elsewhere) to a new audience. If this is the case, clearly state at the outset that this is your purpose. Avoid making reviewers guess what the "newness" of your paper entails.

Discussions about what is worth publishing are always interesting in light of the "publish or perish" imperative faced by junior researchers and faculty members. It has been said that good scholars publish only when they have something to say whereas good academics publish at every opportunity. Don't waffle about whether to submit your work, especially if your colleagues and mentors have suggested that it has clear appeal. However, if in doubt about whether your manuscript contains a "message" that is of sufficiently broad interest to merit publication, you would be wise to discuss the basis of your contribution with trusted colleagues. In order to come up with an appealing and interesting manuscript, you may need to re-focus or re-frame your results and discussion.

Concluding Thoughts

By the time a manuscript reaches the editorial offices of *CJNR* or any other journal, a great deal of effort has been invested. The odds of achieving a positive outcome will be dramatically increased if you submit your manuscript to the appropriate journal, after attending to writing mechanics and structure, making sure the strengths and limitations of your methods are clearly articulated (and are reflected in your discussion and conclusions), and establishing the contribution of your work to the scholarship in your field. For you and for us, few things are as depressing as rejection letters and nothing is as uplifting as receiving (or sending) an acceptance letter and seeing your ideas in print. A little extra work on the basics can really pay off.

Sean P. Clarke
Associate Editor

CJNR 2005, Vol. 37 Nº 3, 10–33

Résumé

Capacité de planification et santé émotionnelle des enfants adultes soignants ayant subi des mauvais traitements dans l'enfance

Margaret England

Le but de cette étude était d'explorer les marqueurs associés aux habitudes en matière de planification et à la santé émotionnelle d'enfants adultes soignants présélectionnés en raison de leurs antécédents de mauvais traitements subis au sein de leur famille. Une grille de décision informationnelle et deux procédures de classification ont été utilisées afin d'organiser et de relier 246 plans écrits élaborés par 50 adultes fournissant presque six heures de soins par jour à un parent atteint de troubles cognitifs. Les résultats ont révélé trois constellations d'approches en matière de planification : une approche concrète centrée sur la personne, une approche instrumentale et une autre alimentée par le chagrin. Les 31 participants adoptant une approche instrumentale en matière de planification étaient beaucoup plus susceptibles que les 17 autres adoptant une approche alimentée par le chagrin de rapporter des expériences d'abandon, de trahison, d'idées de suicide et de consommation d'alcool. Les deux participants dont l'approche était centrée sur la personne présentaient beaucoup moins de réactions émotives et de risques de dégradation de la santé ; de plus, ils n'ont rapporté aucune expérience de détresse ou de stratégies d'adaptation centrées sur l'expression d'une détresse émotionnelle. Les infirmières et infirmiers pourront utiliser ces résultats afin de mettre en évidence et de renforcer les capacités en matière de prise de décision et de soins parentaux des soignants ayant subi des traumatismes dans l'enfance.

Mots clés : prise de décision, santé émotionnelle, enfants adultes, soignants, mauvais traitements, famille d'origine, taxonomie, grille de décision informationnelle

CJNR 2005, Vol. 37 N° 3, 10–33

Planning and Emotional Health of Abused Adult Children Caregivers

Margaret England

The purpose of this study was to explore markers associated with the advance-planning patterns and emotional health of adult child caregivers pre-selected for their history of childhood abuse within the family. An informational decision grid and two classification procedures were used to organize and link 246 written plans of 50 adults providing nearly 6 hours of care per day to a cognitively impaired parent. Results revealed 3 constellations of plans describing hands-on person-centred, instrumental, and grief-based approaches to caregiver planning. The 31 participants taking an instrumental approach to planning were significantly more likely than the 17 taking a grief-driven approach to report experiences of abandonment, betrayal, suicidal ideation, and use of alcohol. The 2 participants taking a person-centred approach reported significantly less emotional arousal and risk for loss of health and did not recount experiences of distress or emotion-focused coping. Nurses can use the findings to highlight and strengthen the decision-making and parental-care capacities of caregivers traumatized in childhood.

Keywords: decision-making, emotional health, adult children, caregivers, abuse, family of origin, taxonomy, informational decision grid

Nearly one fifth of all parental-care situations begin with an adult child's observation of the cognitive decline of a parent (Prescop, Dodge, Morycz, Schulz, & Ganguli, 1999). Initially, adult children are unprepared for caregiving despite their awareness of the eventual need for care (Albert, Moss, & Lawton, 1996). They soon realize that they must not only assist dependent parents with basic activities of daily living over a long period, but also provide care once delivered by nurses with specialized education (Hoffman & Mitchell, 1998). They also learn that they must expend considerable energy and resources arranging for parental care (Brody, 1985; Penning, 1998).

Caregivers of parents typically report varying levels of emotional distress related to critical family events; escalating responsibility; and insufficient skills, knowledge, financial resources, and tolerance for parental care despite strong emotional bonds and the best of intentions (Braithwaite, 1996, 2000). Research indicates that children try emotionally to link their own sense of self with that of a dependent parent in order to cope with critical parental-care events and deprivations that accrue in their own lives because of caregiving (Gottlieb & Gignac, 1996;

Wackerbarth, 1999). At the same time, at least one in three adult children do not meet the basic challenges of parental care, reporting high levels of caregiver strain and depression (Alspaugh, Zarit, Stephens, Townsend, & Greene, 1999; Dura, Stukenberg, & Kiecolt-Glaser, 1991). Caregivers of parents are more likely than other caregivers to ignore or avoid the emotional implications of care (Fingerman, Gallagher-Thompson, Lovett, & Rose, 1996; Powers, Gallagher-Thompson, & Kraemer, 2002). Such emotion-focused coping suggests that caregivers of parents are at risk for being traumatized by events tied to care.

Research in the area of trauma indicates that a history of physical or sexual abuse, turmoil in the family of origin, multiple lifetime losses, and recent stressful events are related to poor health status (Leserman, Li, & Drossman, 1998). Research with adult children caregivers who were exposed to childhood victimization or who experienced a recent crisis, for example, reveals that those with weak confidence resources report greater emotional arousal and poorer subjective health than more resourceful caregivers (England, 1997; Fingerman et al., 1996). Those who do not envision outcomes of caregiving very well appear less able to balance care demands (Shyu, Archbold, & Imle, 1998). Thus, it is not surprising that some caregivers of parents report a significant loss of personal mastery the longer they remain in the caregiving role (Skaff, Pearlin, & Mullan, 1996). The implication is that more must be done to assist those at risk for toxic consequences of parental care.

The burden and suffering shared by caregivers of parents, together with a growing social acceptance of caregiver support, provide a window of opportunity for more research into the evolution and treatment of emotional arousal secondary to dependent parental care. Little is known about how adult children, abused in their family of origin, respond to parental-care events. The purpose of this exploratory, descriptive study was to explore markers for emotional distress and coping associated with the perceived health and planning patterns of this population of caregivers.

The findings can inform our understanding of how childhood victimization affects the well-being and decisional capabilities of caregivers of parents and how clinicians might help these caregivers apply decision-making principles to emotional self-care, parental care, and use of informal support. This information will help set the stage for further research on the association of caregiver planning with parental-care involvement and health of adult children caregivers abused in the family of origin. It will help nurses and other service providers appreciate differential patterns of risk among caregivers of parents and how best to target resources and support for this population.

Background

Caregiving within the context of family-of-origin variables is an understudied area of research (Dwyer, Henretta, Coward, & Barton, 1992). A review of databases for nursing, medicine, psychology, and social work, for example, yielded no studies of adult children caregivers specifically reporting on a history of childhood victimization in their family of origin. Yet at least one in four adults report having been emotionally, physically, or sexually abused within their family of origin (Finkelhor, Hotaling, Lewis, & Smith, 1990; Kamsner & McCabe, 2000). Given these figures, it is highly probable that some survivors of childhood abuse within the family will, at some point, provide care to a dependent parent.

Trauma of Abuse

Research reveals that childhood victimization plays a key role in the etiology of chronic distress and existential well-being and ability of the abuse survivors to form or sustain trusting relationships (Coffey, Leitenberg, Henning, Turner, & Bennett, 1996; Feinauer, Middelton, & Hilton, 2003). Physical abuse, coupled with low family cohesion and exposure to parental violence, has been tied to symptoms of trauma and impaired self-esteem (Draucker, 1996; Kamsner & McCabe, 2000). Signs of trauma are tied to alcohol-related problems in adulthood and use of insecure-attachment behaviours (Caetano, Craig, & Nelson, 2003).

Female survivors of abuse are more likely than members of other female groups to report chronic fatigue or pain and to report depression; they are also likely to report more illness or disability days in bed and more health-related visits to a physician (Ohayon & Schatzberg, 2003; Vertommen, Van Houdenhove, Onghena, Westhoven, & D'Hooghe, 2001). In addition, they are more likely to view day-to-day distress as a catastrophic event and are less likely to maintain positive relationships with an intimate partner (Drossman et al., 2000). Yet, to their credit, hardy abuse survivors compared with their less hardy counterparts exhibit greater creativity, resourcefulness, determination to succeed, and ability to take advantage of opportunities for self-enhancement (DiPalma, 1994; Feinauer, Hilton, & Callahan, 2003).

Decision-Making

Although adult children anticipate the eventuality of care, few make concrete plans for care before a perceived crisis emerges (Soerensen & Zarit, 1996). Planning typically begins with a precipitating event, at which point the person becomes aware of the need to aid a parent in decline, think ahead, and make decisions. It involves anticipation of the need for care, decisions and concrete plans, and role socialization. In theory, parental-care decision-making is most effective when there is a family ethos for resolving family conflicts about the assistance to be given to the parent and when responsibilities and privileges tied to parental care are focused and concentrated in a single family caregiver (Cath, 1972; Owens & Qualls, 1997). Adult children who are less burdened with life events and are more able to communicate, make decisions, and resolve conflicts report less parental-care distress than those who are more burdened with life events, have poorer communication and conflict-resolution skills, and possess less focused decision-making styles (Lieberman & Fisher, 1999).

Research suggests that childhood victimization compromises the development of decisional resources for coping with life events in adulthood (Coffey et al., 1996; Kamsner & McCabe, 2000). An analysis of the concerns and expressed needs of highly distressed caregivers of parents in one study, for example, revealed an accumulation of losses and other problematic life events in the lives of the caregivers, high use of tension-reducing behaviours, and a host of unresolved conflicts with siblings and other family members (England & Tripp-Reimer, 2003); many concerns pointed to a loss of existential well-being and a history of childhood neglect or abuse. Missing from the research, however, are clear descriptions of the day-to-day decision-making of adult children abused in their family of origin. Also missing are clear descriptions of decisions pointing to how the adult children resolved personal needs while engaged in the role of caregiver. Such descriptions could help nurses and other clinicians appreciate differential patterns of risk among caregivers of parents and how best to target resources and support for them.

Conceptual Framework for Planning

Rapaport and Orbell (2000) argue that a clinician's ability to integrate an adult child's self-concept and perspective on caregiving is an important consideration for how clinicians might help adult children organize their care decisions. Kasch and Holder (1999) propose the analysis of strategic messages as a framework for this purpose and recommend the use of classification systems for analysing language contained in the decisions of caregivers. The informational decision grid shown in Table 1 provides a framework for the organization and analysis of the language contained in the written plans of caregivers in this study.

Conceptualization of the grid was based upon two critical attributes of planning: goal structure and human need orientation (England, 1996). Goal structure refers to an arrangement of mental actions designed to

Table 1 ***Informational Decision Grid[a] for Organizing the Plans of Adult Children Caregivers***

Goal Structure	**Human Need Orientation**			
Categories of caregiver planning	***Physical and physiological***	***Safety and security***	***Relational***	***Person-enhancing***
Goal state	11	12	13	14
Goal operation	21	22	23	24
Goal strategy	31	32	33	34

[a] The first number of the two-digit classification code in each cell represents the goal structure of a caregiver decision; the second number represents the human need orientation of the decision.

fulfil some trajectory or object of satisfaction. A goal structure represents a cognitive component of planning that can be operationalized at the level of a goal state, goal operation, or goal strategy. A goal state is an awareness of an anticipated state of being or way of acting. A goal operation is a specific intention to act (or not) derived from knowledge, personal values, motivations, or social norms. A goal strategy is a prescription or objective involving deliberative action within a specific time frame or context.

Human need orientation refers to an arrangement of mental actions designed to fulfil some purpose or function for which a goal structure is constructed. It represents a motivational component of planning that can be operationalized at four levels of imminent concern: physical or physiological need, safety and security need, relational need, and self-enhancement need. Table 2 provides examples and classification codes for the decisions of two adult children reporting physical abuse in their family of origin. The first digit of the classification code represents the goal structure of the decisions and the second digit represents the human need orientation of the decision.

The Study

The informational decision grid and rules for classification were used in the study to organize and link up the written plans of the different adult children. Patterns of planning were then tied to parental-care involvement, emotional arousal, distress and coping, and perceived health of the participants. Approval to obtain this information was granted by the Internal Review Board of a large, publicly supported health science centre in the Midwestern region of the United States.

Table 2 *Written Caregiving Plans of Two Adult Children Caregivers Abused in Their Family of Origin*[a]

Written Plans[b]	**Physical or Physiological**	**Safety and Security**	**Relational**	**Person-Enhancing**
Goal state	"For her to gain a little weight" (code 12).			"She will have a good time when I come visit" (code 14).
Goal operation		"Take care that she doesn't trip on anything because she doesn't always watch where she puts her feet" (code 22).	"I will treat her well… better than the way my dad treated her" (code 23). "Encourage the nurses to spend a little chit chat time with her as well" (code 23).	
Goal strategy			"Take her for a stroll in the park this weekend" (code 33). "Ask my sister to help me with Mother's laundry" (code 33).	
Written Plans[c]	**Physical or Physiological**	**Safety and Security**	**Relational**	**Person-Enhancing**
Goal state		"I want to know that he's being fed and bathed" (code 12). "I really can't stand the way [not tolerant] he slobbers all over himself" (code 12).	"I wonder what he'll think after all these years if I told him that I'm beyond caring" (code 13).	
Goal operation	"Obviously, he has to be fed and bathed" (code 21).			
Goal strategy		"Visit the nursing home every 6 months to obtain a report on my father" (code 32).		

[a] The first digit of each two-digit classification code represents the goal structure of the caregiver decision; the second digit represents the human need orientation of the decision.
[b] Hands-on, personal approach to planning. [c] Grief-driven approach to planning.

Sample

Funding for the research allowed for the recruitment of a convenience sample of 50 volunteers from a listing of urban-dwelling adults attending a caregiver support group, limiting the pool of participants to those most likely to voice their concerns and need for help. Self-report criteria for inclusion in the study were that participants be English-speakers reporting a history of victimization in the family of origin and primary responsibility for decisions about the welfare of a cognitively impaired parent.

The sample consisted mostly of high-school-educated (82%), married (76%), employed (90%), Caucasian (88%) women who had been caring for a dependent parent for less than 9 months (Table 3). Two thirds of the participants were firstborn daughters. The dependent parents were mostly mothers (88%) diagnosed with Alzheimer disease (90%) or cerebral vascular disease (10%) resulting in severe confusion and loss of judgement concerning activities of daily living; 14 (28%) resided with the study participant, 12 (24%) resided with a spouse, and the remainder (48%) resided in an institution.

Nearly all participants had been emotionally (98%), physically (30%), or sexually (42%) abused or neglected (22%) while growing up. Eleven (22%) had experienced multiple forms of abuse and seven (14%) acknowledged events in which they had emotionally or physically abused their dependent parent. More than 80% recounted experiences of betrayal, abandonment, being alone in the world, and suicidal ideation. The majority had left home before the age of 18 (78%) and used alcohol (76%) for coping. Of the 13 participants (26%) reporting parasuicide, four had made an attempt within the preceding year.

Measures

Hours of care was defined as a relative amount of time spent performing parental-care tasks and was measured using the revised Caregiver Burden Inventory (England & Roberts, 1996). The CBI is a 27-item instrument that measures engagement in physical, instrumental, and psychosocial tasks of parental care on five-point ordinal rating scales. Adult children completing the CBI average 3 to 5 hours of care per day to a cognitively impaired parent (England, 2000). Coefficient alpha for the CBI is in the range of 0.88 to 0.93. Previous research indicates that data collector/study participant agreement with calculated estimates for hours of care is 0.96 (England & Roberts) — that is, the number of hours of care reported by adult children is equivalent to the hours of care credited to them.

Table 3 ***Background Variables of 50 Adult Children Caregivers Abused in Their Family of Origin***

Variable		*N*	%
Gender	Male	5	10
	Female	45	90
Race	Caucasian	44	88
	Black	2	4
	Hispanic	4	8
Birth order	Firstborn	33	66
	Lastborn	7	14
Marital status	Married	38	76
	Not married	12	24
Education	High-school diploma	41	82
	Post-high school	9	18
Employment	Yes, full-time	45	90
	Yes, part-time	2	4
	No	3	6
History of abuse	Emotional	49	98
	Physical	15	30
	Sexual	21	42
	Physical and sexual	11	22
	Neglect	11	22
Indicators of distress	Left home before age 18	39	78
	Being alone in the world	48	96
	Abandonment	41	82
	Betrayal	43	86
	Suicidal ideation	43	86
Indicators of coping	Recounting	46	92
	Use of alcohol	38	76
	Elder abuse	7	14
	Parasuicide	13	26

Emotional arousal was defined as a caregiver's self-report of pleasant and unpleasant feeling states and was measured using the revised Emotional Arousal Scale of the Caregiver Strain Questionnaire (England & Roberts, 1996). The ERS is a six-point ordinal rating scale that measures the extent to which 12 words reflect feeling states associated with a current parental-care situation. Coefficient alpha for items on the ERS is in the range of 0.79 to 0.88.

Perceived health was defined as an adult child's rating of how far he or she is from an ideal state of health or well-being while in the role of filial caregiver (England, 2000). ***Perceived health risk*** was defined as the caregiver's rating of how close he or she is to loss of health or well-being. Both of these variables were measured with single-item, ordinal rating scales. The scales were formatted as a 10-rung ladder and participants were asked to rate their distance from an ideal health state and their risk for loss of health. Average values of perceived health for adult children reporting crises within the previous 6 months are in the range of 6.5 to 6.7.

Caregiver planning was defined as the process of securing a future caregiving situation by integrating concerns, ideas, and values regarding how that situation ought to unfold. Planning consisted of an adult child's written declaration of awareness, intention, or strategy for promoting self-care or the care of a dependent parent, including the physical, security, relational, or person-enhancing orientation of this effort. The construct was operationalized as a set of decision units termed caregiver decisions.

Caregiver decisions were defined as the "most important" outcomes of a planning process pertaining to self-care or parental care. The variable was operationalized as content-substantiated "most important" written plans — that is, the participants were asked to write down, on a Caregiver Planning Form (CarePL), what they considered their most important plans for self-care and parental care in the next 2 weeks, and were then invited to orally describe the meaning of the plans to a nurse and, if they wished, to revise the substance of the plans in order to better reflect their concerns, ideas, or goals.

Procedure

Data were obtained at the site where caregivers attended meetings of a support group led by a doctorally prepared female social worker. Following consent to take part in the study, 50 adult children completed a demographic data form, a survey of dichotomous indicators for distress and coping, and other paper-and-pencil measures for hours of care, emotional arousal, perceived health, and perceived health risk. The participants later took part in a 90-minute interview with a clinical nurse specialist. The interview was scheduled at the convenience of both parties.

During the interview, the nurse queried the participant about concerns and goals for self-care or parental care using communication strategies to elicit ideas and link them together. The participants were asked to discuss their relationship with their dependent parent, their feelings, and their goals and plans for caregiving. They were directed to write down, on the CarePL, and then clarify, their most important plans for caregiving in the next 2 weeks.

The nurse provided preparatory information about the writing task in order to reduce any uncertainty associated with it. The nurse discussed with the participant dictionary definitions for the terms caregiver, caregiving, planning, important, plans, and decisions. The nurse also shared written examples of plans and decisions that did not pertain to caregiving. The participants were informed that no presumptions would be made about the relative goodness of any plan they wrote down. Also, they were assured that writing a plan for the purposes of the study in no way implied that they could not revise the plan or choose not to follow through with it.

The meaning of "most important" plans for care was clarified orally with the participants once the plans were written down. Points of clarification consisted of identifying the action component (verb) of the plan, the object of the plan (purpose), and the content and context of the plan (situation for planning). The nurse invited the participants to reword their written plans if necessary to better reflect particular concerns or ideas.

At the end of the interview the nurse calculated the number of hours of care per day provided to the parent and confirmed the figure with the participant. The nurse then assigned a two-digit classification code to each written plan generated in the interview and plotted the codes for each plan on an informational decision grid for the participant to reflect on (see Table 2 for examples). Following data collection, the investigator independently assigned a two-digit code to each written plan and content validated the coding with the nurse. One month later, the investigator and the nurse independently recoded the plans with discrepant classification codes and validated these judgements with one another.

Research Questions

1. *What content emerged from classification of adult children's plans for caregiving?* 2. *What patterns of caregiver planning emerged from the organization of adult children's plans?* 3. *Can patterns of caregiver planning be tied to parental care involvement, emotional arousal, distress and coping, and perceived health of adult children?*

Analysis

Two classification procedures were used to organize the participants' most important written plans for caregiving. In the first procedure a two-digit code was assigned to each written plan, the first digit representing the goal structure of the plan and the second digit representing human need orientation of the plan (see Table 2 for examples). In the second procedure an ethnographic software program and typology of decision content were used to further codify the written plans. The purpose was to generate more detailed classes of human concern given one of four basic human need orientations. Codified plans in each category of human need orientation were cross-referenced iteratively with one another and with data from other categories of human need orientation. The purpose was to illuminate meaningful patterns of human concern embedded in the data.

Decision rules to facilitate accurate classification consisted of identifying the verb or action component of each written plan, the intent or object of the plan, the content or theme, and, whenever possible, the context of the plan. The recording of the action component of a plan was meant to facilitate discernment of the overall goal structure of the plan. The recording of the object of the plan was meant to facilitate discernment of the goal operation of the plan. The recording of the content, theme, and context of the plan was meant to facilitate discernment of the specific goal structure and human need orientation of the plan. The rationale for this manner of classification was to achieve an efficient best fit between the meaning of a plan, given the organizing principles for the informational decision grid, and the perspectives of the participants.

Results

The participants had, on average, been caring for a cognitively impaired parent for 8.91 months and were currently providing 5.84 hours of care per day (Table 4). Their respective mean ratings for emotional arousal, perceived health, and risk for loss of health were 40.57 (*SD* = 13.61), 5.85 (*SD* = 1.88), and 7.92 (*SD* = 1.85). The participants reported multiple indicators of distress and emotion-focused coping (Table 3).

Table 4 ***Age, Income, Parental Care, and Perceived Health of 50 Adult Children Caregivers Abused in Their Family of Origin***

Variable	***Range***	***M***	***SD***
Age in years	37–66	51.87	5.69
Annual personal income	$0.00–$70,500	$37,600	$10,776
Parental-care hours/day	1–12	5.84	4.22
Parental-care months	2–46	8.91	7.90
Emotional arousal	23–62	40.57	13.61
Health rating	2–8	5.85	1.88
Health risk	4–10	7.92	1.85
Written plans	1–10	4.92	2.51

Table 5 ***Number and Percentage of Written Plans Classified on the Basis of Goal Structure and Human Need Orientation***

Categories of Caregiver Planning	**Physical and Physiological**		**Safety and Security**		**Relational**		**Enhancement**		**Total**	
	F	%	*F*	%	*F*	%	*F*	%	*F*	%
Goal state	18	7.3	52	21.1	18	7.3	9	3.7	97	39.4
Goal operation	9	3.7	56	22.8	21	8.6	3	1.2	89	36.3
Goal strategy	5	2.0	49	19.9	5	2.0	1	0.4	60	24.3
Total	32	13.0	157	63.8	44	17.9	13	5.3	246	100.0

Note: Coefficient κ for classifications = 0.79.

Written Plans

All participants provided written plans for the study; six (12.0%) sought clarification as to whether their plans met the study criteria for planning. Initial classification procedures produced 246 most important written plans for caregiving in the next 2 weeks, an average of 4.92 decisions per adult child. Classification of the goal structure of the plans yielded 97 (39.4%) goal states, 89 (36.3%) goal operations, and 60 (24.3%) goal strategies (Table 5). Corresponding classification of the human need orientation of the decisions yielded 32 (13.0%) plans for physical care, 157 (63.8%) plans for safety and security of the parent, adult child, or other family member, 44 (17.9%) plans pertaining to filial or other relationships, and 13 (5.3%) plans relating to personal enhancement of the parent or adult child. Cohen's (1960) coefficient *k* for inter-rater reproducibility of the two-digit classification codes assigned to the plans was 0.79. Mean percentage agreement for the classifications was 0.97.

Content of Planning

A typology of decision content based on the human need orientation of the participants' plans yielded more detailed description of the plans. Classifications (*n* = 32) with a physical or physiologically orientation described plans detailing participant concerns about health, self-care requisites, and material resources for care. The plans were grouped into 18 goal states, 9 goal operations, and 5 goal strategies, including *"be mindful of her health" (code 11), "feed her" (code 21),* and *"put on her shoes and socks every day" (code 31).*

Classifications (*n* = 157) oriented to safety and security described plans addressing participant concerns with the management of day-to-day events, tasks, or finances; protection of self or the parent; and perceived condition of a parent, situation, or care environment. The plans were grouped into 52 goal states, 56 goal operations, and 49 goal strategies, including *"hope she doesn't burn the house down" (code 12), "lock the doors so that she doesn't wander off" (code 22), "reassure myself that I can cope" (code 22),* and *"talk to the nurses tomorrow about cleaning my mother's wheelchair" (code 31).*

Classifications (*n* = 44) with a relational orientation described plans addressing participant worries, family relationships, reciprocity, and agency. The plans were grouped into 18 goal states, 21 goal operations, and 5 goal strategies, including *"don't argue with Dad about her care" (code 13), "grieve privately so that my children will not worry about me" (code 23), "go with my sister to the nursing home so that she doesn't talk Mother into signing papers" (code 23),* and *"read the Bible to her on Sunday morning" (code 33).*

Table 6 ***Associations of Caregiver Planning With Parental-Care Involvement and Emotional Health of 50 Adult Children Abused in Their Family of Origin***

Planning Pattern	**Person-Centred** $n_1 = 2$		**Instrumental** $n_2 = 31$		**Grief** $n_3 = 17$		**Test of Significance**
Study variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*F(2,47)*
Parental-care hours/day	5.22	0.77	7.27	5.51	3.31	2.27	4.69
Written plans	5.50	0.53	5.66	3.18	3.50	1.52	5.81
Emotional arousal	25.25	4.56	44.21	14.79	35.73	12.53	7.49
Perceived health	7.45	1.29	5.31	2.06	6.65	1.63	7.61
Perceived health risk	5.34	1.22	8.51	1.57	7.14	2.44	8.17
Indicators of distress and ccoping	*f*	%	*f*	%	*f*	%	Cochran's Q *(2)*
Recounting	0	0.0	31	100.0	15	88.0	31.35
Aloneness	1	50.0	31	100.0	16	94.0	28.13
Abandonment	1	50.0	30	97.0	11	65.0	31.00
Betrayal	0	0.0	29	94.0	14	82.0	29.35
Suicidal ideation	0	0.0	30	97.0	13	76.0	31.58
Parasuicide	0	0.0	9	29.0	4	24.0	9.39
Use of alcohol	0	0.0	29	94.0	9	53.0	34.79

Finally, classifications (*n* = 13) with a person-enhancing orientation described plans concerning personhood or the personal development of a parent, family member, or the participant. The plans were grouped into 9 goal states, 3 goal operations, and 1 goal strategy, including *"try to be all that I can be to my mother" (code 14), "see to it that she is well dressed, like a real person" (code 24), "take my dad fishing once in a while" (code 24), "commend my sister for helping me fight off my dad's advances" (code 24),* and *"talk with the pastor tonight about the songs we want for her funeral" (code 34).*

Patterns of Planning

The organization and linking of participants' plans yielded three hypothetical patterns of caregiver planning. The first pattern, assigned to two adult children, described a hands-on, personal approach to planning. It consisted of providing care or respite, asking a family member for help, acting on behalf of the parent, sharing a relational event with the parent, and attending to the personhood of the parent (e.g., first pattern in Table 2). Plans dealt with taking care, taking precautions, being watchful, and presenting the parent in a positive way. The participants who were assigned this pattern of planning reported significantly less emotional arousal and risk for loss of health than other participants, despite comparable number of hours of parental care (Table 6).

The second planning pattern, assigned to 31 adult children, described an instrumental, task-oriented approach to planning that addressed resources for caregiving, sense of security, and taking things step by step. Plans included custodial aspects of care and the appropriateness of the environment for care. Some plans addressed assessment of the health, safety, or functional status of the parent or caregiver, while others suggested a tit-for-tat manner of relating within the family. Plans for achieving personal security included *"need to cope" (code 12), "get a grip on myself" (code 12),* and *"be in control" (code 12).* Plans for relational security included *"make sure that we all do things equally" (code 22), "don't want him bothering the children" (code 12), "she's better off being in a nursing home" (code 12), "[I] long for stability in the family" (code 12),* and *"have nothing to do with him [Dad]" (code 22).*

The participants who were assigned an instrumental pattern of planning reported high scores for emotional arousal and risk for loss of health (Table 6). According to the nurse interviewer, these participants had engaged in particularly repetitive, negative narratives of distress and urgency or showed an inability to engage in the usual activities of daily living because of caregiving. Most reported experiences of aloneness, abandonment, betrayal, suicidal ideation, and use of alcohol. All had left home before the age of 18 and four had attempted suicide within the previous year.

The third planning pattern, assigned to 17 adult children, described grieving that illuminated elements of suffering and concern for the personal welfare of the caregiver, parent, or another family member. More than half of the plans falling into this pattern were written in the form of goal states. Issues tied to the goal states included loss of mastery, freedom from threat, conservation of energy, and needing help. Some plans dealt with distress, separation, or control of the filial relationship, while others dealt with memories, meaning in life, or a parent's legacy (e.g., second pattern in Table 2). The participants who were assigned this pattern of planning reported experiences of aloneness, abandonment, betrayal, suicidal ideation, and use of alcohol (Table 6). They also reported high scores for emotional arousal and risk for loss of health, but the scores were not as high as those of the participants who were assigned an instrumental pattern of planning (Table 6).

Discussion

This exploratory study was developed to identify markers tied to emotional health and planning patterns of adult children caregivers with a history of victimization in their family of origin. Given the expectations and complexity of long-term care in the case of a cognitively impaired parent, it is not surprising that the participants spent nearly 6 hours per day, on average, on tasks associated with parental care. Their written plans homed in on issues of safety and security more than on other aspects of care, a finding consistent with the results of previous research (England, 1994). At the same time, the participants generated 40% fewer relational plans and fewer plans for physical or person-enhancing care than found in previous research. The absence of physical and relational plans may be linked with the residence of the dependent parent and the fact that some parents retained sufficient long-term memory to permit self-care. It is also possible that some adult children preferred not to engage in physical or person-enhancing parental care because of ambivalence with role-reversing or physically intimate aspects of such care. It is possible that these caregivers, given their history of childhood victimization, did not have sufficient reciprocity, interpersonal boundaries, or tolerance for close engagement with a parent.

The participants in this study generated 70% more goal states than those in previous research (England, 1994), and in the process they sacrificed a focus on the development of goal operations. While the participants clearly had concerns about and hopes for themselves and their parents, they may not have been sufficiently mindful, resilient, or confident to consistently develop plans on the basis of knowledge, values, or norms for self-care or parental care. According to crisis theory, upset individuals with a narrowed perceptual field and high concentration of goal states for planning are at increased risk for failure to thrive in their situation, and thus may need help with practical aspects of planning (Roberts & Dziegielewski, 1995).

The procedures used to organize and link the plans of the different participants yielded person-centred, instrumental, and grief-based patterns of planning among the adult children in the study. Two of the participants who were assigned a person-centred pattern of planning differed from the other participants in that they reported significantly better perceived health and did not recount negative indicators of abuse or emotion-focused coping. Their plans incorporated three levels of abstraction and a range of human needs suggesting a practical, flexible understanding of how to meet particular caregiving challenges. It is possible that these participants had somehow reconciled conflicts tied to their family of origin, developed more affiliation with their dependent parent, and derived more positive meaning from the caregiving situation. According to cognitive appraisal theory (McCarthy, Mejia, & Liu, 2000), this rather holistic conceptualization of caregiving plans is likely the result of how the caregivers deconstructed and reconstructed their situation and their emotional responses.

The 31 adult children who were assigned an instrumental pattern of planning reported the highest scores for emotional arousal and risk for loss of health. They also provided explicit oral accounts of abuse, trauma, and emotion-focused coping, including alcohol use, elder abuse, and parasuicide. Their plans were consistent with their oral reports, alluding to negative appraisals of caregiving, intrusive experiences, and use of palliative or avoidance strategies for coping. Their plans, however, lacked general coherence and did not lead to corresponding practical plans to resolve concerns about personal or relational insecurities. These findings suggest that many participants were engaged in passive or reactive decision-making and did not have sufficient resources to fulfil important desires. It is possible that chaotic circumstances and abuse within the family of origin had predisposed these persons to view caregiving as an ill-fated endeavour, and to reduce their ability or willingness to make definitive plans, especially for a parent who had contributed to their abuse.

The 17 adult children who were assigned a grief-based pattern of planning reported significantly fewer plans and hours of parental care than the other participants. More than 50% of their plans were in the form of goal states that addressed desires to ameliorate relational concerns and suffering. Their failure to link desires with specific planning suggests that they were less able than other participants to translate ideas into practical solutions to problems, or were more caught up in their inability to commit resources to parental care.

Interestingly, the adult children who were assigned an instrumental or grief-based pattern of planning were similar to one another in that they had high scores for emotional arousal and perceived risk for loss of health, a finding that is consistent with their accounts of aloneness, abandonment, betrayal, suicidal ideation, and use of alcohol (Table 6). At the same time, the emotional arousal and perceived health scores of the grief-based planners were significantly lower than those of the instrumental planners, but higher than those of adult children in other research (England, 1994). It is possible that grief-based planners were more prepared than instrumental planners, but less so than secure caregivers, to face conflicts and losses accrued from their role within the family.

In theory, grieving provides an avenue for individuals to relinquish harmful affect and re-contextualize relationships within the family of origin (Fingerman, 1997). Thus, grieving can provide adult survivors of childhood abuse avenues for becoming more attuned to their own needs, capacities, and purposes in life. Nevertheless, it must be noted that while a combination of high arousal, grief-based planning, and low involvement with parental care might conserve well-being in the short term, it may not ensure effective parental care and resolution of concerns in the long run.

Conclusions and Implications

The findings from this study indicate that many adult children victimized in their family of origin do not form patterns of planning that can sustain emotional health or effective parental care over the long term. Compared to the plans of caregivers of parents in previous research (England, 1994), those of the participants in this study were linked with significantly fewer goal operations in general and fewer relational and person-enhancing plans in particular. These more abstract, task-oriented and security-oriented plans are associated with significantly greater emotional arousal and perceived risk for loss of health. This combination of variables points to difficult relationships with dependent parents and insecurity concerning how adult children might effect change while in the role of caregiver. The implication is that highly aroused adult children need to modify the structure of their plans. These caregivers might also modify or supplement goal states and concentrated instrumental planning with more holistic, person-centred approaches.

In theory, individuals moderate their emotional distress according to how they conceptualize emotions and decisions for self-management

(McCarthy et al., 2000). When individuals understand how decisions are connected with memory and emotional sense experience, they are more likely to intuit meaning from their efforts and plan accordingly. The findings from this study suggest that many adult children victimized in their family of origin do not have sufficient memories and emotional sense experience to intuit meaningful plans for self-care and parental care. It is likely that the inner resources and affiliation of the caregivers are not potent enough to offset the burdens of parental care. The implication is that these caregivers need critical supportive care to enhance their meaningful engagement with and tolerance for caregiving.

Given the prevalence and long-term negative consequences of childhood victimization, nurses need to increase their ability to recognize and respond to survivors of abuse. An important goal of nursing, then, is to sustain partnerships with survivors of abuse that foster perceptions of worth, mastery, competence, and control. By doing so, nursing can affirm and accommodate the needs of survivors and avoid contributing to the root causes of their sense of abandonment, betrayal, or alienation (Gallant, Beaulieu, & Carnevale, 2002; Nolan, 2001). Nurses should consider caregivers of parents as experts in their own needs and affirm their inherent decision-making capabilities. Nurses can encourage caregivers who have been abused in the family of origin to recall, acknowledge, and re-contextualize traumatic incidents so that they can reclaim a sense of self as well as a purpose for caregiving. In addition, they should commend the caregivers for having the courage to care and help them access and use informal means of support.

Implementation of study procedures suggests that caregivers of parents can tolerate plan-writing and discourse on their present parental-care situation. The effort of participants to make visible their concerns and desires in the form of written plans demonstrates well that adult children can take reasoned action to change their situation. It appears that plan-writing and discourse can offer caregivers a value-added opportunity to make coherent plans and at the same time negotiate conflicts connected with the family of origin. Insertion of their written plans into an informational grid can assure these caregivers of the validity of their needs and desires.

Future Directions

The findings suggest that informational decision grids and plan-writing can help caregivers victimized in their family of origin to conceptualize reasoned actions for emotional self-care, parental care, and use of informal support. Future research should examine the efficacy of these heuristic decisional aids for case finding and decision support. In addition, it should target more particularized narratives from caregivers abused in childhood in order to more fully reveal the meaning of caregiving for this population. Such research would set the stage for formal validation of a decision-support intervention for this population.

References

Albert, S. M., Moss, M., & Lawton, M. P. (1996). The significance of the self-perceived start of caregiving. *Journal of Clinical Geropsychology, 2*(3), 161–174.

Alspaugh, M. E., Zarit, S. H., Stephens, M. A., Townsend, A. L., & Greene, R. (1999). Longitudinal patterns of risk for depression in dementia caregivers: Objective and subjective primary stress as predictors. *Psychology and Aging, 14*(1), 34–43.

Braithwaite, V. (1996). Understanding stress in informal care: Is burden a problem of the individual or of society? *Research on Aging, 18*(2), 139–174.

Braithwaite, V. (2000). Contextual or general stress outcomes: Making choices through caregiving appraisals. *Gerontologist, 40*(6), 706–717.

Brody, E. M. (1985). Parent care as a normative stress. *Gerontologist, 25*(1), 19–29.

Caetano, R., Craig, A., & Nelson, S. (2003). Association between childhood physical abuse, exposure to parental violence, and alcohol problems in adulthood. *Journal of Interpersonal Violence, 18*(3), 240–257.

Cath, S. (1972). The geriatric patient and the family: The institutionalization of a parent – a nadir of life. *Journal of Geriatric Psychiatry, 5*(1), 25–51.

Coffey, P., Leitenberg, H., Henning, K., Turner, T., & Bennett, R. T. (1996). Mediators of the long-term impact of child sexual abuse: Perceived stigma, betrayal, powerlessness, and self-blame. *Child Abuse and Neglect, 20*(5), 447–455.

Cohen, J. (1960). A coefficient of agreement for nominal scales. *Education and Psychological Measurement, 20*(1), 37–46.

DiPalma, L. M. (1994). Patterns of coping and characteristics of high-functioning incest survivors. *Archives of Psychiatric Nursing, 8*(2), 82–90.

Draucker, C. B. (1996). Family-of-origin variables and adult female survivors of childhood sexual abuse: A review of the research. *Journal of Child Sexual Abuse, 5*(4), 35–63.

Drossman, D. A., Leserman, J., Li, Z., Keefe, E., Hu, Y. J., & Toomey, T. C. (2000). Effects of coping on health outcomes among women with gastrointestinal disorders. *Psychosomatic Medicine, 62*(3), 309–317.

Dura, J., Stukenberg, K., & Kiecolt-Glaser, J. (1991). Anxiety and depressive disorders in adult children caring for demented parents. *Psychology and Aging, 6*(3), 467–473.

Dwyer, J. W., Henretta, I., Coward, R. T., & Barton, A. J. (1992). Changes in the helping behaviors of adult children. *Research on Aging, 14,* 351–375.

England, M. (1994). Caring for a demented parent by adult offspring with and without crisis experience. *Scholarly Inquiry for Nursing Practice, 8*(3), 295–314.

England, M. (1996). Content domain for caregiver planning identified by adult offspring caregivers. *Journal of Nursing Scholarship, 28*(1), 17–22.

England, M. (1997). Self-coherence, emotional arousal, and perceived health of adult offspring caring for a brain-impaired parent. *Journal of Advanced Nursing, 26*(6), 672–682.

England, M. (2000). Caregiver strain: Considerations for change. *Nursing Diagnosis: International Journal of Nursing Language and Classification, 11*(4), 162–175.

England, M., & Roberts, B. (1996). Theoretical and psychometric analysis of caregiver strain. *Research in Nursing and Health, 19*(6), 499–510.

England, M., & Tripp-Reimer, T. (2003). Key issues of filial caregivers reporting experiences of crisis. *International Journal of Aging and Human Development, 56*(1), 67–88.

Feinauer, L., Hilton, G. H., & Callahan, E. H. (2003). Hardiness as a moderator of shame associated with childhood sexual abuse. *American Journal of Family Therapy, 31*(1), 65–78.

Feinauer, L., Middelton, K. C., & Hilton, G. H. (2003). Existential well-being as a factor in the adjustment of adults sexually abused as children. *American Journal of Family Therapy, 31*(3), 201–213.

Fingerman, K. L. (1997). On being more than a daughter: Middle-aged women's conceptions of their mothers. *Journal of Women and Aging, 9,* 55–72.

Fingerman, K. L., Gallagher-Thompson, D., Lovett, S., & Rose, J. (1996). Internal resourcefulness, task demands, coping, and dysphoric affect among caregivers of the frail elderly. *International Journal of Aging and Human Development, 42,* 229–248.

Finkelhor, D., Hotaling, G., Lewis, I. A., & Smith, C. (1990). Sexual abuse in a national survey of adult men and women: Prevalence, characteristics, and risk factors. *Child Abuse and Neglect, 14*(1), 19–28.

Gallant, M. H., Beaulieu, M., & Carnevale, F. A. (2002). Partnership: An analysis of the concept within the nurse-client relationship. *Journal of Advanced Nursing, 40*(2), 149–157.

Gottlieb, B. H., & Gignac, M. (1996). Content and domain specificity of coping among family caregivers of persons with dementia. *Journal of Aging Studies, 10*(2), 137–155.

Hoffman, R. L., & Mitchell, A. M. (1998). Caregiver burden: Historical development. *Nursing Forum, 33*(4), 5–11.

Kamsner, S., & McCabe, M. P. (2000). The relationship between adult psychological adjustment and childhood sexual abuse, childhood physical abuse, and family of origin characteristics. *Journal of Interpersonal Violence, 15*(12), 1243–1261.

Kasch, C. R., & Holder, T. (1999). Nursing and communication: A reflection. *Scholarly Inquiry for Nursing Practice, 12*(3), 289–300.

Leserman, J., Li, Z., & Drossman, D. A. (1998). How multiple types of stressors impact on health. *Psychosomatic Medicine, 60*(2), 175–181.

Lieberman, M. A., & Fisher, L. (1999). The effects of family conflict resolution and decision making on the provision of help to an elder with Alzheimer's disease. *Gerontologist, 39*(2), 159–166.

McCarthy, C., Mejia, O. L., & Liu, H. T. (2000). Cognitive appraisal theory: A psycho-educational approach for understanding connections between cognition and emotion in group-work. *Journal for Specialists in Group Work, 25*(1), 104–121.

Nolan, M. (2001). Working with family carers: Towards a partnership approach. *Reviews in Clinical Gerontology, 11*(1), 91–97.

Ohayon, M. M., & Schatzberg, A. F. (2003). Using chronic pain to predict depressive morbidity in the general population. *Archives of General Psychiatry, 60*(1), 39–47.

Owens, S. J., & Qualls, S. H. (1997). Family stress at the time of a geropsychiatric hospitalization. *Family Relations, 46*(2), 179–185.

Penning, M. J. (1998). In the middle: Parental caregiving in the context of other roles. *Journals of Gerontology, 53–B*(4), S188–S197.

Powers, D. V., Gallagher-Thompson, D., & Kraemer, H. C. (2002). Coping and depression in Alzheimer's caregivers: Longitudinal evidence of stability. *Journals of Gerontology, 57–B*(3), 205–211.

Prescop, K. L., Dodge, H. H., Morycz, R. K., Schulz, R. M., & Ganguli, M. (1999). Elders with dementia living in the community with and without caregivers: An epidemiological study. *International Psychogeriatrics, 11*(3), 235–250.

Rapaport, P., & Orbell, S. (2000). Augmenting the theory of planned behavior: Motivation to provide practical assistance and emotional support to parents. *Psychology and Health, 15*(3), 309–324.

Roberts, A. R., & Dziegielewski, S. F. (1995). Foundation skills and application of crisis intervention and cognitive therapy. In A. R. Roberts (Ed.), *Crisis intervention and time-limited cognitive treatment* (pp. 3–27). Thousand Oaks, CA: Sage.

Shyu, Y. I., Archbold, P. G., & Imle, M. (1998). Finding a balance point: A process central to understanding family caregiving in Taiwanese families. *Research in Nursing and Health, 21*(3), 261–270.

Skaff, M. M., Pearlin, L. I., & Mullan, J. T. (1996). Transition in the caregiver career: Effects on sense of mastery. *Psychology and Aging, 11*(2), 247–257.

Sorensen, S., & Zarit, S. H. (1996). Preparation for caregiving: A study of multi-generational families. *International Journal of Aging and Human Development, 42*(1), 43–63.

Vertommen, H., Van Houdenhove, L., Onghena, P., Westhoven, R., & D'Hooghe, M. B. (2001). Victimization in chronic fatigue syndrome and fibromyalgia in tertiary care: A controlled study on prevalence and characteristics. *Psychosomatics: Journal of Consultation Liaison Psychiatry, 42*(1), 21–28.

Wackerbarth, S. (1999). Modeling a dynamic decision process: Supporting the decisions of caregivers of family members with dementia. *Qualitative Health Research, 9*(3), 294–314.

Author's Note

Comments or queries may be directed to Margaret England, 401-307 Grand Marais Road West, South Windsor, Ontario N9E 4S2 Canada. E-mail: drmcengland@yahoo.com

---

Margaret England, PhD, RN, is Associate Professor, Faculty of Nursing, University of Windsor, Ontario, Canada.

CJNR 2005, Vol. 37 Nº 3, 34–46

Résumé

Amélioration de la recherche sur les soins de santé : une approche collaborative et interdisciplinaire

Susan M. Fox-Wasylyshyn, Peggy Oldfield,
John Muscedere et Maher M. El-Masri

De nombreux programmes de recherche s'attaquent à des questions trop complexes pour qu'un(e) chercheur(euse) seul(e) ou une équipe de recherche formée de membres de la même profession puisse en faire entièrement le tour. Les équipes interdisciplinaires peuvent, collectivement, produire une masse de connaissances communes, élargir l'étendue de la recherche et obtenir des résultats plus pertinents sur le plan clinique qui sont sensibles aux réalités de la pratique. Les auteurs décrivent l'expérience d'une équipe de recherche du point de vue de ses membres. Le document de recherche vise à mettre en lumière les avantages d'une approche collaborative et interdisciplinaire en recherche ainsi qu'à décrire les caractéristiques d'une équipe gagnante. Certains des avantages décrits comprennent notamment la productivité et la qualité de la recherche, le perfectionnement professionnel et l'encadrement, le soutien et l'encouragement, des réseaux de ressources élargis, et le rapprochement du monde universitaire et de la pratique. Les auteurs abordent également les questions des caractéristiques d'une équipe de recherche gagnante et des défis qui y sont associés, et ils font des recommandations pour l'amélioration des projets de recherche par la collaboration.

Mots clés : équipes de recherche, recherche en collaboration; recherche interdisciplinaire; programme de recherche

CJNR 2005, Vol. 37 Nº 3, 34–46

Enhancing Health-Care Research: An Interdisciplinary Collaborative Approach

Susan M. Fox-Wasylyshyn, Peggy Oldfield,
John Muscedere, and Maher M. El-Masri

Many research programs tackle complex problems that cannot be comprehensively investigated by a sole researcher or a research team from a single profession. Interdisciplinary teams can develop a collective mass of common knowledge, broaden the scope of research, and produce more clinically relevant outcomes that are sensitive to the realities of practice. The authors describe the experience of a research team from the perspective of its members. The purposes of the paper are to highlight the benefits of an interdisciplinary collaborative approach to research and to describe the characteristics of a successful team. Some of the benefits discussed include increased research productivity and quality, professional development and mentorship, support and encouragement, expanded resource networks, and bridging of the gap between academia and practice. The authors also discuss the characteristics of a successful research team, associated challenges, and recommendations for enhancing research endeavours through collaboration.

Keywords: research teams, collaborative research, interdisciplinary research, research program

The primary purpose of health-care research is to enhance evidence-based practice through theory generation and testing. Clinical problems are often of interdisciplinary concern and therefore require that clinicians collaborate to resolve them. It can be argued that if there is a need for clinical collaboration, there is also a need for collaborative research. In fact, the complexity of the research process and the growing trend among funding institutions to mandate interdisciplinary research necessitate collaboration among researchers.

The purposes of this paper are to highlight the benefits of a collaborative approach to research and to describe the characteristics of a successful research team.

Collaborative research can be conducted in the context of either an interdisciplinary or an intradisciplinary approach. An *inter*disciplinary team includes investigators from two or more disciplines, while an *intra*disciplinary team is composed of investigators from a single discipline. The literature suggests that the interchangeable terminology used to describe the two different levels of collaboration leads to confusion (Ryan & Hassell, 2001; Zungolo, 1999). In this paper the term collaborative research is used to encompass both intra- and interdisciplinary collaboration; when the discussion is unique to a particular type of collaboration, the more specific terms intra- and interdisciplinary collaboration are used.

Rationale for Interdisciplinary Collaborative Research

The goal of nursing is to preserve and promote the health of individuals, families, and communities. However, this goal is not unique to nursing. A truly holistic approach to helping individuals and groups achieve optimal health frequently requires the coordination of several health professions. Similarly, more thorough and rigorous research is possible when several investigators work together to address a researchable health issue. Many research programs tackle complex problems that cannot be comprehensively investigated by a sole researcher or by a research team from a single profession (Zungolo, 1999). In addition, research conducted in isolation by individual investigators or intradisciplinary teams can result in a culture of defensive debate among disciplines (Donaldson, 1999). Interdisciplinary teamwork, in contrast, can potentially lead to the development of a collective mass of common knowledge, broaden the scope of research, and produce more clinically relevant outcomes that are sensitive to the realities of practice (Donaldson; Merwin, 1995; Ryan & Hassell, 2001). An added advantage of interdisciplinary research pertains to the dissemination of findings — when nurses engage in interdisciplinary research their work has the potential to reach a broader audience and thus have a greater impact. These advantages of interdisciplinary research explain the growing trend towards its endorsement as a priority in many Canadian research centres (Stewart, 1997). Therefore, nurse researchers are encouraged to seek and develop interdisciplinary opportunities. Our collaborative research experience, which is described below, demonstrates the many advantages of conducting research within the context of an interdisciplinary team.

The Research Program

Our team's research interest is clinical issues pertaining to acute care. The team has embarked on two research projects concerning nosocomial infections among the critically ill. The first project, which is nearing completion, examines the contribution of trauma-induced immune depression on the risk of developing nosocomial infection. The second, which has been recently funded, is a clinical trial examining the impact of an oral-care protocol on the prevention of nosocomial pneumonia among mechanically ventilated patients. The team is also in the process of writing reports on several research projects and preparing a third proposal. As an advantage of collaborative thinking, the team has identified several other topics for future investigation.

Team Building

The Starting Point

Our research team began to develop approximately 1 month after one of its members joined the nursing faculty at a medium-sized university in southern Ontario, Canada. The university is not associated with a teaching hospital but is located in a city with two community hospitals.

In the process of orientating oneself to a new faculty, one socializes with colleagues, discussing, among other things, one's research interests. During one such process, a new faculty member with experience in collaborative research learned that another faculty member had similar practical experience as well as similar research interests and aspirations. The two colleagues recognized the difficulties and challenges inherent in initiating and sustaining a research program while attending to teaching and other responsibilities in the university community. They tentatively discussed the possibility of collaborating on research projects as a means of furthering their careers. As they got to know each other, they sensed that they had compatible personalities and work ethics, and, perhaps just as important, that they could trust each other's scholarship and motivation. They believed they would make good collaborators and therefore committed to working together on research projects. Approximately 3 months after establishing this collaboration they decided to expand the team to include clinicians, in order to strengthen the intended clinical research program. Initially the two founding team members were concerned that the lack of a teaching hospital would be an obstacle. However, they reached out to clinicians from the local community hospital, which presented an opportunity for inter-institutional and interdisciplinary collaboration.

The Intradisciplinary Phase

The choice of a third team member was an obvious one: a clinically based resource-utilization nurse and research ethics coordinator at one of the local community hospitals with whom both team members had had recent contact. A graduate student in nursing, she had over 15 years' experience in critical-care nursing and continued to have close ties with the intensive care unit. On the basis of her rich professional background and her obvious interest in research, she was invited to join the team. She eagerly accepted the offer. The inclusion of a graduate student with a rich clinical background would help the team to reach its objectives and create a unique opportunity for student mentorship. Despite her student status and her need for research mentorship, it was understood that she was joining the team as a full partner who would enrich the clinical perspective of the team's collaborative effort.

The Interdisciplinary Phase

Although some nurses conduct research with the goal of furthering nursing theory and differentiating nursing from other health disciplines, the reality is that many clinical research problems are of interdisciplinary interest. The clinical and acute-care nature of our research program and its interdisciplinary relevance called for the expertise of an intensive-care physician. It was decided that such expertise would enrich the clinical validity of our work and broaden its audience. One month after the team had been expanded to three members, a meeting was arranged with the chief physician of the intensive care unit, a person with a research background. Following a discussion of the team's research program and some of its upcoming projects, the physician expressed interest in joining and has since been functioning as a full member. The inclusion of a physician on the team was important in facilitating the diagnosis of our research outcomes (nosocomial infections) and providing clinical guidance in our research. In addition to participating in the team's research activities, the physician has increased its opportunities for funding from medical foundations that would otherwise be inaccessible to nurse researchers.

Determining the Team's Size

The team was cognizant of the need to include sufficient manpower to achieve its goals while avoiding the problems associated with unnecessarily large groups. It was therefore decided that four was a sufficient number of members to provide the human resources needed for efficient communication and frequency of meetings. Our decision to limit membership to four should be interpreted in the context of the unique needs of our team. While some teams might need to be large in order to secure necessary expertise and knowledge, it is important that size does not overwhelm the team's work processes. Other than a relatively old recommendation by Santora (1982), that five to ten members is optimal for effective team processes, no literature was found concerning the relationship between team size and productivity in collaborative research. However, the literature revealed that different collaborative research programs ranged from two to eight members (Fitzgerald et al., 2003; Ryan & Hassell, 2001; Stoner, 1998). Larger groups are likely to be associated with inability to achieve equitable division of labour, formation of splinter groups, and protracted decision-making (Santora). Should the need arise, additional expertise may be sought from consultants in order to preserve the team's size and avoid the negative consequences of unnecessary inflation.

Benefits of Conducting Research as a Team

Working within the context of a research team offers many advantages. Improving the research output in terms of quality and quantity was the main reason for the establishment of our group. Additional advantages of working within a group include increased research knowledge and skills, improved motivation and support among the members, and an expanded network of resources (Fitzgerald et al., 2003; Ryan & Hassell, 2001; Stoner, 1998). These additional advantages are valuable in and of themselves. They also have the benefit of enhancing the quality and productivity of our work. For instance, increased motivation among team members stimulates them to put greater effort into their work and thus improves the calibre of our output.

Productivity

Research is a labour-intensive and time-consuming activity in which investigators working alone may do so at the expense of other pursuits. Collaboration has allowed us to be more productive and to participate more fully in other professional endeavours. Division of the workload among four individuals has made the complex tasks of preparing proposals, writing manuscripts, and conducting research much more manageable. It has allowed us to complete projects in a timely manner and to have several projects in progress at any given time. In addition, distributing the workload among four team members frees up time for other pursuits and obligations such as teaching, committee work, clinical responsibilities, and professional development.

Quality

A collaborative approach to research has not only increased our output but, more importantly, strengthened its quality. The diversity and sharing of expertise is essential to the success and quality of our research program. Each team member brings a unique set of clinical and research skills that contribute to the quality of our work in different ways. The integration of members' specialized knowledge allows for research that is broader in scope, based on a more rigorous design, and more clinically relevant (Merwin, 1995).

A key component of any research team is the development of proposals and reports. The members of our team generally share writing tasks, reviewing and critiquing each other's drafts. This is a useful exercise because individual writers tend to become mired in their work and may overlook weaknesses that another reader is able to identify. The process of critiquing each other's work requires that team members put aside their egos to provide, request, and accept constructive feedback. Team members view each research project from their own philosophical, professional, and experiential perspective. They therefore tend to read and write from different perspectives. The blending of these various perspectives strengthens the overall quality of our work and reduces the potential for weaknesses detected by external reviewers.

Professional Development and Mentorship

Participation in a truly collaborative research team creates a supportive and nurturing environment in which individual members can further develop their skills (Gelling & Chatfield, 2001). The opportunity to work within a group that provides mutual support and criticism in a non-threatening manner is highly conducive to learning in our team. Group discussions provide a forum for members to share their unique expertise. The learning that occurs is not restricted to research. Self-development may extend to such areas as ethics, clinical issues, negotiation and group-functioning issues, and even writing skills.

Mentorship is a valuable dimension of professional development. It requires that one be available as a role model and a source of information, advice, and counsel. Traditionally it has been viewed as a unidirectional relationship from mentor to protégé (Whelley, Radtke, Burgstahler, & Christ, 2003). However, such a unidirectional relationship may not reflect the dynamics of mentorship as it takes place in a collaborative research environment. The nurse clinician member of our team is currently a master's student in nursing. As a student she is mentored with respect to research skills. As a clinician she brings a wealth of clinical experience that allows her to provide mentorship and insight with respect to our research endeavours. While it is clear how the nurse clinician on our team provides and receives mentorship, all team members participate in a mutual and reciprocal mentorship relationship as they shift roles according to their respective areas of expertise.

The participation of graduate students on collaborative teams provides them with a unique opportunity to take part in research in a challenging but non-threatening environment. The comfort of being able to develop skills gradually without having responsibility for the entire research project can be very conducive to learning. Active involvement in collaborative research, in fact, prepares graduate students to undertake their thesis or dissertation project and to establish a foundation for future research programs. Participation in direct research activities offers students a hands-on learning experience and unique exposure to the entire research process. For instance, the graduate student on our team witnessed the struggles inherent in the research process without becoming discouraged. She learned that researchers must accept criticism from external reviewers and use it to strengthen the quality of their work. Further, she had an opportunity to present some of her ideas to the team and see them developed into a full-scale research proposal with significant clinical implications.

Support and Encouragement

The support and encouragement that takes place within our team is a significant positive outcome of collaboration. Mutual support and the sharing of individual and group successes and challenges have strengthened relationships and facilitated team functioning. For example, when a member's motivation wanes during difficult stages of proposal writing, perhaps in association with the accumulation of stresses from work or family obligations, the support and encouragement of other team members helps to re-motivate him or her. Occasionally the support is more tangible, as when one member offers to do part of another's assigned work in response to a personal issue that has arisen, or when meetings are rescheduled or deadlines altered in response to team members' professional and academic responsibilities. The support and encouragement in relation to expectations and appreciation of unforeseen circumstances was not spontaneous but developed over time as we came to value each other's dedication to the team and its goals.

Expanded Network of Accessible Resources

An additional advantage of a team approach to research is the network of resources accessible to the team. Although our collective expertise is greater than that of any individual team member, we are occasionally in need of additional expertise. Each partner is part of a different network of valuable resources. For example, one member has close ties with a biostatistician whose expertise and advice have been extremely helpful for writing research proposals. Another member works part time at a large teaching hospital and therefore has access to a patient population that can be accessed for studies. Our clinical partners are well acquainted with both administration and nursing at their hospital and have a good understanding of clinical issues. They are well placed to use their connections to enhance our research agenda and promote relationships between clinicians and academics. Also, the physician on our team is affiliated with a university-based hospital in another community that could provide an opportunity for multi-centre collaboration. These connections provide additional sources of research participants as well as a valuable network of professional expertise.

The Building of Relationships

Nursing has long struggled for recognition as a profession and as a legitimate academic discipline (Ryan & Hassell, 2001). This struggle has been made all the more difficult by negative stereotyping among disciplines, which often creates a culture of rivalry that acts as an impediment to inter-professional collaboration (Watkins, Gibbon, Leathley, Cooper, & Barer, 2001). Active involvement of nurses in research and collaboration between nurses and other health professionals help to break down such barriers and lead to greater inter-professional cohesiveness, collegiality, and respect (Gelling & Chatfield, 2001; Whelley et al., 2003). In addition to establishing relationships among health professionals and promoting interdisciplinary research, the composition of our team helps to bridge the gap between the worlds of practice and academia in nursing. Hunt (1996) suggests that the boundaries between university and service settings should become more fluid because the clinical setting is a source of ideas and is also where data collection takes place and where research findings are applied. Indeed, our sharing of ideas and findings with clinical staff has served to enhance their interest in research and to facilitate our work.

Characteristics of a Successful Research Team

Gelling and Chatfield (2001) discuss collaborative research in relation to the six Cs: commitment, contribution, credit, compatibility, consensus, and communication. Although these concepts may exist to varying degrees, the extent to which they are present in a research group influences the overall effectiveness of the team.

Commitment is concerned with members' belief in and attachment to the group's objectives (Whelley et al., 2003). The commitment of our members is demonstrated in the way in which they give of their time and resources (Whelley et al.). In addition to their responsibilities to the group, team members have multiple obligations and demands on their time: teaching and clinical duties, committee work, academic development, and family obligations. Yet each member has consistently demonstrated a high level of commitment and made a sizeable contribution. If commitment and contribution levels vary among members, a situation could arise in which some contribute little while taking credit for work done primarily by others. Our group has not experienced such a situation. In fact individual productivity has increased due to a sense of commitment to the group. Members are more likely to volunteer to undertake a task or complete an assignment when they are accountable to the team than when they are accountable only to themselves.

Credit pertains to the way in which team members are rewarded for their contribution (Whelley et al., 2003). Prior to the commencement of any activity, credit-related issues such as authorship should be discussed in an open and frank manner that serves the interests of mutual respect and responsibility. It is important that fairness and equitable distribution of credit be observed so that each member receives due recognition. However, individual needs for professional advancement may be considered when credit issues are discussed. For instance, a team member seeking a promotion may offer or request to take the lead in a given project so that she/he will qualify for the promotion.

Compatibility is concerned with how individuals work together towards a shared goal (Whelley et al., 2003). Compatibility of personalities was deemed so important to the success of our collaborative endeavours that it was a key factor in determining who would be invited to join the group. As each individual was being considered as a possible addition to the team, careful consideration was given to his or her "goodness of fit" with the other members. As the team members had little experience working closely with one another, there was a risk that early impressions would prove false. Fortunately this has not been the case. Group members have similar work ethics and have consistently been respectful of each other's unique situations and obligations.

The matter of decision-making within a research group holds high potential for conflict. All of our team members are concerned more with matters of quality, efficiency, and respect for others than with power. Thus this issue has not arisen. From its inception, the group decided that decision-making would be a shared function. Decisions are generally made by means of discussion, negotiation, and eventual consensus. However, the expertise of each member carries a great deal of weight when individual decisions are made.

Because effective and open communication is an important part of successful collaboration, our team purposefully discussed the need to create an atmosphere in which members feel free to give voice to their opinions and ideas. Team members are expected to question, challenge, and discuss each other's ideas in a respectful and non-confrontational manner. A number of factors have served to foster this approach within our group. One is the effort made to establish an atmosphere of mutual respect and caring. A second factor is the absence of power struggles. Although team meetings are not intended as social functions, they are often conducted in an informal way that facilitates ease of negotiating, debating, and critiquing. Frequency of meetings, which varies with the task at hand, has been central to maintaining momentum and keeping the team focused on its goals. Team members have been extremely flexible with regard to meeting locations. In addition, the use of electronic communications tools to review drafts and provide feedback minimizes the need for lengthy face-to-face meetings.

Challenges

One of the issues that our team has had to contend with is the availability of time. All team members have multiple responsibilities, including full-time employment, committee work, educational pursuits, and family obligations. Thus the team's success depends on a delicate balance of responsibilities at both the individual and group levels. Although the group often sets ambitious goals, we have learned to be both flexible and realistic with regard to deadlines.

Although the team members have individual research achievements, our group has been functioning as a team for approximately 2 years. We have not yet established a collective track record and are just beginning to establish credibility as a research team. We anticipate that it will take some time to achieve a strong record of publication and funding.

Conclusions and Recommendations

Our experience with conducting research has taught us the benefits of working in the context of interdisciplinary collaboration. We have found that many of the difficulties inherent in conducting research become more manageable when several people are working together towards a shared goal. With an individual approach, research is often conducted at the expense of many other important duties. A collaborative team approach, in contrast, provides opportunities to increase research output without having to sacrifice other obligations. In addition, teamwork and an interdisciplinary approach generate credible research programs that can form a collective knowledge base and promote a culture of communication, collaboration, and support among health professionals.

While we argue that a collaborative approach offers unique opportunities for nurse researchers, we must point out that research teams should be formed with care to ensure maximal opportunities for success. Issues such as compatibility of personalities, a common work ethic, flexibility, mutual support, and a sense of commitment and dedication need to be carefully considered in the team-development process. Team size and diversity of expertise are other important considerations. We recommend that the team be large enough to provide human resources adequate to ensure research quality and productivity but small enough to ensure efficient communication and decision-making. While it is beneficial for team members to have common research interests, we recommend that each team member bring a unique perspective to the research program.

Finally, we recommend that academic programs emphasize the value of intra- and interdisciplinary collaboration in health-care research. Such an approach will positively influence the attitude of future graduates towards teamwork and collaboration, and may provide unique opportunities for mentorship. The inclusion of a graduate student on our team has been a highly successful move. Students can benefit from being closely mentored by experienced team members while also bringing a unique perspective to the team. We recommend that students and clinicians be offered more opportunities to take part in collaborative research.

References

Donaldson, S. (1999). The growth of collaborative and interdisciplinary research. In J. Sullivan (Ed.), *Creating nursing's future: Issues, opportunities and challenges*. St. Louis: Mosby.

Fitzgerald, M., Milberger, P., Tomlinson, P. S., Peden-Mcalpine, C., Meiers, S. J., & Sherman, S. (2003). Clinical nurse specialist participation on a collaborative research project: Barriers and benefits. *Clinical Nurse Specialist, 17*(1), 44–49.

Gelling, L., & Chatfield, D. (2001). Research collaboration. *Nurse Researher, 9*(2), 4–16.

Hunt, J. (1996). Barriers to research utilization. *Journal of Advanced Nursing, 23,* 423–425.

Merwin, E. (1995). Building interdisciplinary mental health services research teams: A case example. *Issues in Mental Health Nursing, 16,* 547–554.

Ryan, S., & Hassell, A. (2001). Interprofessional research in clinical practice. *Nurse Research, 9*(2), 17–28.

Santora, D. (1982). Problems in doing nursing research: Maximizing the group research process. *Western Journal of Nursing Research, 4*(3), 320–323.

Stewart, M. (1997). Centres for health promotion research in Canada. *Canadian Journal of Nursing Research, 29*(1), 133–154.

Stoner, M. H. (1998). Putting a research team together. *Journal of Emergency Nursing, 24*(4), 362–364.

Watkins, C., Gibbon, B., Leathley, M., Cooper, H., & Barer, D. (2001). Performing interprofessional research: The example of a team care project. *Nurse Researcher, 9*(2), 29–48.

Whelley, T., Radtke, R., Burgstahler, S., & Christ, T. (2003). Mentors, advisors, role models, and peer supporters: Career development relationships and individuals with disabilities. *American Rehabilitation, 27*(1), 42–49.

Zungolo, E. (1999). Interdisciplinary practice and education. In J. Sullivan (Ed.), *Creating nursing's future: Issues, opportunities and challenges*. St. Louis: Mosby.

Authors' Note

Comments or queries may be directed to Susan M. Fox-Wasylyshyn, Faculty of Nursing, University of Windsor, Health Education Centre, 401 Sunset Avenue, Room 322, Windsor, Ontario N9B 3P4 Canada. Telephone: 519-253-3000, ext. 2284. Fax: 519-973-7084. E-mail: sfox@uwindsor.ca

---

Susan M. Fox-Wasylyshyn, RN, MScN, is Assistant Professor and a doctoral candidate, Faculty of Nursing, University of Windsor, Ontario, Canada. Peggy Oldfield, RN, BScN, is Research Utilization Nurse, Hôtel-Dieu Grace Hospital, Windsor. John Muscedere, MD, FRCPC, FCCP, is Director, Intensive Care Unit, Hôtel-Dieu Grace Hospital. Maher M. El-Masri, RN, PhD, is Associate Professor, Faculty of Nursing, University of Windsor.

CJNR 2005, Vol. 37 N° 3, 48–65

Résumé

Du point de vue des personnes âgées : étude qualitative exploratoire visant à déterminer les entraves et les aides à la marche dans le milieu environnant

Donna Lockett, Alette Willis et Nancy Edwards

Cette étude qualitative exploratoire examine les facteurs environnementaux influant sur les habitudes de marche des personnes âgées en utilisant l'approche de messages par l'image (photovoice). Au total, 13 personnes âgées d'Ottawa, Canada, ont pris des photos des éléments qui compliquaient ou facilitaient la marche dans leurs quartiers. Les photos ont été exposées dans le cadre de trois séances de groupes de discussions, où elles ont servi de point de départ pour la discussion. Ont participé aux groupes de discussions 22 personnes âgées au total, dont 8 des 13 photographes. Les résultats montrent que les dangers environnants liés à la circulation et aux risques de chute peuvent constituer des entraves importantes à la marche chez les personnes âgées et que pour celles-ci, la connectivité ne peut réellement exister que si des parcours convenables et sans danger sont disponibles. Les résultats indiquent également que de simples commodités, comme des bancs et des toilettes, pourraient faciliter la marche chez les personnes âgées. Un quartier dont les activités prennent en considération les personnes âgées sera aussi pour toutes et tous un bon endroit où vivre, travailler et se divertir. L'utilisation de la méthode de messages par l'image a été bien accueillie par les participants et a fourni une riche information qui n'aurait peut-être pas pu être recueillie par d'autres moyens.

Mots clés : messages par l'image (photovoice), vie active, marche, personnes âgées, aides et entraves dans le milieu environnant

CJNR 2005, Vol. 37 Nº 3, 48–65

Through Seniors' Eyes: An Exploratory Qualitative Study to Identify Environmental Barriers to and Facilitators of Walking

Donna Lockett, Alette Willis, and Nancy Edwards

This qualitative exploratory study examined environmental factors influencing the walking choices of elderly people using the photovoice approach. A total of 13 seniors in Ottawa, Canada, took photographs of barriers to and facilitators of walking in their neighbourhoods. These photos were displayed during 3 focus-group sessions and served as touchstones for discussion. A total of 22 seniors, including 8 of the 13 photographers, participated in the focus-group sessions. The findings show that environmental hazards related to traffic and falls risks can be significant barriers to walking for seniors, and that connectivity can truly exist for the elderly only if convenience, hazard-free routes are available. They also indicate that simple amenities such as benches and washrooms might facilitate walking for seniors. A neighbourhood that is activity-friendly for seniors will also be a good place for everyone else to live, work, and play. The use of photovoice as a method was well received by the participants and provided rich information that may not have been captured through other means.

Keywords: photovoice, active living, walking, seniors, environmental facilitators, barriers

Introduction

Older adults represent the fastest-growing segment of the Canadian population (Everitt & Rosenberg, 2001). The quality of life of older adults is a critical element of the social fabric of communities. Physical activity is an indicator of this quality of life. However, despite overall gains in life expectancy, researchers are seeing a trend towards higher rates of inactivity amongst older adults in Canada (Canadian Fitness and Lifestyle Research Institute [CFLRI], 1996). Inactivity has important implications for the health and well-being of seniors. Inactive seniors are at increased risk for falling and for developing chronic health conditions such as cardiovascular disease and diabetes and, in general, experience a lower quality of life than their active counterparts (Campbell et al., 1997; Christmas & Andersen, 2000).

Integrating walking into everyday activities has been identified as an excellent strategy for increasing the physical-activity levels of sedentary older adults (Christmas & Andersen, 2000). Walking is the preferred mode of exercise for Canadian older adults (CFLRI, 1998). It is an effective way to improve cardiovascular fitness as well as strength and balance (Woolf-May, Bird, & Owen, 1997). Our research suggests that seniors who walk on a regular basis have a lower rate of falling than those who do not (Lockett, Edwards, & Sveistrup, 2003). Being able to walk places is also important for seniors' sense of independence, especially if they do not drive, have lost their driver's licence, or wish to limit their driving (Frank & Engelke, 2000; Traffic Safety Center, 2002).

When promoting active living, including walking, we know that it is not enough to simply tell people they should be active. Their personal choices need to be supported by amenable physical, social, and cultural environments (Giles-Corti & Donovan, 2003; Health Canada, 2002). It has been suggested that promoting the safe use of the environment among seniors may increase their levels of physical activity (CFLRI, 1997). And in surveys of the general public, although respondents mention both personal and environmental barriers to active means of transportation (Environics, 1998; Frank & Engelke, 2000), they also argue that interventions to alter the physical environment have greater potential for increasing physical activity than those aimed at changing individual behaviour (Frank & Engelke).

The physical environment comprises both the built and natural environments. Ideally, the two co-exist to create a sense of place, order, and beauty. The physical environment consists of human-built structures (e.g., buildings, roads, furniture) and naturally occurring features (e.g., topography, flora and fauna). Its spatial, aesthetic, and physical dimensions create a tacit context for living (Seamon, 2000). Several studies with younger populations have shown that features of the built environment (e.g., accessibility of stairs, public-transportation infrastructure) can affect the extent to which people choose to walk (Cervero & Radisch, 1996; Filion, McSpurren, & Huether, 2000; Fisher & Dunphy, 1994; Frank & Engelke, 2000; Frank & Pivo, 1994; Friedman, Gordon, & Peers, 1994; Furuseth, 1999; Handy, 1996; Shriver, 1997; Zacharias, 1997). However, seniors' perceptions of barriers to walking may differ from those of younger populations. It has been found that perceived risk of crime in a neighbourhood adversely influences the physical activity patterns of older adults more than younger adults (Centers for Disease Control and Prevention, 1999).

The literature exploring the influences of the built environment on active living choices is small, since this is an emerging field (Frank & Engelke, 2000; Giles-Corti & Donovan, 2003; Jackson, 2003; Leyden, 2003; Pikora, Giles-Corti, Bull, Jamrozik, & Donovan, 2003). Researchers have documented the combined importance of individual, social, and environmental factors for walking among the general population. Given that seniors are particularly vulnerable to environmental stresses (Lawton, 1982), and given that the well-being of community-dwelling seniors depends upon their mobility within the community (Metz, 2000), addressing barriers to and facilitators of walking for seniors should be of paramount importance to health promoters, urban planners, and decision-makers. This paper describes a qualitative exploratory study of environmental factors influencing seniors' walking choices.

Methods

The study was guided by a qualitative data-collection method referred to as photovoice (Wang & Burris, 1994). In this method, members of the community take photographs and then use the images to facilitate dialogue between themselves and outside groups. In contrast with studies that employ photographs taken by the researcher, in studies that use photovoice the camera is placed in the hands of the participant (Wang & Burris, 1994, 1997). The camera provides older adults with a means to describe features of their environment that likely would not be disclosed through an interview format. A discussion of a photograph taken by a participant provides the researcher with "direct entry into their point of view" (Radley & Taylor, 2003; Wang, Burris, & Ping, 1996). Photographs also trigger feelings and impressions (Cronin & Gale, 1996). Nurse researchers have used photographs to elicit rich data on people's lived experiences (Berman, Ford-Gilboe, Moutrey, & Cekia, 2001; LeClerc, Wells, Craig, & Wilson, 2002; Wang, Yi, Tao, & Carovano, 1998). However, the literature includes no reports on the use of photovoice to capture seniors' perspectives on how the environment influences their levels of physical activity.

Seniors from across the city of Ottawa, Ontario, Canada, were recruited through seniors' centres. A convenience sampling frame of three centres was initially selected from different regions of the city, to give the researchers access to a sample of seniors representing distinct and varied geographical domains. The research team had established rapport with managers in the selected centres while conducting previous studies; this facilitated access. Two urban centres (one French-speaking, one English-speaking) and one rural centre (English-speaking) were selected, affording a sample reflective of the two dominant cultures in Canada. At each recruitment site, seniors were invited to participate in the study by taking photographs and/or by joining one of three follow-up focus groups designed to facilitate discussion around environmental barriers to and facilitators of walking. A total of 13 seniors took 86 photographs of environmental barriers to and facilitators of walking. Of these seniors, 8

Table 1 ***Participant Profiles by Recruitment Site* (n = 27)**

	Urban English	**Urban French**	**Rural English**	**Rural French**
Level of participation				
Photographs and focus group	33	2	3	8
Focus group only	1	2	11	14
Photographs only[a]	2	1	2	5
Total	**6**	**5**	**16**	**27**
Age (mean)	71.0	70.8	79.4	76.0
Gender				
Male	1	0	3	4
Female	3	4	11	18
Missing	2	1	2	5
Preferred language				
English	4	0	13	17
French	0	4	0	4
Missing	2	1	3	6
History of falls in previous year				
Yes	2	1	2	5
No	2	3	9	14
Missing	4	1	5	8
Walk regularly				
Yes	3	3	6	12
No	0	1	8	9
Missing	3	1	2	6

participated in the focus-group sessions. Seniors who took cameras were asked to keep a log of what they had photographed. These logs were returned with the cameras. An additional 14 seniors participated in the sessions but did not take photographs. A breakdown of participation by recruitment site is provided in Table 1. As can be seen, the distribution of participants who took photographs is similar for each focus group. However, a disproportionately large number of seniors who had not taken photographs participated in the rural focus-group session.[1]

The focus-group sessions were held in specific geographical locations, the intention being that participants would have shared knowledge of a particular community. One was held in English in an inner suburb, one in French in central Ottawa, and one in English in a rural community south of the city. Ethics approval for the study was obtained through the University of Ottawa.

Three weeks prior to the focus-group sessions, the photographer volunteers completed a consent form and were asked to photograph areas in their neighbourhood where they felt safe and comfortable or where they thought other seniors might feel safe and comfortable pursuing leisure activities such as walking. They were encouraged to photograph only what they were comfortable shooting and to avoid putting themselves at risk when taking photographs. Each participant was provided with a 12-exposure disposable camera. Two weeks later the cameras were collected and the films were developed. Both printed photographs and digital versions on CD were produced for all of the returned cameras. Duplicate prints were made for participants who requested copies of their own shots. The digital photos were loaded onto a laptop computer according to the identification number of the participant who had returned the camera.

During the focus-group sessions, seniors who had taken photographs were asked to select, from among the prints of their photographs, the one that best represented a barrier to being active outside the home (in particular, walking) and the one that best represented a facilitator. The two photographs were then projected onto a screen using an LCD projector attached to the laptop, to enable all participants to view the images. Focus-group participants were asked to complete a brief questionnaire on socio-demographic characteristics, activity levels, and falls.

The focus-group discussions centred on the selected photographs. First, each volunteer photographer was asked to explain why the image he or she had selected was a good example of what facilitates or hinders

---

[1] This may be attributable to the fact that a snowstorm developed during the morning when the focus-group session was held, leaving several patrons of the seniors' centre stranded there for the morning.

physical activity among seniors. Following these individual descriptions, discussion was generated among the group. Probes were used to clarify which features of the photographed environment facilitated or hindered activity and, where discussion centred around a photograph, whether there was anything significant about the location that could not be captured in the image. All comments were audiotaped and data were transcribed verbatim. Transcripts, logs, and the photographs themselves were analyzed qualitatively using Atlas.ti version Win 4.2 software (Scientific Software Development, 1997). This software enables researchers to content code and retrieve not just textual data but also specific components of visual data, such as that provided by the photographs. Rather than forcing data into categories, the researchers allowed the categories to emerge from the data (Strauss, 1987).

Findings

Focus-Group Profile

The majority of the focus-group participants were female (18 out of 22). The youngest was 60 and the oldest 90, with an average age of 76. Five participants (26.3%) reported having fallen during the previous year, with representation in all three focus groups. Most participants were physically active and the most common activity reported was walking (57% reported walking regularly). Of note, the proportion of participants who walked on a regular basis was higher in rural areas (85.7%) as compared to urban areas (42.8%).

Barriers to Walking

In total, 39 photographs of barriers to walking were taken. Participating seniors identified safety as the main consideration for choosing whether and where to walk. Although a couple of participants identified personal safety related to crime as deterring them from walking in their environment, risks related to traffic and falls hazards emerged as the predominant safety issues.

Traffic hazards were featured in nine photographs. Discussions around these images revealed that the seniors were concerned about being hit or splashed by a car, having insufficient time to traverse intersections, poor visibility in busy intersections, and traffic lights located at inconvenient spots on a route, forcing them to either walk out of their way or risk traffic and jaywalk:

> *I feel that we need…something…because in the winter you don't want to hurry across the street when you see there's no traffic… It's fine once you get to the crossing, but there may be long, long, long distances.*

Pedestrian crosswalks were also identified as a hazard. Participants identified insufficient time to cross the street, speeding traffic, and vehicles that did not stop when signalled to do so at crosswalks as particularly hazardous:

> *It's almost worse, because people will stop because of the pedestrian [crossing]. The pedestrian thinks they're safe. But the motor crowd doesn't think it's anything to even bother with. And there's not enough enforcement. So there are more people hurt on pedestrian crossings. People have a false feeling of safety.*

Falls hazards were featured in 27 photographs. Discussions around falls hazards revealed that seniors' concerns included sidewalks that were cracked and had uneven or slanted surfaces that made it difficult to ambulate, especially when using an assistive device such as a walker. In some cases, particularly in rural areas, there were no sidewalks. A rural-dwelling woman with osteoporosis described her choices:

> *You can go on the…paved roads, but it's dangerous because cars go by at 100 kilometres an hour. So you go out on the country roads. And here…you have the rocks.*

In other cases, sidewalks would just end, "dumping" seniors into a parking lot. This appeared to be a particular concern in areas adjacent to shopping malls and grocery stores. Participants acknowledged that occasionally there were ramps linking sidewalks to parking lots. However, the ramps were frequently cracked, uneven, or steeply sloped with no railings, and did not resolve the problem of an older pedestrian being forced to cross a parking lot:

> *The entrance of the shopping centre…is not constructed with pedestrians in mind. So [for] someone that doesn't have a car and walks to the store, they are stuck and really have to watch for themselves.*

Inaccessible stairs and entranceways were also identified as a barrier. One woman who used an assistive device could not open the door to her apartment building and had to rely on another person being there when she wanted to enter or leave the building. Seniors living in rural areas also reported that some public buildings were inaccessible. One woman took a photograph of a narrow staircase, which she described during the focus-group session:

> *One of the most dangerous places…for seniors is going down to our pharmacy…. They put it down in the basement of the health centre…there was a lady broke her leg on those stairs… Also, the hearing centre is down [there].*

Another senior described the town hall building:

> *The way the town hall is built is that you come in on one level and you go up to pay your tax bill. Or you go down to access the offices that are down below. So when you arrive there isn't an access door that will open automatically for you. You have to struggle with that.... There is a ramp to get up to the outside door, but then you've got to fight like mad to get the door open on your own. And once you get in there, you're stuck unless you can walk upstairs or downstairs.*

Many of the exterior falls hazards identified were intensified by the presence of snow and ice. One particularly poignant series of photographs (Figure 1) documents a senior's odyssey in getting from her home to the mall and back, a round trip of no more than 600 metres. If one were to examine the route on a map, the woman's apartment building and the mall would appear to be well connected by streets and an intersection with traffic lights. From the perspective of an elderly person using a walker, however, walking the short distance involved navigating a number of almost insurmountable barriers: snow and ice on the sidewalk, a sloping sidewalk, curbs almost impossible to negotiate using a walker, and a parking lot with its attendant risk of being hit by a car.

Figure 1 ***A Participant's 600-Metre Round Trip to the Mall Using a Walker***

The sidewalk outside the woman's apartment building is covered in snow and ice.

2

This woman must cross a wide intersection to get to the mall; she often finds herself stuck in the median because the timing of the lights does not permit her to finish crossing.

3

4

Photograph 3: The doors to the mall are heavy and difficult to open; there is a lip on the threshold that the woman often trips over with her walker.
Photograph 4: On her way home, the woman must mount curbs that have no ramps and must cross a parking lot.

The sidewalk the woman must use to return home is sloped and in poor repair.

Facilitators of Walking

In total, 47 photographs of facilitators of walking were taken. Facilitators that were photographed and discussed included amenities in close proximity that provided a convenient and efficient destination for a walk — for example, mailboxes, newspaper boxes, and shops. Some seniors said that having good public transit was important so that they could consider bus transportation when planning their route. For example, one man described how he integrated physical activity into his daily routine:

> *[I live] close enough… So I walk downtown. And when I get downtown I hop on a bus back… It's convenient.*

Others identified the need for safe options when weather conditions are poor and places that are free from falls hazards, traffic, and crime year round:

> *[I like to walk in] places where snow has been cleared…because our winters are very long and very depressing…and, apart from needing exercise, we need to be out in the light and fresh air.*

Amenities such as washrooms and places to sit were seen as important in facilitating walking connectivity between places for seniors who require frequent rest stops:

> *I like to walk in…[the] park. It's a good place to walk as it has picnic tables, paved trails, washrooms, water fountains, and…easy access. And it has beautiful waterfalls. [translated from French]*

Finally, aesthetic qualities increased the enjoyment of the walking experience for the seniors:

> *There's that little walk-through to the post office, down towards the back of the shopping centre. …it's in through the trees. It's a nice, almost covered, area you can go through… You can escape the rush of the cars and trucks and go down there for a while.*

Discussion

The seniors who participated in this study were engaged in both organized and non-organized physical activities outside the home. More than half walked regularly, and in all three focus groups walking was described as the most common form of physical activity. This finding is consistent with data reported from Canada-wide surveys of seniors (CFLRI, 1996). The participants walked for exercise specifically, for recreation, and as a means of getting from one place to another.

Safe environments and aesthetically pleasing routes have been identified as important determinants of walking in two previous studies (Environics, 1998; Frank & Engelke, 2000), as well as in a recent survey of seniors in the Ottawa area (CFLRI, 2003). Our findings are consistent with those reported in these studies, suggesting that, for seniors, walking is facilitated by aesthetically pleasing environments, convenient routes, and efficient and readily accessible transit services. Our findings also suggest that walking among seniors is facilitated by amenities, such as public washrooms and benches for the elderly to rest when they become fatigued. In addition, our findings indicate that attention to environmental hazards related to traffic and falls is essential for the promotion of safe walking among older people.

The use of photovoice and focus-group discussions revealed that key barriers to walking among older adults include insufficient time to traverse intersections, failure of drivers to stop at crosswalks, lack of sidewalks and pedestrian connections, and poor maintenance of sidewalks, including clearing of snow and ice. Participants also identified access barriers related to unsafe stairs and entranceways. Depending upon an individual's physical abilities, obstacles that for some seniors represented falls hazards were for others partial or complete barriers. A senior who is unable to leave her apartment building is effectively hindered from being physically active in her neighbourhood.

The literature on environmental features, particularly that on hazards related to falls, focuses on individual hazards in space, as if they existed in isolation (Gallagher & Scott, 1997; Speechley & Tinetti, 1991). The use of photography demonstrates that these hazards exist in context. An interesting theme to emerge from the use of photovoice in the present study was that seniors are often forced to consciously trade one form of risk for another. For example, one woman's photograph of a gravel shoulder abutting the asphalt pavement illustrated the choices faced by a senior who wishes to walk in a rural area; she can either take her chances on the gravel and risk falling, or step onto the road and risk getting hit by a vehicle. Similarly, many of the urban photographs highlighted falls hazards on sidewalks. While the seniors categorized these as falls hazards but not as traffic hazards, the images illustrated something that could be lost in text: sidewalks are adjacent to streets. If an elderly person steps into the street to avoid the risk of falling posed by a cracked sidewalk, the crack becomes a traffic hazard. Conversely, if she chooses to risk traversing the cracked sidewalk to avoid being hit by a car, traffic becomes a falls hazard. A visual image captures the inseparability of these two concepts better than a purely verbal or textual description ever could.

Another theme that emerged through the use of photovoice was the need for efficient, barrier-free *routes* between destinations. In some instances, individual photographs managed to capture site-specific gaps in safe routes, especially as related to links (or lack thereof) between sidewalks and commercial buildings. Parking lots posed a hazard when pedestrians were forced to cross them in order to reach a mall or a store. In a broader context, maintenance issues such as broken sidewalks can also be understood as breaks in connectivity between points for pedestrians. The series of photographs illustrating one woman's 600-metre journey to the mall and back powerfully conveys the importance of understanding hazards in terms of their placement on routes. Hazards must not only be analyzed and treated in terms of their immediate surroundings, but also be understood in relation to broader routes and destinations.

Finally, although many of the photographs and much of the discussion regarding factors influencing physical activity pertained to features of the physical environment, some descriptions of social environmental factors also surfaced. Examples included concerns about crime and the failure of drivers to respect pedestrians at crosswalks.

Although rich information was captured through use of the photovoice technique, this approach has several limitations. First, had we asked the seniors to photograph not only features of their community that made it easy or difficult for them to be active, but also social factors that encouraged or discouraged them from engaging in physical activity, we may have elicited a wider range of images. Second, since patterns of physical activity may change markedly from one season to another, a longer study period, allowing seniors to take photographs during both winter and summer, would be useful. Third, because the cameras were in the hands of the participants, what they chose not to photograph was, for the most part, excluded knowledge. In future studies it may be useful to have the researcher accompany some of the participants as they take photographs, in order to inquire about what they have not chosen to photograph.

Conclusions

Most previous studies on physical activity among older adults have used quantitative data-collection methods (Markula, Grant, & Denison, 2001). Although these studies have contributed to our understanding of behavioural and social influences on physical activity, photovoice is a qualitative method that furthers our understanding of contextual influences on active living. Cameras provided a different "lens" or orientation through which seniors could document their experiences of place.

Overall, photovoice was well suited for our area of inquiry, as it allowed seniors to note features of the environment that are important but risk being overlooked in semi-structured interviews that elicit narrative stories. The use of photovoice as a data-collection method provided a contextual perspective for our research on active living and environmental hazards. Photovoice allowed us to not only identify individual hazards and facilitators of walking among community-dwelling seniors, but also gain an understanding of how these factors related to each other and to the broader environment, which included routes linking destinations. Although we did not specifically ask the participants for feedback on the use of photovoice as a technique, their comments were overwhelmingly positive and suggested that they felt empowered by the experience. Remarks made by participants indicated that photographing hazards served to heighten their awareness of the prevalence of falls hazards, thereby increasing their likelihood of not only avoiding hazards but also reporting them. Future work is needed to explore how photovoice may be used to raise awareness around environmental hazards. Photovoice has the potential to mobilize seniors to take action on environmental hazards, as evidenced by its previous use in social action research (Gallagher & Scott, 1997; Killion & Wang, 2000; McIntyre, 2003; Wang, 1999). It is a promising method for community-based research with older adults and a way for seniors to become involved in identifying and reporting hazards in their neighbourhood. If used more extensively, photovoice may provide a tool for action-oriented surveillance by seniors, an "environmental watch" strategy to encourage timely modifications to the built environment.

Finally, the findings indicate the need for intersectoral collaboration in order to make neighbourhoods more walker-friendly for seniors. Nurses can play a key role by proactively working across sectors and advocating for changes to the built environment. It is important that nurses be aware of the breadth of intersectoral strategies needed to alter the built environment in order to support safe walking for seniors. For example, transportation engineers can reduce friction at intersections and crosswalks, through the use of a temporal strategy (traffic lights), to restrict access to different times, and can designate certain spaces on the street as spaces where pedestrians have right of way. Planners can implement traffic-calming strategies, and police can ensure that traffic speeds are monitored and pedestrian rights are respected. Municipal officials need to be encouraged to enforce bylaws related to safe passageways and snow/ice clearing. Parks professionals and local environmental groups could be strong allies in lobbying for the provision and upkeep of areas that are, or are likely to be, frequented by seniors. Finally, intersectoral collaboration requires that nurses be familiar with fiscal priorities and budgetary decisions that impact on environmental safety.

References

Berman, H., Ford-Gilboe, M., Moutrey, B., & Cekia, S. (2001). Portraits of pain and promise: A photographic study of Bosnian youth. *Canadian Journal of Nursing Research, 32*(4), 21–41.

Campbell, A. J., Robertson, M. C., Gardner, M. M., Norton, R. N., Tilyard, M.W., & Buchner, D. M. (1997). Randomised controlled trial of a general practice programme of home based exercise to prevent falls in elderly women. *British Medical Journal, 315*(7115), 1065–1069.

Canadian Fitness and Lifestyle Research Institute. (1996). *Older Canadians becoming less active*. Lifestyle Tips series. Ottawa: Author.

Canadian Fitness and Lifestyle Research Institute. (1997). *Foundation for joint action: Reducing physical inactivity.* Ottawa: CFLRI; Fitness/Active Living Unit, Health Canada; Interprovincial Sport and Recreation Council.

Canadian Fitness and Lifestyle Research Institute. (1998). Popular physical activities. *Progress in Prevention Bulletin, 32,* 1–6.

Canadian Fitness and Lifestyle Research Institute. (2003, May 14). *Ottawa physical activity strategies: Considerations*. Unpublished data presented at Physical Activity Strategy meeting, Ottawa.

Centers for Disease Control and Prevention. (1999). Neighborhood safety and the prevalence of physical inactivity. *Morbidity and Mortality Weekly Report, 48*(7), 143–146.

Cervero, R., & Radisch, C. (1996). Travel choices in pedestrian versus automobile oriented neighborhoods. *Transport Policy, 3*(3), 127–141.

Christmas, C., & Andersen, R. A. (2000). Exercise and older patients: Guidelines for the clinician. *Journal of the American Geriatrics Society, 48,* 318–324.

Cronin, O., & Gale, A. (1996). Photographs and the therapeutic process. *Clinical Psychology Forum, 89,* 24–28.

Environics. (1998). *1998 National Survey on Active Transportation: Summary report.* Ottawa: Go for Green.

Everitt, J., & Rosenberg, M. (2001). Planning for aging populations: Inside or outside the walls. *Progress in Planning, 56*(3), 119–168.

Filion, P., McSpurren, K., & Huether, N. (2000). Synergy and movement within suburban mixed-use centers: The Toronto experience. *Journal of Urban Affairs, 22*(4), 419–438.

Fisher, R., & Dunphy, K. (1994). Transportation, congestion, and density: New insights. *Transportation Research Record, 1552,* 89–96.

Frank, L., & Pivo, G. (1994). Impacts of mixed use and density on utilization of three modes of travel: Single-occupant vehicle, transit, and walking. *Transportation Research Record, 1466,* 44–52.

Frank, L. D., & Engelke, P. (2000). *The impacts of the built environment on physical activity and public health.* Atlanta: Centers for Disease Control and Prevention.

Friedman, B., Gordon, S., & Peers, J. (1994). Effects of neotraditional neighborhood design on travel characteristics. *Transportation Research Record, 1466,* 63–70.

Furuseth, O. J. (1999). New urbanism, pedestrianism, and inner-city Charlotte neighborhoods. *Southeastern Geographer, 39*(2), 145–160.

Gallagher, E. M., & Scott, V. J. (1997). The Steps Project: Participatory action research to reduce falls in public places among seniors and persons with disabilities. *Canadian Journal of Public Health, 88(2)*, 129–133.

Giles-Corti, B., & Donovan, R. J. (2003). Relative influences of individual, social environmental, and physical environmental correlates of walking. *American Journal of Public Health, 93*(9), 1583–1589.

Handy, S. (1996). Understanding the link between urban form and nonwork travel behaviour. *Journal of Planning Education and Research, 15,* 183–198.

Health Canada. (2002, October). *Fitness and active living.* Retrieved September 8, 2003, from http://www.hc-sc.gc.ca/hppb/fitness/textonly/index.html.

Jackson, R. J. (2003). The impact of the built environment on health: An emerging field. *American Journal of Public Health, 93*(9), 1382–1384.

Killion, C. M., & Wang, C. C. (2000). Linking African American mothers across life stage and station through photovoice. *Journal of Health Care for the Poor and Underserved, 11*(3), 310–325.

Lawton, M. P. (1982). Competence, environmental stress, and the adaptation of older people. In M. P. Lawton, P. G. Windley, & T. O. Byerts (Eds.), *Aging and the environment: Theoretical approaches.* New York: Springer.

LeClerc, C. M., Wells, D. L., Craig, D., & Wilson, J. L. (2002). Falling short of the mark: Tales of life after hospital discharge. *Clinical Nursing Research, 11*(3), 242–263.

Leyden, K. M. (2003). Social capital and the built environment: The importance of walkable neighbourhoods. *American Journal of Public Health, 93*(9), 1546–1551.

Lockett, D., Edwards, N., & Sveistrup, H. (2003). [Stair safety and stair use among community-living seniors]. Unpublished raw data. University of Ottawa.

Markula, P., Grant, B. C., & Denison, J. (2001). Qualitative research and aging and physical activity: Multiple ways of knowing. *Journal of Aging and Physical Activity, 9,* 245–264.

McIntyre, A. (2003). Through the eyes of women: Photovoice and participatory research as tools for reimagining place. *Gender, Place and Culture, 1*(1), 47–66.

Metz, D. H. (2000). Mobility of older people and their quality of life. *Transport Policy, 7*(2), 149–152.

Pikora, T., Giles-Corti, B., Bull, F., Jamrozik, K., & Donovan, R. (2003). Developing a framework for assessment of the environmental determinants of walking and cycling. *Social Science and Medicine, 56,* 1693–1703.

Radley, A., & Taylor, D. (2003). Images of recovery: A photo-elicitation study on the hospital ward. *Qualitative Health Research, 13*(1), 77–99.

Scientific Software Development. (1997). *Atlas.ti, the Knowledge Workbench, Visual Qualitative Data Analysis, Management and Theory Building. Version WIN 4.2.* Berlin: Author.

Seamon, D. (2000). A way of seeing people and place: Phenomenology in environment-behavior research. In S. Wapner, J. Demick, T. Yamamoto, & H. Minami (Eds.), *Theoretical perspectives in environment-behavior research* (pp. 157–178). New York: Plenum. Retrieved Febuary 10, 2004, from http://www.phenomenologyonline.com/articles/seamon1.html.

Shriver, K. (1997). Influence of environmental design on pedestrian travel behaviour in four Austin neighbourhoods. *Transportation Research Record, 1578,* 64–75.

Speechley, M., & Tinetti, M. (1991). Falls and injuries in frail and vigorous community elderly persons. *Journal of American Geriatrics Society, 39*(1), 46–52.

Strauss, A. L. (1987). *Qualitative analysis for social scientists.* Cambridge: Cambridge University Press.

Traffic Safety Center. (2002). Special Issue: Older adults and safe mobility. *Online Newsletter, 1*(1).

Wang, C. C. (1999). Photovoice: A participatory action research strategy applied to women's health. *Journal of Women's Health, 8*(2), 185–192.

Wang, C., & Burris, M. A. (1994). Empowerment through photo novella: Portraits of participation. *Health Education Quarterly, 21*(2), 171–186.

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology and use for participatory needs assessment. *Health Education and Behaviour, 24*(3), 369–387.

Wang, C. C., Burris, M. A., & Ping, X. Y. (1996). Chinese village women as visual anthropologists: A participatory approach to reaching policymakers. *Social Science and Medicine, 42*(10), 1391–1400.

Wang, C. C., Yi, W. K., Tao, Z. W., & Carovano, K. (1998). Photovoice as a participatory health promotion strategy. *Health Promotion International, 13*(1), 75–86.

Woolf-May, K., Bird, S., & Owen, A. (1997). Effects of an 18 week walking programme on cardiac function in previously sedentary or relatively inactive adults. *British Journal of Sports Medicine, 31*(1), 48–53.

Zacharias, J. (1997). The impact of layout and visual stimuli on the itineraries and perceptions of pedestrians in a public market. *Environment and Planning B: Planning and Design, 34*(1), 23–35.

Authors' Note

Funding for this project was provided by the Health Canada/Veterans Affairs Canada Falls Prevention Initiative.

Donna Lockett is with the University of Ottawa's Community Health Research Unit, a Health System Linked Research Unit funded by the Ontario Ministry of Health and Long-Term Care. Alette Willis holds a Queen's Doctoral Fellowship funded through the Social Sciences and Humanities Research Council. Nancy Edwards' Nursing Chair is funded by the Canadian Health Services Research Foundation, the Canadian Institutes of Health Research, and the Ontario Ministry of Health and Long-Term Care.

The opinions expressed in this paper are those of the authors. No support of these opinions by the Ontario Ministry of Health and Long-Term Care, Health Canada, or Veterans Affairs Canada is intended or should be inferred.

Comments or queries may be directed to Nancy Edwards, School of Nursing, University of Ottawa, 451 Smyth Road, Room 1118, Ottawa, Ontario K1H 8M5 Canada. Telephone: 613-562-5800, ext. 8395. Fax: 613-562-5658. E-mail: nancy.edwards@uottawa.ca

---

Donna Lockett, PhD, is Research Associate, Community Health Research Unit, University of Ottawa, Ontario, Canada. Alette Willis, MA, MSc, is Doctoral Fellow, Department of Geography, Carleton University, Ottawa. Nancy Edwards, RN, PhD, is Professor and Chair, School of Nursing, and Director, Community Health Research Unit, University of Ottawa.

CJNR 2005, Vol. 37 Nº 3, 66–85

Résumé

La culture d'unité et la pratique infirmière fondée sur des données probantes en soins de courte durée

Carolyn J. Pepler, Linda Edgar, Sara Frisch,
Janet Rennick, Marika Swidzinski, Carole White,
Thomas G. Brown et Julie Gross

Cette étude de cas multiples sur l'utilisation de la recherche avait pour objectif d'examiner si, et de quelle manière, la pratique infirmière dans les unités de soins de courte durée se fonde sur la recherche, ainsi que de trouver des explications potentielles aux pratiques observées. Des données ouvertes ont été recueillies parmi le personnel infirmier ainsi que les infirmières et infirmiers responsables dans huit unités de soins de courte durée au moyen d'entrevues et d'observations. L'utilisation de la recherche variait à l'intérieur des unités et d'une unité à l'autre, mais la culture d'unité est apparue comme le principal facteur influençant les habitudes d'utilisation de la recherche. Les thèmes de la culture d'unité déterminant cette influence étaient l'harmonie de la perspective de recherche, la motivation à apprendre, l'orientation des objectifs, la créativité, le questionnement critique, le respect mutuel et la maximisation des ressources. Les résultats fournissent une riche description qui pourrait servir de base à l'auto-évaluation de la culture d'unité dans les unités de soins de courte durée en milieu hospitalier et dans les services de consultations externes.

Mots clés : culture d'unité, pratique infirmière fondée sur des données probantes, culture organisationnelle, étude de cas multiples

CJNR 2005, Vol. 37 N° 3, 66–85

Unit Culture and Research-Based Nursing Practice in Acute Care

**Carolyn J. Pepler, Linda Edgar, Sara Frisch,
Janet Rennick, Marika Swidzinski, Carole White,
Thomas G. Brown, and Julie Gross**

The purpose of this multiple-case study of research utilization (RU) was to examine whether and how nursing practices in acute-care units are built on research and to identify potential explanations for the observed patterns. Open-ended data were collected from staff nurses and nursing leaders on 8 acute-care units through interviews and observation. RU varied within and across units, but unit culture emerged as the principal factor linked to patterns of RU. Unit-culture themes that formed the links were harmony of research perspective, motivation to learn, goal orientation, creativity, critical inquiry, mutual respect, and maximization of resources. The findings provide a rich description that could serve as a basis for self-assessment of unit culture in inpatient and outpatient acute-care units.

Keywords: unit culture, research-based nursing practice, evidence-based nursing practice, organizational culture, multiple case study

The introduction of new treatments and approaches is a reality of nursing practice. It is critical that these changes be based on the most recent best-practice information, particularly in terms of patient outcomes. Studies have been conducted on the diffusion of innovations and ongoing development of research-based practice within the health-care system, largely in medicine (Dobbins, Ciliska, & DiCenso, 1998). A few have examined nursing practice (Hodnett et al., 1996; Tranmer, Lochhaus-Gerlach, & Lam, 2002), but the vast majority of recent nursing studies have focused on perceived barriers. Little is known about how and why nurses build their own practice on research-based evidence and what facilitates the process.

The purpose of this multiple-case study was to examine whether and how nursing practices in acute-care units are built on research and to identify potential explanations for the observed patterns. Many terms have recently emerged relating to the notion of research-based practice. These include evidence-based practice, knowledge-based practice, best practice, technology transfer, knowledge transfer, knowledge utilization, and research utilization. The broad terms evidence, knowledge, and best practice include critical inquiry using a variety of sources such as experience, expert opinion, or research. Our focus was more specifically research and its use as a basis for decision-making in nursing practice. This is only one aspect of evidence-based practice and includes the use of research methods in critical inquiry, the use of research findings, and the conduct of research.

Background

Nurses have been discussing the gap between knowledge and practice for over 40 years (Henderson, 1964; Malone, 1962). They seek knowledge that will ultimately be relevant and practical in nursing.

The literature suggests that research dissemination and utilization are affected by complex factors: pre-research conditions, such as funding and priorities; the research itself, its relevance to practice, and its applicability; methods of synthesis and dissemination strategies; individual and organizational characteristics of the setting; utilization strategies; and patient outcomes. Kitson, Harvey, and McCormack (1998) propose that three key dimensions are crucial to the successful use of evidence in clinical practice: evidence, context, and facilitation. Evidence refers to qualities of the research and the fit of the findings with clinical practice and patient preference. Context includes characteristics of the environment, such as unit composition, culture, and leadership. Facilitation comprises attributes of the facilitator, facilitation style, and the facilitator's role in the setting.

Nurse researchers have developed several models of research utilization (RU) based on dissemination theory (Horsley, Crane, Crabtree, & Wood, 1983; Krueger, Nelson, & Wolanin, 1978; Stetler, 2001). Each involves retrieval of findings, critique and determination of scientific merit, interpretation, assessment of relevance and fit with the setting, consideration of level and type of utilization, testing and implementation, evaluation of initial outcomes, and decision-making about adoption.

The utilization process is a complex one. It is not expected that all nurses will have the skills to complete all the steps nor that any one nurse will carry out the process alone. Still, individual factors such as sociodemographics, education, personality traits, participation in activities external to the workplace, work motivation, autonomy, values, and commitment to the organization have all been found to be associated with RU (Battista, 1989; Rogers, 1983). Findings are inconsistent, and some authors have raised questions about the current conceptualization of forces that influence RU (Estabrooks, 1997). The interaction between workplace and personal factors such as autonomy, job motivation, and commitment add to the complexity.

Organizational characteristics found to be related to the adoption of innovations include size, complexity, available resources, functional differentiation, culture, communication channels, and decision-making processes (Kimberly, 1981; Scott, 1990). A landmark study (Funk, Champagne, Wiese, & Tornquist, 1991) found that clinicians perceived the setting to be the greatest hindrance to RU, accounting for eight of the ten most important barriers.

In summary, the phenomenon of RU has been studied over many years and several models have been developed. Actual testing of nursing interventions to facilitate RU is rare and findings from quantitative studies of factors related to RU are inconclusive. Much of the research has focused on barriers. The purpose of this study of RU was to examine whether and how nursing practices in acute-care units are built on research and to identify potential explanations for the observed patterns.

Method

This was a multiple-case study of RU in eight clinical units at four sites of a recently merged tertiary-care setting with a strong research tradition. Yin (1994) defines a case study as an empirical inquiry that "investigates a contemporary phenomenon within its real-life context, especially when the boundaries between the phenomenon and the context are not clearly evident" (p. 13). In a multiple-case study, cases are examined individually, followed by cross-case analyses.

Data collection had four components: (1) an anonymous questionnaire for nurses concerning individual and organizational characteristics; (2) interviews with nurses (group and individual); (3) interviews with nursing leaders on the units, including head nurses (HNs), clinical nurse specialists (CNSs), and nurse clinician educators (NCEs); and (4) observation of activities and resources, including documents and their use. The objective of data collection was to obtain information from a variety of sources and perspectives in order to provide as full a picture as possible of RU on the selected units. This paper reports the qualitative analysis of the results of the interviews and observations.

Ethical approval was granted from the Research Ethics Board of the Faculty of Medicine and of each of the hospital sites. The study was described to the HN and other nurses on each unit at a time convenient for the unit, and the researchers completed the data collection and preliminary analysis for each unit before proceeding to the next.

Twenty focus-group interviews, two to four on each unit, were conducted by one of the authors, L.E., to address general issues of RU. Questions included: What is research utilization? How does it happen on this unit? Why does it happen? Who does it? What facilitates and hinders it? What effect does it have? Nurses were asked to give examples of unit practices they considered to be research-based and how and why these practices had come about. Four other interviews were conducted with staff nurses who had taken responsibility for a particular project identified during data collection such as the development of aromatherapy for oncology patients. These nurses were asked about the initial idea, the assessment of the problem, the literature review, issues of time and access, implementation of the plan, and planned or completed evaluation of the outcomes. The research coordinator interviewed unit leaders, the HN, and the CNS and/or NCE on each unit. These respondents were asked to give their views on the questions listed above, their role in the RU process, and the possible influence of administrative policies and practices on that role. All interviews were audiotaped and transcribed.

Field notes were kept in relation to ongoing practices observed on each unit. These practices included those related to communication patterns, regular nursing staff meetings, and tasks such as medication preparation. The research coordinator noted such issues as how nurses dealt with the situation when they needed information or how new ideas evolved and were pursued. Data were also collected on resources such as literature, documents, procedure manuals, and computers and their use on each unit. Each unit provided from seven to ten data sources, two to four focus groups, two to four leader interviews, and one observation period initially, plus one interview with the HN and one observation period 6 months later to assess change. The latter was based on the knowledge that clinical units are not static entities, and while the initial data-collection period on each unit was approximately 1 month and both nurses and leaders often reported historical phenomena, the researchers wanted to see if and how the initial description of RU had altered; this was thought to be important in capturing the process of building practice on research.

Settings

Units were selected with a view to examining a variety of settings. Initially, two units, a medical oncology unit and a surgical oncology unit at an adult general hospital site, were studied in a pilot phase. The extension of the study to all sites of the merged hospital added another adult general hospital, a children's hospital, and a neurological hospital. The chosen units had similar patient populations but were located at different sites. In addition to the two pilot units, this led to the selection of an outpatient oncology unit at the first site; an inpatient oncology unit, an outpatient oncology unit, and a neurology unit at the second general site; a neurosurgical children's unit; and a neurosurgical adult unit. The actual level of RU on each unit was unknown, but the units varied in terms of size and patient population, access to online searching and the Internet, length of nursing experience, numbers of nurses with baccalaureate education, presence of facilitators, and presence of students — all of which are factors thought to influence RU.

In total, there were 180 nurses in the eight units, with about half of them participating in a focus-group interview.

Analysis

Each case — that is, the phenomenon of RU on one unit — was analyzed separately, using Atlas.ti (Muhr, 1997). Data from the interview transcriptions were examined utterance by utterance and, where necessary, thought expression by thought expression within utterances — that is, when a comment expressed more than one thought or opinion, these were coded separately. Data from the first clinical unit were coded by all researchers using open-ended coding, so a code list was created. Codes were clustered into categories and codes and categories were defined through a consensus process. This was refined by all researchers for the second unit. Subsequently, researchers worked in pairs to code all sources of data, reaching consensus between the two researchers and bringing innovative or controversial coding to group discussions. Two of the researchers summarized the data by category for each unit, which were then discussed within the team. Finally, the researchers wrote a descriptive analysis of each unit focusing on the reported or observed RU in the unit and the phenomena that might have been associated with it. Cross-unit comparison was made using these descriptive analyses. The researchers constructed a grid of the themes in the descriptive analyses and noted patterns across units. These patterns were condensed and shaped into a framework linking RU practices with characteristics of the units.

Results

Unit culture emerged as the principal factor, with themes within the cultures linking to RU. The results are presented in three sections: presence of RU across units, the components of unit culture, and a framework linking cultural themes with RU. Quotations are provided to illustrate the phenomenon reported.

Presence of Research Utilization

Reported RU varied within each unit but variability was more evident across units. Data from all sources illustrated well the presence or absence of RU. Four codes were combined to create the descriptions of actual RU: research as a basis for practice, change based on research, research as persuasion, and evaluating options. The following examples illustrate situations in which RU occurred:

> Interviewer: *Are there any other practices based on research?*
>
> Nurse: *The TBI [traumatic brain injury] program…a reality-based orientation board,… Everyone — all staff as well as family members — are supposed to use it to help orient the patients. The nurses have seen good patient outcomes with it…they see patients actively using the board to orient themselves.*
>
> *I did a project recently on pain in the elderly. …it was…looking at the literature, finding information, and then trying to get that information out to nurses.… We found a pain-assessment tool that was applicable for geriatric patients and we held three in-services looking at pain in the elderly…and we got feedback from nurses on it — that was our evaluation tool.… It's [the assessment tool] being used to a certain extent, but it could be used more.* (staff nurse)
>
> During report the nurses were discussing an incident in which a physician had asked one of the nurses to flush a pigtail (similar to a chest tube). The AHN said, "We refused to flush it. I said [to the physician], 'Do you have any literature on flushing chest tubes?'" (observation)

The absence of RU was determined by the inability of nurses to define it or to give an example, nurses' statements that it was not occurring, or nurses' comments about why it was not occurring. The picture with regard to RU was also based on observations of situations in which a known body of research, such as that on pain management, was deliberately not consulted. Again, multiple sources were drawn upon to complete the description:

> *And then there are those [nurses] that reject certain ideas, because they're saying, "I'm not sure about that, this always worked, and I'm going to keep doing this." So there are certainly some nurses like that, but for the most part I think…most of the nurses are not closed to the idea. But I think what's lacking is many nurses don't know how to go about doing it.* (leader)
>
> Interviewer: *Are you familiar with the term "evidence-based practice"? Do you talk about it on the floor?*
>
> Nurse: *Us, working on the floor, no. It's addressed more by the CNS and NCE. I think as the staff gets more senior, you can start to address these things. For somebody who's starting, there's not a lot of interest in addressing that — it's more advanced practice.*
>
> The nurses were discussing the use of a non-adhering dressing for a patient. One nurse went and got the non-adhering dressings

> available on the unit and showed them to the other nurses. Another nurse said, "We should have an in-service on all these different dressings!" The HN said, "They change so often it's not worth it." (observation)

Unit Culture

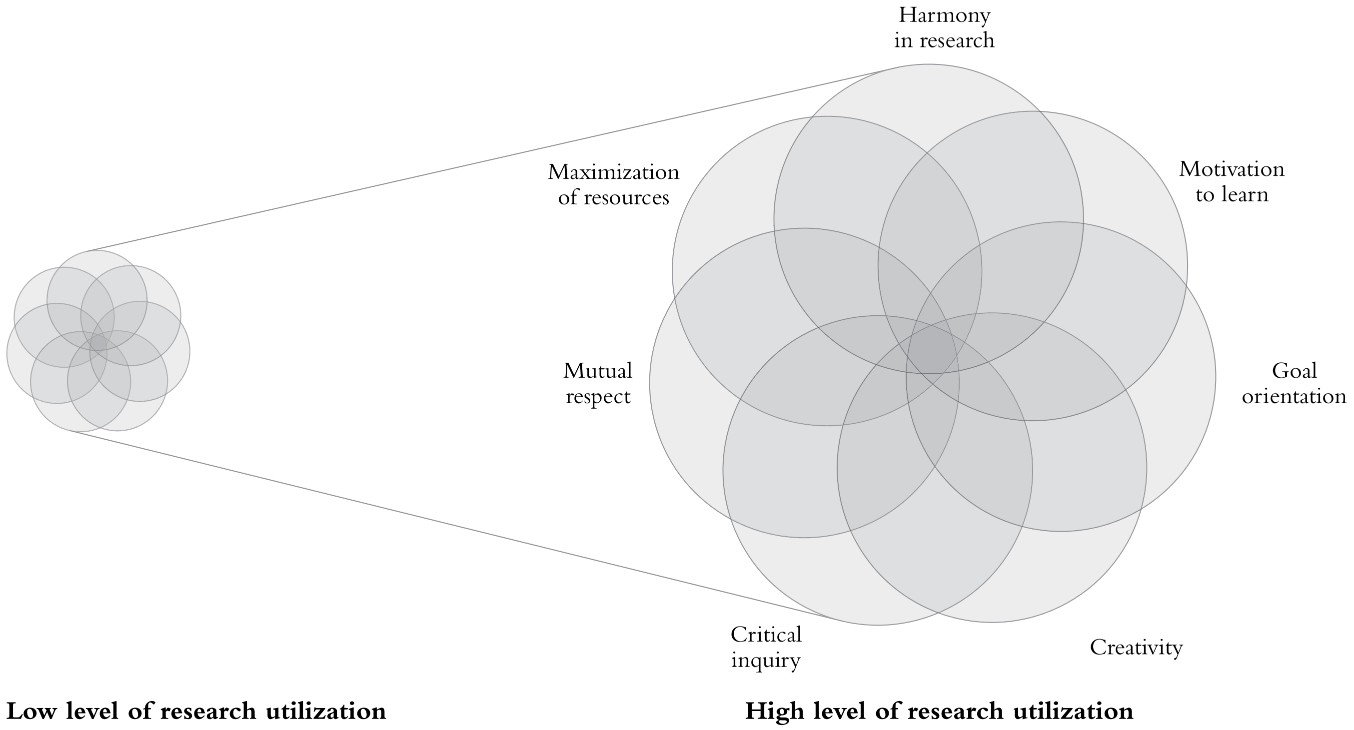
Unit culture was defined as the beliefs, values, and practice norms on a given unit. Although the primary focus of data collection was research-based practice, a broader description of the overall culture emerged as relevant in the analysis. The observed characteristics of the culture were clustered into six categories: structural factors, bases for decision-making for practice, characteristics of the nurses, ongoing research, understanding of the meaning of RU, and facilitator strategies. Structural factors included such issues as patterns of staff stability, patient continuity, perceived limitations to practice, shift work, and unit communication patterns (report, communication book, interdisciplinary interactions, etc.). Bases for decision-making for practice included nurses' body of knowledge, such as that learned from education and experience; information from unit-based resources — that is, peers, leaders, and members of other disciplines; documents and literature; and information from extra-unit resources such as the hospital-based nursing consultants, research data managers, the pharmacy department, and other literature. Characteristics of nurses comprised those inherent in the individual, competencies and skills, personal motivation, and negativism; those related to nurses on the unit as a whole such as beliefs about nurses' needs and stressors and about professional autonomy; and concepts such as the value of students, "fresh blood," and variability across nurses. Ongoing research related to norms of either the conduct of or participation in research projects on the unit, whether nursing, medical, or interdisciplinary. Understanding of the meaning of RU referred to the leaders' and nurses' comprehension of RU, its value, and its differentiation from the conduct of research. Finally, facilitator strategies encompassed efforts to create or support learning opportunities, stimulate critical inquiry, and conduct research.

The Links Between Unit Culture and RU

Certain themes were identified across units, linking unit culture and its components with RU (see Figure 1): harmony of research perspective, motivation to learn, goal orientation, creativity, critical inquiry, mutual respect, and maximization of resources.

Each theme incorporated a group of characteristics found to a greater or lesser degree on each unit along a continuum of *linkage to high versus low level of RU.* The themes could be conceptualized as separate entities

Figure 1 *Themes Linking Unit Culture and Research Utilization*



on a given unit for the purposes of description and discussion, but in fact they were intertwined. Their interdependence led to the complexity that was the distinctive culture of each unit. No one unit was uniformly high or low on all themes. Each had a mix, although some units had a *predominance* of high or low RU characteristics.

***Harmony of research perspectives*.** As linked to a high level of RU, this meant that leaders and nurses had a similar understanding of the meaning of RU and could differentiate it from research. The individuals and groups were able to articulate the other's perspective. They valued research and understood its usefulness in informing practice. They also had similar ideas about how RU was practised and who was involved in it. In general, they thought all nurses were involved in RU to some extent, although they recognized differences in readiness, interest, and capability across nurses and across roles. Leaders, especially CNSs and NCEs, were expected to focus more of their attention on RU and nurses were expected to focus more on direct patient care. Nurses could give examples of RU on their unit, describe how it had come about, and briefly describe the merits of the research base. The basic steps in RU were described by nurses and leaders and were observed to be taking place on the unit. Participation in nursing, medical, and interdisciplinary research was supported by leaders and nurses, even if it took time and effort. Nursing staff were well informed about research projects and the importance of their contribution. Past research projects in which the staff had participated were associated with RU when the outcomes were seen to be beneficial for patients:

> *I would have hoped [CNS] would have been on TV. She did a fantastic research and we…could see the outcome. It was very satisfying.* (nurse)

Current research was described as a potential basis for practice and nurses felt a sense of ownership or self-worth because of their participation.

At the other end of the continuum there was misinformation or lack of awareness. In some cases the leaders had a clear understanding and vision but the staff nurses were less aware or thought RU was something that someone else did. In other cases the nurses were prepared to question but, for various reasons, the leaders did not support opportunities to pursue RU. Nurses were able to describe a practice that had a research base only with considerable prompting and questioning by the interviewer. Awareness of previous research conducted on the unit was non-existent or hazy and there was no sense of self-worth attached to participating in current projects. Research projects were seen as belonging to someone else and were generally thought to create more work for nurses:

> *They come to us and they tell us, "You're doing the study," the physical part of the work. We're not asked whether we want to do it or not. I think it's like that with all the studies.* (staff nurse)

Motivation to learn. A high level of motivation to learn, as it was linked to RU, was characterized by nurses possessing or pursuing advanced education and regularly attending conferences and continuing-education courses. Learning was described as a lifelong process and experienced nurses were enthusiastic about learning, although it was noted that the need for learning was greater for novice nurses. Leaders encouraged nurses to participate in learning activities and supported them with resources such as time off and fee payment. While resources for learning were appreciated, nurses also recognized the reward of learning itself and the need to cover their own costs. Participation came with the responsibility to give a presentation upon return to the unit. This theme was interconnected with goal orientation in the sense of having a learning or achievement goal such as a degree or certification. It was also related to maximizing and taking advantage of resources for funding and learning:

> *I don't find they [nurses on other units] get the same encouragement to go to conferences, to present at conferences. …we tease her [HN] a lot; she expects a lot from us…but at the same time she's very proud of you, she's very supportive of you.* (staff nurse)

Low motivation to learn was linked to a low level of RU. It included limited attendance at conferences and continuing-education courses, or attendance only when fully financed and during working hours. Barriers to attendance were identified by both leaders and nurses. Attendance was seen as compulsory or as an opportunity to sit for a day. Sometimes it was feasible only when the organizers provided perquisites or rewards:

> *I gave them each one [conference notice] and said, "You can go." And they said, "Who's going to pay?" And I said, "Well, we can pay with [funding from the nurses' contract]." "Oh, okay." And then I say, "Lunch is paid…." "Lunch is paid?" And then they say, "Well, what about parking?" It never ends.* (leader)

There was no obligation or opportunity to bring feedback from a learning session.

Goal orientation. When this was associated with a high level of RU it was characterized by a vision or perspective on the future. There was harmony of the visions held by the leaders and the nurses. They were aware of each other's perspectives and held similar opinions about the goals of the unit, although the nurses may have seen the leaders as having greater responsibility for achieving these goals. Individual goals varied, but they were expressed and there were opportunities and support systems to meet them:

> *It gives you a goal, a goal to work towards…. [The CNS] helped me a lot with my…slide presentation… I did the slides and then we worked together on the laptop to figure things out. She connects — she sort of got me connected with somebody in the hospital who's good at doing slides.* (staff nurse)

Improvement in details of patient care and measurable patient outcomes were goals associated with clearly articulated ideas and plans. Nurses identified goals for improvements in working conditions that were focused beyond their own situation to outcomes for patients. When one project was nearing completion, nurses and leaders planned another. Goal orientation was linked to participation in learning activities such as conferences, in the sense that nurses wished not only to learn but also to share their knowledge. Similarly, projects were planned with publication of results as a goal.

In contrast, little or no goal orientation was exemplified by a viewpoint of "getting through today," or moving from task to task or crisis to crisis. Improved patient care was sometimes identified as a goal, but only in vague terms, and goals for improved working conditions were focused solely on the nurses with no consideration of the impact of their worklife on patient outcomes:

> *…the thing is, they usually make research on patients, on what's going to happen to the patient,…but if there's no nurse to take care of the patient…we need to do some research to change our condition.* (staff nurse)

There was a lack of awareness of or disagreement about the future direction of the unit, or there was frustration that a particular goal could not be achieved. No examples were given about plans for the future.

Creativity. Creativity shared some characteristics with other themes, notably identifying goals, creating learning opportunities, and finding resources to achieve individual and unit objectives. It also had unique characteristics: originality of projects pursued by nurses and leaders and innovative approaches to unit activities. Greater creativity was linked to a higher level of RU:

> *We said it would be nice to have a nurse who would be knowledgeable about this and…would be able to help us assess and deal with it… [The staff nurse] said, "I'd like to do wound care"…and another one was interested [in] conjugal violence.* (leader)

Ideas from the literature or from conferences or other settings were adapted innovatively to suit the unit culture — the patients, the nurses, the environment, the resources. This approach to innovative thinking and acting was supported by the leaders and the other nurses. When one nurse came up with an idea, she or he was encouraged to pursue it. Others recognized that time and effort were needed and they were willing to share regular responsibilities to allow time for innovation. Nurses were encouraged to explore their ideas in a rigorous way with critical inquiry or development of proposals and actual research. Creative thinking also involved making connections among personal experience, observations, sources of information, literature, and expert opinion, and then moving forward to test clinical hypotheses.

On the other hand, the lack of creativity that was linked to a low level of RU was characterized by few or no new ideas or a lack of support for new ideas when they did come up:

> *There's not enough time to discuss it; you just leave it, and then unfortunately forget about it. I know that we're constantly generating ideas.* (staff nurse)

Questions, suggestions, and ideas were ignored or dismissed. Tradition and previous experience were the primary bases for practice decisions. Change was avoided, and change brought about by external pressures was resented.

Critical inquiry. The presence of in-depth inquiry following from questions or new ideas was connected with a high level of RU. It appeared in the questioning behaviour of nurses. Questions went beyond "What should I do?" to "What do I need to know in the future to make a decision?" or "What will the outcomes be?" The process could be pursued by the nurse asking the question, or prompted by a leader or another nurse:

> *We were using so many different products and nothing was working. So I researched about…25 different papers, and the best thing…the simplest and cheapest, was just using normal saline rinses. …I presented it to the ward.* (staff nurse)

Expert advice was sought, often with a request for the substantiating evidence. The body of literature on the topic was explored in a systematic fashion. Group process was often entailed, so that one or two nurses pursued different aspects of the question and brought the information back to the group. A formal critique might be carried out by a group of nurses on their own, it could be stimulated by a leader, or the review could be done by a leader for nurses to discuss and critically appraise. Rigorous critique of research design or method was not observed, but there was an awareness of the limitations of some methods or some sources in the literature. Leaders and nurses said they tried to bring in literature that was methodologically sound. Students were welcomed because they came with inquiring minds and stimulated thinking with their questions. Students were also seen as a resource and stimulus to learning because they provided literature that they had reviewed.

In cases where critical inquiry was lacking, there was an absence of questioning beyond "What should I do?" Information may have been sought from peers or others in one-on-one situations, but issues were not pursued. Group meetings and opportunities for group process were few:

> *Once in a while during report in the morning, the assistant head nurse will talk with us about a new thing or maybe a change in a protocol, since the research says that or that, but it's quite rare.* (staff nurse)

Students were seen as a burden because of their questioning. If a literature review was conducted by a leader, it was presented to the nurses and there was little indication that nurses engaged in any critical thinking in this process. This theme was linked to a lack of creativity, where tradition or previous experience provided answers without exploration of current or future circumstances.

Mutual respect. A high level of RU was associated with mutual respect across nurses, leaders, and disciplines; interdisciplinary collegiality; unit identity; pride in one's unit; and positive working relationships among nurses. There was a high level of satisfaction with communication. Nurses felt that they were in control of their practice and their work environment and that change was possible. They felt good about coming to work. Their unit was recognized by other units as having expertise:

> *We know we specialize in oncology and giving chemo and things to do with oncology and symptom management. …we're a resource for other floors.* (staff nurse)

There was mutual respect between leaders and nurses. Differences across nurses in terms of interests and capabilities were accepted and valued. Leaders capitalized on these differences and helped nurses to achieve goals within their own scope as individuals or as members of a group with special interests. Nurses' wholeness was recognized in the form of support for events in their personal lives.

When mutual respect was not in evidence nurses were unhappy with their work situation. They differed with leaders in terms of their roles and responsibilities, and in some cases believed their needs were not being addressed. Interdisciplinary relationships were either negative or based solely on information exchange. Nurses did not feel respected or recognized for their contributions. They believed they lacked the autonomy to take control of their own practice:

> *Sometimes you hear about the results of research and then you're wanting to put it into place. But you can't do that because the doctors will always… It's the doctors, right, who control it?* (staff nurse)

Maximization of resources. Maximization of resources in order to meet unit and individual goals as well as a high level of RU had several components. One was a clearly expressed awareness of the existence and accessibility of resources. Another was an atmosphere of success in obtaining and using a broad range of resources such as expertise, funding, and computers. Barriers were seen as challenges. This theme was linked to mutual respect in that the nurses believed the leaders were doing everything possible to maximize the resources needed for patient care and for RU. Nurses were also motivated and encouraged to use their own initiative in finding and using resources. This theme was linked as well to creativity in seeking innovative ways to address resource limitations:

> *Nurses are becoming a little more skilled at soliciting from physicians, from pharmaceutical companies and all of that.* (leader)

At the other end of the continuum, barriers were seen as insurmountable. The issue of barriers was raised by both leaders and nurses to explain their inability to obtain resources or practise RU. Computers were available in all units but nurses lacked either the time or the knowledge to use them to advantage. Although experts in nursing and other disciplines were present, nurses believed they lacked the authority to consult them. In some instances nurses were unaware of or failed to acknowledge existing resources:

> *There's a lot of girls on the unit that think about something — you know, "We should study that"…but then how are you going to study if you have no time to do it?* (staff nurse)

No unit was high RU or low RU in all of its characteristics. All units had some aspects of both types of characteristics, but some had more supportive than non-supportive ones and a fairly high level of RU, while others showed the reverse trend.

Discussion and Conclusion

The findings indicate that unit culture — the set of beliefs, values, and practice norms on a unit — is a major factor in the ongoing use of research as a basis for practice. Unit culture was found to be a composite of interdependent factors, including the level of understanding of research and research utilization, the conduct of research on the unit, structural factors such as work and communication patterns, the pattern of decision-making as a basis for practice, characteristics of the nurses, and the process of facilitation. These findings are inconsistent with some of the recent literature on organizational culture (Gershon, Stone, Bakken, & Larson, 2004; Jones, 2003) in that the data revealed the existence of a distinct culture on each unit, as opposed to an overall organizational culture. The study did not differentiate between culture — the norms and values governing how things are done — and climate — the perception of the culture (Verbecke, Volgering, & Hessels, 1998). While some of the interview and observational data addressed climate in terms of nurses' perceptions of the RU culture, the primary focus of the data was to provide a vivid description of practice norms and values.

Unit culture as linked to RU could be described in terms of understanding of research and the expectation that nursing practice can be built on research; the learning atmosphere, including motivation to learn and resources for learning; level of questioning and critical inquiry; mutual respect and interdisciplinarity; a sense of unit identity; pride in expertise and a desire to share it; and an orientation towards goals and future achievements. These findings are consistent with the conceptual framework revisited by Rycroft-Malone and colleagues (2002) except for our inclusion of facilitation within culture. The framework separates evidence, context — including culture and leadership — and facilitation. In their original work (Kitson et al., 1998) the authors note that this separation is essential for analyzing the contribution that each of these elements makes to research-based practice. In their recent analysis of facilitation they identify different roles a facilitator may assume and note that the role may be internal or external to the organization. The facilitators in our study were internal and integral to the unit. For this reason their values, beliefs, and behaviours were part of the essence of the culture of the unit, as was the degree of harmony between their beliefs and those of the nurses. Leaders' strategies of facilitation were fundamental and integral to the culture.

In addition, the significance of the role of the leaders was linked to RU in many ways. These included the valuing of and support for use of research, the transmission of the research orientation in the hospital mission and the administrative supports to the unit, the support for learning and goal achievement, role modelling in relation to nursing and interdisciplinary relationships on the unit, and the encouragement to question and maximize the pursuit of multiple sources of knowledge.

In the present study, information frequently came from human sources and may or may not have been based on research, whereas in the study by Thompson and colleagues (2001) the information was found to be based on research. However, in our study a culture of in-depth pursuit of information from a variety of sources was linked to RU.

Although harmony across leaders and nurses was clearly linked to RU, there was considerable variation in the way the leaders' efforts were seen by nurses, a finding similar to that of LeMay, Mulhall, and Alexander (1998). In their study of research culture with 21 nurses and 9 managers at three sites, LeMay and colleagues found that leaders in general saw research as important for strategic reasons but that it was a luxury, while nurses revealed a paradox of emotional response of fear/excitement and wariness/desire when asked about research. In the present study, enthusiasm for RU coalesced on units where the leaders and most of the nurses believed that research was important and useful in guiding practice and improving care.

In discussions of global organizational culture and RU (Tranmer et al., 2002; Varcoe & Hilton, 1995), factors such as administrative support, participation in learning experiences related to research, expectations of RU, the presence of facilitators and research consultants, and motivation of nurses have been found to be important. Some researchers have used surveys to study overall beliefs and practices (Estabrooks, 1997; Rodgers, 2000; Van Mullen et al., 1999). Elements of their results are supported in the present findings, whose richness makes a contribution to our knowledge of the determinants of research utilization at the unit level, one aspect of the field of study in Estabrooks' (1999) model.

Because of the complexity of intertwining factors, we did not expect to establish a "package" of characteristics that a unit might adopt in order to increase its RU. Rather than offering a prescriptive approach to enhancing RU, the present findings may be useful for self-assessment and consideration of themes on a unit. Leaders and staff nurses might together assess their own culture on the basis of the themes described in order to determine their RU potential. The development of RU is a function of not only the organizational culture but also the unit culture, and the facilitation behaviour of the leaders is an integral part of that culture.

References

Battista, R. N. (1989). Innovation and diffusion of health-related technologies. *International Journal of Technology Assessment in Health Care, 5,* 227–248.

Dobbins, M., Ciliska, D., & DiCenso, A. (1998). *Dissemination and use of research evidence for policy and practice: A framework for developing, implementing and evaluation strategies.* Ottawa: Canadian Nurses Association.

Estabrooks, C. A. (1997). Research utilization in nursing: An examination of formal structure and influencing factors. Unpublished doctoral dissertation, University of Alberta.

Estabrooks, C. A. (1999). Mapping the research utilization field in nursing. *Canadian Journal of Nursing Research, 31*(1), 53–72.

Funk, S. G., Champagne, M. T., Wiese, R. A., & Tornquist, E. M. (1991). Barriers to using research findings in practice: The clinician's perspective. *Applied Nursing Research, 4*(2), 90–95.

Gershon, R., Stone, P. W., Bakken, S., & Larson, E. (2004). Measurement of organizational culture and climate in healthcare. *Journal of Nursing Administration, 34*(1), 33–40.

Henderson, V. (1964). Current issues and interest in nursing research as reflected by field interview. In L. W. Simmons & V. Henderson (Eds.), *Nursing research: A survey and assessment.* New York: Appelton-Century-Crofts.

Hodnett, E. D., Kaufman, K., O'Brien-Pallas, L., Chipman, M., Watson-MacDonald, J., & Hunsburger, W. (1996). A strategy to promote research-based nursing care: Effects on childbirth outcomes. *Research in Nursing and Health, 19,* 13–20.

Horsley, J. A., Crane, J., Crabtree, M. K., & Wood, D. J. (1983). *Using research to improve practice: A guide.* New York: Grune & Stratton.

Jones, J. M. (2003). Dual or dueling culture and commitment: The impact of a tri-hospital merger. *Journal of Nursing Administration, 33*(4), 235–242.

Kimberly, J. R. (1981). Managerial innovation. In P. Nystrom & W. Starbuck (Eds.), *Handbook of organizational design,* Vol. 1 (pp. 84–104). Oxford: Oxford University Press.

Kitson, A. L., Harvey, G., & McCormack, B. (1998). Enabling the implementation of evidence-based practice: A conceptual framework. *Quality in Health Care, 7,* 149–158.

Krueger, J. C., Nelson, A., & Wolanin, M. O. (1978). *Nursing research: Development, collaboration, and utilization.* Germantown, MD: Aspen.

LeMay, A., Mulhall, A., & Alexander, C. (1998). Bridging the research-practice gap: Exploring the research cultures of practitioners and managers. *Journal of Advanced Nursing, 28*(2), 428–437.

Malone, M. F. (1962). Research communication. *Nursing Forum, 1*(Spring), 56–59.

Muhr, T. (1997). *ATLAS.ti: The Knowledge Workbench: Short user's manual.* Berlin: Scientific Software Development.

Rodgers, S. (2000). A study of the utilization of research in practice and the influence of education. *Nurse Education Today, 20,* 279–287.

Rogers, E. M. (1983). The innovation-decision process. In E. M. Rogers, *Diffusion of innovations* (pp. 163–209). London: Collier Macmillan.

Rycroft-Malone, J., Kitson, A., Harvey, G., McCormack, B., Seers, K., Titchen, A., et al. (2002). Ingredients for change: Revisiting a conceptual framework. *Quality and Safety in Health Care, 11,* 174–180.

Scott, W. R. (1990). Innovation in medical care organizations: A synthetic review. *Medical Care Review, 47*(2), 165–192.

Stetler, C. B. (2001). Updating the Stetler Model of Research Utilization to facilitate evidence-based practice. *Nursing Outlook, 49*(6), 272–279.

Thompson, C., McCaughan, D., Cullum, N., Sheldon, T. A., Mulhall, A., & Thompson, D. R. (2001). Research information in nurses' clinical decision-making: What is useful? *Journal of Advanced Nursing, 36*(3), 376–388.

Tranmer, J. E., Lochhaus-Gerlach, J., & Lam, M. (2002). The effects of staff nurse participation in a clinical nursing research project on attitude towards, access to, support of and use of research in the acute care setting. *Canadian Journal of Nursing Leadership, 15*(1), 18–26.

Van Mullen, C., Burke, L. J., Dobmeyer, K., Farrell, M., Harvey, S., John, L., et al. (1999). Strategic planning for research use in nursing practice. *Journal of Nursing Administration, 29*(12), 38–45.

Varcoe, C., & Hilton, A. (1995). Factors affecting acute-care nurses' use of research findings. *Canadian Journal of Nursing Research, 27*(4), 51–71.

Verbecke, W., Volgering, M., & Hessels, M. (1998). Exploring the conceptual expansion within the field of organizational behaviour: Organizational climate and organizational culture. *Journal of Management Studies, 35,* 303–329.

Yin, R. K. (1994). *Case study research: Design and methods.* Thousand Oaks, CA: Sage.

Authors' Note

This project was funded by the Fondation de recherche en sciences infirmières du Québec, the National Health Research Development Program, and the Canadian Institutes for Health Research.

Carolyn J. Pepler, N, PhD, is Associate Professor (Retired), School of Nursing, McGill University, and former Consultant for Nursing Research, Royal Victoria Hospital (now McGill University Health Centre), Montreal, Quebec, Canada. Linda Edgar, N, PhD, is Assistant Professor, School of Nursing and Department of Oncology, Faculty of Medicine, McGill University, former Consultant for Nursing Research, Royal Victoria Hospital site, McGill University Health Centre, and Adjunct Professor of Nursing, Brock University, St. Catharines, Ontario, Canada. Sara Frisch, PhD, is former Associate Professor, School of Nursing, McGill University, and former Director of Nursing Research, Montreal General Hospital site, McGill University Health Centre. Janet Rennick, N, PhD, is Consultant for Nursing Research, McGill University Health Centre, and Assistant Professor, School of Nursing, McGill University. Marika Swidzinski, N, MEd, is Clinical Nurse Specialist, McGill University Health Centre. Carole White, N, PhD, is Faculty Associate, SPS3 Study Coordinator, University of Texas Health Science Center at San Antonio, Texas, United States, former Assistant Professor, Faculty of Nursing, McGill University, and former Clinical Nurse Specialist and Consultant for Nursing Research, Montreal Neurological

Hospital site, McGill University Health Centre. Thomas G. Brown, PhD, is Associate Professor of Psychiatry and Co-director, Alcoholism and Drug Abuse Research, Douglas Hospital, McGill University. Julie Gross, N, MSc(A), is Clinical Research Nurse/Research Coordinator, McMaster University Medical Centre, Hamilton, Ontario, and former Research Coordinator, McGill University.

CJNR 2005, Vol. 37 N° 3, 86–102

Résumé

L'allocation de services par catégorie et les entraves aux soins destinés aux enfants souffrant de maladies chroniques

Lynne D. Ray

Les parents qui élèvent des enfants atteints de maladies chroniques font face au défi de trouver et de coordonner les ressources et les services communautaires appropriés pour leur enfant. Cette analyse secondaire avait pour objectif de déterminer l'opinion des parents sur les mécanismes de prestation des services de santé et d'éducation et des services sociaux aux enfants atteints de maladies et d'incapacité chroniques, ainsi qu'aux familles qui s'occupent d'eux. Une analyse thématique a été effectuée à partir des données d'entrevues réalisées auprès de 30 mères et de 13 pères. Les parents ont décrit 11 mécanismes qui étaient utilisés pour déterminer l'admissibilité aux services ou le rationnement de ces derniers : le diagnostic, l'âge, la dépendance à la technologie, la gravité du problème, la capacité fonctionnelle, le statut de tutelle, l'emplacement géographique, les ressources financières, la capacité d'adaptation estimée des parents, le défaut d'informer les parents des services offerts, ainsi que la cyclicité du financement. Il s'agissait de mécanismes complexes, erratiques et sujets au changement. Des mécanismes intégrés, participatifs, souples et justes sont nécessaires afin de réduire la charge de travail des parents et d'assurer une prestation plus équitable des services.

Mots clés : soins pédiatriques à domicile, critères d'admissibilité, maladie pédiatrique chronique, incapacité pédiatrique, enfants ayant des besoins de santé spéciaux, aide familiale, politique en matière de santé, services de santé destinés aux enfants, accessibilité des services de santé

CJNR 2005, Vol. 37 Nº 3, 86–102

Categorical Service Allocation and Barriers to Care for Children With Chronic Conditions

Lynne D. Ray

Parents raising children with chronic conditions face the challenge of locating and coordinating appropriate community-based resources and services for their child. The purpose of this secondary analysis was to determine parents' view of the mechanisms used to allocate health, education, and social services to children with chronic illness and disability and their caregiving families. A thematic analysis was conducted on data from interviews with 30 mothers and 13 fathers. These parents described 11 mechanisms that were used to determine eligibility and/or to ration services: diagnosis, age, technology dependence, severity, functional ability, guardianship status, geographic location, financial resources, judged parental coping, failure to inform parents about available services, and cyclical funding. These mechanisms were complex, inconsistent, and subject to change. Mechanisms that are integrated, proactive, flexible, and fair are needed to reduce parents' workload and to ensure more equitable allocation of services.

Keywords: pediatric home care, eligibility criteria, pediatric chronic illness, pediatric disability, children with special health-care needs (CSHCN), family caregiving, noncategorical, continuity of care, health policy, child health services, health-services accessibility

Introduction

Parents who are raising children with chronic conditions face numerous challenges related to their child's care and the consequences of care for the family. Children with chronic illness and disability often require special arrangements and skilled care in order to remain clinically stable and capable of participating in typical childhood activities. These children may need specialized developmental programs, medical equipment, and communication and mobility aids. Their parents may require in-home support or respite in order to keep up with caregiving demands. To support a child and his or her family in the community, appropriate programs, services, and funding must be located and coordinated (Atkin & Ahmad, 2000; Hall, 1996; Jerrett & Costello, 1996; Ray, 2002; Rodriguez & Jones, 1996). Matching the child's or family's needs with available programs is no simple task. With the exception of acute inpatient episodes, ongoing care and developmental support for this population takes place in the community, where the *Canada Health Act*'s principle of universality does not apply. Policies that govern access to community-based services may be developed at a provincial, regional, or municipal level, and the funding may come from a combination of ministerial, private-insurance, philanthropic, and fee-for-service mechanisms.

When a child is first diagnosed with a chronic condition the parents assume that their primary-care provider will refer them to the services they need. Over time parents may find that their child does not meet the eligibility criteria for these referred services. Parents gradually realize that it is they who have ultimate responsibility for locating and coordinating community services. Professionals may not have authority across the range of services that a child requires and may not be aware of all the family's needs (Perrin, Lewkowicz, & Young, 2000).

This paper presents a secondary analysis of data from a study conducted to validate a model of the work required in raising a child with a chronic condition (Ray, 2002). In that model, "working the systems" refers to the work that caregiving parents do in locating services, funding, and equipment; arranging appointments; completing paperwork; and relaying information to various professionals. Parents in that study claimed that working the systems was the most frustrating aspect of raising a child with a chronic condition. An important finding of that study was the degree to which eligibility criteria served as barriers to care and sources of frustration for parents. A secondary analysis was conducted to examine these issues in greater detail. Its purpose was to determine parents' view of the mechanisms used to allocate health, education, and social services to children with chronic illness or disability and their caregiving families.

Methods

Recruitment and Sample

Participants were recruited through five agencies serving children in the community. The agencies were purposively selected to gain access to a broad range of clinical conditions, as is congruent with the noncategorical approach to sampling from populations of children with chronic conditions (Perrin et al., 1993; Pless & Perrin, 1985; Stein, Bauman, Westbrook, Coupey, & Ireys, 1993; Stein & Jessop, 1982; Stein & Silver, 1999). Children with exclusively developmental or behavioural conditions were excluded. Clinicians at the five agencies contacted families and sought permission to release their names to the investigator. The sample included English-speaking parents (30 mothers and 13 fathers) from 30 families in which at least one child had a chronic health condition

(34 children in total). The children ranged in age from 15 months to 16 years and the complexity of their care needs ranged from mobility aids to 24-hour ventilator support. Eighteen children had communication problems; nine used some sign language. Ten children had cognitive delays, which ranged from mild to severe. Another four children, believed to have normal intelligence, had severe motor disabilities that affected their communicative ability. Twenty children had mobility difficulties, ranging from impaired balance to total wheelchair dependency. Twenty-four children had a condition or treatment that was visible in some way. Enteral feeding was the most common form of technical care ($n = 11$), followed by mobility aids ($n = 8$) and oxygen and suctioning ($n = 5$). All of the children required multiple forms of care.

Data Collection

All but two of the interviews were conducted in the family home. Each family was interviewed once. When both parents participated, they were interviewed together. Parents were given a pie-chart model depicting topics related to their child's care and the consequences of the child's care for the family. The pie chart contained seven equal-sized sections labelled as follows: doing special care, parenting plus, working the systems, changing relationships, keeping yourself going, keeping the household going, and changing family priorities. *Special care* comprised the medical care, treatments, and symptom monitoring that the child required at home. *Parenting plus* referred to typical parental tasks such as supporting development, but because of the child's chronic condition persisted for a long period and with unusual intensity. *Working the systems* referred to coordinating care with health, education, and social-service professionals. *Changing relationships* included shifts within the nuclear family, extended family, and friends. *Keeping yourself going* referred to parents' efforts to cope with the emotional and physical demands of their situation. *Keeping the household going* included efforts to balance the needs of the ill child with those of the rest of the family. *Changing family priorities* referred to sacrificing some family activities and goals to accommodate the child's needs. These topics were explained both verbally and in the pie chart. The parents were thus prompted to elaborate on the meaning of each topic for their family. The interviews, which were audiotaped, lasted from 1 to 3.5 hours.

Data Management and Analysis

The interviews were transcribed verbatim and imported into Folio-Views™ (Ray, 1997) for data management. In the original study, the data were coded according to the seven segments of the pie chart. This served as a means of partitioning the 1,300 pages of transcript into manageable sections. The current analysis was conducted on the segments initially coded under the broad category "working the systems." These data contained all segments in which parents discussed their working relationship with the health, education, and social-service sectors and therefore reliably captured all data on service-allocation mechanisms.

A thematic analysis (Kvale, 1996; Tesch, 1988) was used to identify issues related to service allocation reported by parents. All data on eligibility, refusal of services, unsuccessful referrals, change in programmatic policies, and parental efforts to locate services or funding were coded as a separate subset. These data were then analyzed to identify all forms of eligibility criteria or mechanisms for rationing services that parents described either directly or indirectly.

Findings

Parents described a total of 11 different types of eligibility criteria or rationing mechanisms related to children's services. These were diagnosis, age, technology dependence, severity, functional ability, guardianship status, geographic location, financial resources, judged parental coping, failure to inform parents about available services, and cyclical funding.

Diagnosis

The fundamental prerequisite for services was a specific medical diagnosis. Children who did not have a clear or common diagnosis were at a serious disadvantage:

> *The best thing is for that person to have a labelled problem, because if you have a labelled problem — those are the people who are best off. You get more help because people know about it. They've got groups that handle this. They've got clinics that handle it. But [not] if you have a case like [our son], and there's lots like him, who don't have a "syndrome" or something.*

When diagnoses were clear and specific, both parents and professionals gained a sense of legitimacy, confidence, and predictability. In contrast, parents of children with unclear, uncommon, or multiple diagnoses were frequently told that their child fell into a "grey zone." For example, a child who was unable to speak but could hear was not eligible for programs that taught sign language. Similarly, a child who was unable to speak but could hear and write and had normal motor skills was not eligible for speech computers. While the fundamental issue was communication, allocation of resources was based on hearing capacity alone.

Diagnosis not only served as a means of inclusion and exclusion, but it marked the boundaries of professional knowledge and scope of treatment. For example, one child who was deaf-blind had been cared for in a program for multi-handicapped children. Her mother arranged for her to switch to a deaf-blind program, with the following results:

> *When people started approaching her as deaf-blind, anything she did was wonderful; she just started coming out of herself. We now had a kid who was out of herself, and not turned totally in. It was a phenomenal experience.*

Professionals interpreted symptoms and priorities from the perspective of their clinical specialty, and if the fit was not appropriate the child's care could be suboptimal.

At a more abstract level of diagnostic categorization, children could be grouped according to whether their diagnosis was predominantly medical or predominantly neuro-developmental or behavioural. When families had one child with a medical condition and another child with a neuro-developmental condition they were able to compare service availability. They found that there were far more services for the child with a medical condition. One child with behavioural problems had no services while his medically ill brother had so many professionals following him that his mother was asking professionals to leave his case. This pattern of more services for medical conditions was observed across families as well. A mother made the following comment about her son who had both medical and behavioural problems:

> *I've always found the medical things a lot easier to deal with than the behaviour. With the medical, you feel like you can actually do something about it. Whereas this behaviour is, like, are you ever going to be able to get a handle on it?*

Age

The age of the child often played a role in eligibility. Early-development programs seek to capitalize on the developmental window from birth to age 3 and many services stopped at that age. Other services were linked to the typical age of school entry or the transition to adult care. These typical developmental markers did not always correspond with the service needs of the children with chronic conditions. Parents of older children noted that the number of programs decreased as the child grew older. Another problem occurred when parents found out about services too late. One couple was told that they would have been eligible for respite had they applied when their child was younger.

Age became a troublesome issue as the gap between a child's chronological age and his or her developmental age became more noticeable. Debates about age-appropriate school placement were particularly challenging for parents, and solutions often depended on flexible programming within the school system:

> *I think that's what we need to look at: "Is what we're doing with this child giving him a chance to succeed? Or are we going to hinder him? Are we going to send him on the road to failure by pushing him ahead because of his chronological age?" So there are a lot of things that need to be considered. I think that's where we can change a bit and learn to be a bit more flexible.*

Technology Dependence

Treatments that required technological support usually had funding priority over the more invisible behavioural management and personal care. Several parents mentioned that it was a piece of technological equipment that determined whether or not their child would receive certain services. One of the first systems for technology-based assessment was that developed by the Office of Technology Assessment (1987) in the United States and many programs have developed similar ones. While technology dependence provides an easy and tangible means of classification, technology-based classification can have unforeseen consequences for families:

> *It totally changes when your special-needs child goes into school. There's level 1, 2, and 3. [My daughter is] a level 3. She's the only child in the district that has an RN, which I am very thankful for because I have a choice in the RN. If your child is a level 2 and has a TA [teaching aide], parents don't have a say in anything and the child is basically bid on. That's how [the unionized system] works.*

In this system, parents of children with less technological care experienced a turnover of teaching aides and some tried various strategies to make their child a more appealing choice for staff.

Severity

Severity is specific to the disease process and was implicit in most discussions of eligibility. Parents often assumed that severity was a prime consideration when professionals made in-home assessments to determine eligibility. However, parents were unable to articulate how judgements about relative severity were made. They did provide examples of severely ill or disabled children receiving less assistance than children who were not severely affected:

> *It seems like once you are on the program you are always on the program. Or they have these people who are on the program who they can't get off. …I know of other kids who went on the program a few years ago that didn't have nearly the needs that [my son] has, but they got onto it then.*

This inequitable access was seen as profoundly unfair. Since there is no universal system for assessing severity across diagnoses, and since severity judgement is a function of one's range of experience with children's conditions, it is unlikely that any global notion of severity will be perceived as fair.

Functional Ability

Categorization by functional ability was based on the child's ability to do age-appropriate tasks of daily living and was a common allocation mechanism. However, this type of categorization rarely reflected the complexity of the child's abilities:

> *I phoned the fellow in [the government office] and I said, "What would you like me to say?" I said, "I really need this." And he goes, "Well, your child can dress herself." Regardless of whether she puts it on backwards it doesn't matter. As long as she can pull those pants up, because they're elastic — and she still wears elastic to this day because she can't do buttons. Or she can pick up that spoon. It doesn't matter that you have to cut it into the tiniest pieces possible. But she can pick up that spoon and sort of put it in her mouth. These were their criteria. And I said, "Well, that may be fine for you to say, but you have no idea of what it took to get her there!"*

Parents found that such screening mechanisms failed to consider the time it took to complete personal-care tasks or the quality and functionality of the result. Yet these qualitative nuances of the child's functioning were what determined the parents' caregiving workload.

Guardianship Status

While biological parents believed that foster parents had enviable access to services, foster parents were quick to note that fostering status was not always advantageous. Couples with both a biological child and a foster child with special needs were able to compare the relative benefits. One couple had sought funding for special equipment:

> *Then you have to go back to Social Services and say, "Hey, I need this." And they say, "Well, we've got nothing in the budget; go somewhere else." And then you've got somebody trying to get community funding, and they say, "No, you are under Social Services so they should be paying." So the Elks Club won't cover. So we were batting that ball for a long time.*

This family's experience showed that a diagnostic label suggesting eligibility for one service can be detrimental regarding eligibility for other services.

Geographic Location

For several families, availability of services was the deciding factor in their choice of where to live. This had consequences for cost of living, the dwelling size they could afford, and options for career advancement. Once families had secured services in their area and had set up a program of care for their child, there was "no way" they were going to move and start the process again. Geographic immobility became a serious consequence of service categorization. The distribution of services also differed markedly by geographic location:

> *You are very limited as to where you can move to. For example, [City A] has very little money for children in the schools with special needs. The neurological centre does not serve them, so they have no resources within their city for special physiotherapy and all that stuff. So even within the [region] you have to be very careful where you move. [City B] is really good. [City C] is good. [City D] [is] not so great. But [City A]! You do not want to live in [City A] if you've got special needs.*

Financial Resources

Needs testing, based on assessment of family income, is a longstanding mechanism for determining eligibility for services. Needs testing can be a degrading experience for parents. In recent years, employment-based or extended health benefits have come to play a greater role in families' ability to piece together services for their child. Families used a combination of funds from public-sector programs, employment-based benefit programs, and personal funds. One couple's son required 24-hour alert caregiving:

> *We actually use 1 day of [public home care] and then we use private hours on the Monday and the Wednesday morning, just through my husband's insurance. And then every other week we have some flex time from [public home care] and we use that to give us 6 nights of sleep.*

This couple had very good coverage; in other provincial jurisdictions there is no public funding for night-time respite.

Judged Parental Coping

Parents believed that judgements about how they were coping played an important role in professionals' decisions about allocation of services such as respite. They told numerous stories of being expected to hold on as long as possible before receiving respite. "I think they're *told* to stall as many people as possible because they have budget constraints." A common pattern was that those perceived to be coping received nothing.

The result was that parents, mothers in particular, were in crisis before they received help. They felt that recovering was a lengthy process and that a more preventative approach to respite would have avoided the cycle of burnout and recuperation. However, other parents tried to hold out and did not want to accept help. Some parents believed they were being perversely punished for successful coping, while others felt a sense of failure when they were deemed in need of respite.

Failure to Inform Parents About Available Services

All caregiving parents provided accounts of not being told about services or programs that might have benefited their child or family. Most attributed the lack of information to overworked staff, lack of knowledge among staff, poor coordination, or a lack of continuity of care. Others had become cynical and believed that professionals purposely withheld information from families to save "the system" money. Parents learned to be vigilant in seeking information about programs and in watching for policy changes in existing programs. One mother said, "We always have to be on our toes a hundred percent, or you get nothing; or you, or you're child, is left to fall in the cracks." When parents lacked the personal resources to invest in this search, they believed their children received inferior care.

Cyclical Funding

Some parents found that the key to accessing services was to apply before the annual budget ran out. This style of budget allocation usually applied to one-time expenditures such as for power wheelchairs or computer-assisted learning devices. Some parents knew which month a certain program usually ran out of funds. Other programs required regular retesting to ensure that the child was still eligible for services. Parents were quick to point out the lack of logic and waste of resources associated with this policy. For example, the parents of a girl who was clearly going to be wheelchair-dependent for life needed to get an annual letter of support from the pediatrician in order to maintain their handicapped-parking status. These routine eligibility checks appeared arbitrary and illogical to parents. As some parents asked: why would they want the trouble and stigma of special care if their child did not require it?

Interpretation

In the literature on parenting and chronic childhood conditions, the issues of eligibility criteria and mechanisms for allocating services to families are occasionally mentioned contextually. For example, Gillman, Heyman, and Swain (2000) note that a diagnosis can bring legitimacy and access to services, while Hoyle (1992) demonstrates that a diagnosis can both facilitate and restrict access to services. Hall (1996) mentions the role of age in eligibility determination. Mahon (2001) notes that some parents find needs testing to be a degrading experience. The Federal Task Force on Disability Issues (1996) and McKellin (1995) illustrate clearly the geographic restrictions associated with access to services. Other studies report that there is a threshold at which parents' inability to cope precipitates intervention and the allocation of resources to the family (Blackman, 1998; Dowling & Dolan, 2001). While these issues are referred to in the literature, they have not been the subject of discussion nor has their collective impact been analyzed. This secondary analysis represents a shift in focus whereby service-allocation mechanisms and their consequences for families are addressed collectively.

Categorization, Rationing, and Fragmentation

While generally not acknowledged as such, categorization is a mechanism by which government ministries or departments, regional health authorities, and institutions allocate finite resources (Albrecht, 2001; Brown, 1995; Mechanic, 1995). Rationing determines both access to services and the quantity of services provided (Bourgeault et al., 2001). The mechanisms for categorization and rationing have profound consequences for families. The current mechanisms for categorizing children and families result in inequitable distribution of services. The participants provided numerous examples of categorical resource allocation based on categories and mechanisms that were incongruent with actual need.

Inequitable distribution or mismatch between need and allocation was a fundamental concern for parents. Some families had no services, others obtained help only after considerable lobbying efforts, some obtained help with relative ease, and others were embarrassed by the amount of help they had been offered. Often, once a child was in a program, eligibility determination for other programs became easier. Arbitrary eligibility criteria create the structural boundaries that result in parents' spending considerable time seeking appropriate services for their child. This situation was variously labelled "the black hole syndrome," "falling through the cracks," or being the "football" bounced between ministries — the common issue being that fixed structural boundaries lead to an abdication of responsibility on the part of government.

The structural and fiscal boundaries between the ministries of health, education, and social services have been causing difficulties for decades (Alexander & Henningsen, 2002). They represent the multiplicity of decisions made under a host of different organizational, social, and political circumstances (Brown, 1995). Categorization and allocation policies are set under different political parties, lobbying pressure, managerial agendas, financial climates, and funding conditions. While each individual decision may have been reasonable in itself, frequently the cumulative result has no apparent logic, especially from the point of view of parents. The public tends to view tax dollars as one public purse, whereas professionals and administrators are accountable for one small portion and the budgetary system rewards the offloading of expenses to other ministries.

The net result of these structural weaknesses is a great deal of work for parents. Finding information, learning how the systems function, and staying current with policy changes is an extraordinarily time-consuming and frustrating process for a parent. Meanwhile, the health professional is put in the uncomfortable position of acting as service provider, advocate, and gatekeeper all at once (Bourgeault et al., 2001). This situation requires considerable tact and diplomacy on the part of both parties in the relationship between client and professional or administrator. Often, the marked power differential and conflicting roles create tensions among administrators, professionals, and parents.

Categorical Allocation and the Research Lens

The categorical distribution of services based on medical diagnosis is virtually unacknowledged in studies with children who have chronic conditions. This is partly a consequence of research design and sampling technique. The participants in the present study were recruited exclusively from community-based agencies, all but one of which served children with any combination of chronic illnesses or physical disabilities. The majority of studies of childhood chronicity, in contrast, recruit from diagnostic-based hospital programs or clinics. This recruitment strategy allows access to a large homogeneous population with minimal effort. For example, diabetes and cystic fibrosis are among the more frequently studied diagnoses (see, e.g., Grey & Sullivan-Bolyai, 1999; Hodgkinson & Lester, 2002; Johnson, Ravert, & Everton, 2001; Schilling, Grey, & Knafl, 2002). These are conditions for which there are specific treatment programs, and pediatric centres usually have multidisciplinary teams that work specifically with the families. While these families face extraordinary difficulties, they are not confronted with the diagnostic barriers to service access that were reported by the families in the present study.

A perennial debate in the chronic illness and disability literature centres around the issue of "lumping or splitting" (Mulvany, 2000; Perrin, 1999). When services for children and families are studied together (lumping), nuances in service needs can be missed. When they are studied by diagnostic group (splitting), those with uncommon diagnoses, multiple diagnoses, or unclear diagnoses are not represented in the research. In the

United States, a lack of comprehensive epidemiological data has led to inadequate funding for services. To address this problem several groups (Davidoff, 2004; McPherson et al., 1998; Newacheck et al., 1998; Stein, Silver, & Bauman, 2001) are attempting to define and identify the total population of children with special health-care needs. This epidemiological example, along with the illustrated ability to identify service barriers in the present study, demonstrates the consequences of studying the population through different research lenses and using different sampling approaches.

Improving Service Allocation

Given the current scarcity model under which resource-allocation decisions are made, some form of categorization and rationing of services is inevitable (Blackman, 1998; Perrin, 1999). However, mechanisms that are integrated, proactive, flexible, and fair are possible.

Integration. The need for better integration of services is clear. Both parents and care providers need to be able to plan a program of care without involving numerous programs and ministries. Various mechanisms have been tried to ensure that money follows the child and family rather than being split between ministries. For example, "block funding" links funds to the child, while other mechanisms allow funds to be shared by ministries. The participants in the present study wished to see truly comprehensive population-based programs that cross ministries. Integration efforts must overcome the funding and jurisdictional disincentives that perpetuate fragmentation (Perrin, 1999). Regardless of approach used, greater integration is a prerequisite to the provision of effective services to families.

Proactivity. Proactive service provision addresses two problems. The current needs-based allocation of services emphasizes deficits in the family's ability to manage on its own. It also reflects a reactive approach. For example, respite should be viewed as preventative. Parents should not be left to reach "rock bottom" before receiving help and should not be made to feel that they have failed. A proactive stance has been adopted by some programs but is by no means universal. Similarly, parents will face new challenges at predictable transition points: school entry, the child's reaching a weight where he or she can no longer be lifted by the parents, transition to adult services. Helping parents to plan for these transitions will save them from having to launch a new search for services at each stage.

Flexibility. The participants gave many examples of existing structures failing to meet the needs of their child and their having to make the child fit. This failing is reflected in all of the eligibility criteria.

Professionals and parents must be given the authority to put together a program of care that matches the child's needs and to allocate funds in a way that suits the family. For example, parents may prefer to have funding for a homemaker, instead of a caregiver for their ill child, so they can spend time with the child. Sensitive judgements about complex family circumstances can be provided only by skilled, knowledgeable professionals who have the authority to make individualized decisions (Blackman, 1998).

Fairness. The mismatch between the need for services and the availability of funding has generated much debate. While the parents in this study used the term "fairness," policy analysts discuss "equity" or the consistency and proportionality with which service-allocation decisions are made (Blackman, 1998). Both parents and policy analysts stress the need for greater transparency and accountability (Blackman; Light & Hughes, 2001). Parents need full access to information on programs, eligibility criteria, and decision-making processes. Cut-off points for eligibility criteria are constructed through fiscal, social, and political processes (Light & Hughes); rarely are eligibility criteria based on evidence that the categorical allocation is effective (Perrin, 1999). Evidence of fair and equitable allocation should be tested for both those who receive services and those who are excluded (Blackman).

The growing mix of public, private, and publicly funded contractual services provides additional complexity and the potential for inequitable allocation. For example, the role played by the child's illness severity, functional status, or technological dependence will vary according to the funding mechanism used. Social values provide public systems with incentives to target those with the greatest severity, while private, for-profit funding mechanisms provide incentives to target those who are "easy to serve." When funding and service-allocation decisions are driven by market forces rather than social policy, addressing the imbalances through advocacy becomes crucial (Pedlar & Hutchison, 2000).

The participants came to realize that, as parents of a child with a chronic condition, they had to develop advocacy skills. They frequently expressed concern for parents who had fewer personal resources or less developed advocacy skills; they believed that the children of these parents were at a disadvantage. Alternatively, caregiving parents may find advocates within the system, employees who are willing to take up the cause of a family, seek real solutions, or bend the rules on behalf of the family. Those participants who had access to insider advocates felt profoundly fortunate. Together these were the inequities that divided families and children into winners and losers. What the parents wished for was a level playing field.

Conclusion

This analysis examined the eligibility barriers that parents face when piecing together a community-based program of care for a child with a chronic illness or disability. The findings illustrate the complexity of the case-management responsibilities that parents assume and some of the factors underlying the inequitable allocation of services. Four principles are offered to guide policy development and the organization of services: integration of all levels of service and policy, provision of proactive planning for children and their families, flexible service planning tailored to each family's unique circumstances, and fair allocation of resources. In addition, both professionals and families need ready access to current information with regard to local services. Parents gave the clear message that they wished to invest their caregiving time and energy in their child rather than in navigating the complexities of the health, education, and social-service sectors.

References

Albrecht, G. L. (2001). Rationing health care to disabled people. *Sociology of Health and Illness, 23*(5), 654–677.

Alexander, T., & Henningsen, N. (2002). *Canadian Home Care Human Resources Study. Phase 1 Report: Setting the stage: What shapes the home care labour market?* Retrieved April 23, 2003, from www.etudesoinsdomicile.ca

Atkin, K., & Ahmad, W. I. U. (2000). Family care-giving and chronic illness: How parents cope with a child with a sickle cell disorder or thalassaemia. *Health and Social Care in the Community, 8*(1), 57–69.

Blackman, T. (1998). Facing up to underfunding: Equity and retrenchment in community care. *Social Policy and Administration, 32*(2), 182–195.

Bourgeault, I. L., Armstrong, P., Armstrong, H., Choiniere, J., Lexchin, J., Mykhalovskiy, E., et al. (2001). Everyday experiences of implicit rationing: Comparing the voices of nurses in California and British Columbia. *Sociology of Health and Illness, 23*(5), 633–653.

Brown, P. (1995). Naming and framing: The social construction of diagnosis and illness. *Journal of Health and Social Behavior, 35*(Extra Issue), 34–52.

Davidoff, A. J. (2004). Identifying children with special health care needs in the National Health Interview Survey: A new resource for policy analysis. *Health Services Research, 39*(1), 53–71.

Dowling, M., & Dolan, L. (2001). Families with children with disabilities – inequalities and the social model. *Disability and Society, 16*(1), 21–35.

Federal Task Force on Disability Issues. (1996). *Equal citizenship for Canadians with disabilities: The will to act.* Ottawa: Minister of Public Works and Government Services.

Gillman, M., Heyman, B., & Swain, J. (2000). What's in a name? The implications of diagnosis for people with learning difficulties and their family carers. *Disability and Society, 15*(3), 389–409.

Grey, M., & Sullivan-Bolyai, S. (1999). Key issues in chronic illness research: Lessons from the study of children with diabetes. *Journal of Pediatric Nursing, 14*(6), 351–358.

Hall, S. (1996). An exploration of parental perception of the nature and level of support needs to care for their child with special needs. *Journal of Advanced Nursing*, *24*(3), 512–521.

Hodgkinson, R., & Lester, H. (2002). Stresses and coping strategies of mothers living with a child with cystic fibrosis: Implications for nursing professionals. *Journal of Advanced Nursing*, *39*(4), 377–383.

Hoyle, J. (1992). Stress in mothers of the disabled. *Canadian Women Studies, 12*(3), 67–69.

Jerrett, M. D., & Costello, E. A. (1996). Gaining control: Parents' experiences of accommodating children's asthma. *Clinical Nursing Research*, *5*(3), 294–308.

Johnson, K. B., Ravert, R. D., & Everton, A. (2001). Hopkins Teen Central: Assessment of an Internet-based support system for children with cystic fibrosis. *Pediatrics*, *107*(2).

Kvale, S. (1996). *InterViews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.

Light, W. D., & Hughes, D. (2001). [Introduction.] A sociological perspective on rationing: Power, rhetoric and situated practices. *Sociology of Health and Illness, 23*(5), 551–569.

Mahon, R. (2001). *"No small matter": Child policy research. 18th annual Davidson Dunton research lecture, Canadian Policy Research Networks*. Retrieved August 15, 2001, from www.cprn.org/cprn

McKellin, W. H. (1995). Hearing impaired families: The social ecology of hearing loss. *Social Science and Medicine*, *40*(11), 1469–1480.

McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., et al. (1998). A new definition of children with special health care needs. *Pediatrics*, *102*(1), 137–140.

Mechanic, D. (1995). Dilemmas in rationing health care services: The case for implicit rationing. *British Medical Journal*, *310*(6995), 1655–1659.

Mulvany, J. (2000). Disability, impairment or illness? The relevance of the social model of disability to the study of mental disorder. *Sociology of Health and Illness*, *22*(5), 582–601.

Newacheck, P. W., Strickland, B., Shonkoff, J. P., Perrin, L. M., McPherson, M., McManus, M., et al. (1998). An epidemiologic profile of children with special health care needs. *Pediatrics*, *102*(1), 117–121.

Office of Technology Assessment. (1987). *Technology-dependent children: Hospital vs. home care, a technical memorandum*. Washington: US Government Printing Office.

Pedlar, A., & Hutchison, P. (2000). Restructuring human services in Canada: Commodification of disability. *Disability and Society*, *15*(4), 637–651.

Perrin, E. C., Lewkowicz, C., & Young, M. H. (2000). Shared vision: Concordance among fathers, mothers, and pediatricians about unmet needs of children with chronic health. *Pediatrics*, *105*(1), 277–285.

Perrin, E. C., Newacheck, P., Pless, I. B., Drotar, D., Gortmaker, S. L., Leventhal, J., et al. (1993). Issues involved in the definition and classification of chronic health conditions. *Pediatrics, 91*(4), 787–793.

Perrin, J. M. (1999). Universality, inclusion, and continuity: Implications for pediatrics. *Pedatrics*, *103*(4), 859–863.

Pless, I. B., & Perrin, J. M. (1985). Issues common to a variety of illnesses. In N. Hobbs & J. M. Perrin (Eds.), *Issues in the care of children with chronic illness* (pp. 41–60). San Francisco: Jossey-Bass.

Ray, L. (2002). Parenting and childhood chronicity: Making visible the invisible work. *Journal of Pediatric Nursing, 17*(6), 424–438.

Ray, L. D. (1997). Qualitative data management using Folio VIEWS. *Qualitative Health Research*, 7(2), 301–308.

Rodriguez, J. A., & Jones, E. G. (1996). Foster parents' early adaptation to the placement of a child with developmental disabilities in their home. *Journal of Pediatric Nursing, 11*(2), 111–118.

Schilling, L. S., Grey, M., & Knafl, K. A. (2002). The concept of self-management of type 1 diabetes in children and adolescents: An evolutionary concept analysis. *Journal of Advanced Nursing*, *37*(1), 87–99.

Stein, R. E. K., Bauman, L. J., Westbrook, L. E., Coupey, S. M., & Ireys, H. T. (1993). Framework for identifying children who have chronic conditions: The case for a new definition. *Journal of Pediatrics*, *122*(3), 342–347.

Stein, R. E., & Jessop, D. J. (1982). A noncategorical approach to chronic childhood illness. *Public Health Reports*, *97*, 354–362.

Stein, R. E., & Silver, E. J. (1999). Operationalizing a conceptually based noncategorical definition: A first look at US children with chronic conditions. *Archives of Pediatric and Adolescent Medicine*, *153*(1), 68–74.

Stein, R. E., Silver, E. J., & Bauman, L. J. (2001). Shortening the questionnaire for identifying children with chronic conditions: What is the consequence? *Pediatrics*, *107*(4), E61.

Tesch, R. (1988). Emerging themes: The researcher's experience. *Phenomenology + Pedegogy*, *5*(3), 230–241.

Author's Note

Financial Support for this study was provided by the National Health Research and Development Program, the Hospital for Sick Children Foundation, and the Canadian Nurses Foundation.

Comments or queries may be directed to Lynne D. Ray, Faculty of Nursing, 3rd Floor, CSB, University of Alberta, Edmonton, Alberta T6G 2G3 Canada. Telephone: 780-492-7558. Fax: 780-492-1926. E-mail: Lynne.Ray@ualberta.ca

---

Lynne D. Ray, RN, PhD, is Associate Professor, Faculty of Nursing, University of Alberta, Edmonton, Canada.

CJNR 2005, Vol. 37 Nº 3, 104–131

Résumé

Les déterminants en matière d'utilisation des services de santé par les personnes à faible revenu

Miriam Stewart, Linda Reutter, Edward Makwarimba, Irving Rootman, Deanna Williamson, Kim Raine, Doug Wilson, Janet Fast, Rhonda Love, Sharon McFall, Deana Shorten, Nicole Letourneau, Karen Hayward, Jeff Masuda et William Rutakumwa

La pauvreté a une influence sur l'état de santé, l'espérance de vie, les comportements en matière de santé et l'utilisation des services de santé. Cette étude avait pour objectif d'examiner les facteurs influant sur l'utilisation des services de santé par les personnes vivant dans la pauvreté. Dans la première phase de l'étude, 199 utilisateurs de services de santé appartenant à la frange pauvre de la population de deux grandes villes canadiennes ont été interviewés par des pairs. Dans la deuxième phase, des entrevues de groupe avec des personnes vivant dans la pauvreté ($n = 52$) ont été effectuées. Les données ont été étudiées à l'aide d'une analyse de contenu thématique. Ainsi, divers services de santé ont été utilisés afin de répondre à des besoins fondamentaux en matière de santé, d'établir des contacts humains et de composer avec les difficultés de la vie. L'utilisation des services dépendait de la proximité de ceux-ci, de la capacité financière des personnes, de la commodité, de l'information fournie ainsi que de l'attitude et des comportements des intervenants. Les obstacles à l'utilisation des services étaient attribuables à des inégalités en matière de revenu. Par conséquent, pour promouvoir la santé des personnes vivant dans la pauvreté, les infirmières, les infirmiers et les autres professionnels de la santé peuvent accroître l'accessibilité et la qualité des services, améliorer leurs interactions avec les personnes à faible revenu, leur fournir de l'information sur les services offerts, procurer des services coordonnés au sein des communautés, collaborer avec d'autres secteurs et préconiser activement la mise en place de services et de politiques plus équitables.

Mots clés : faible revenu, pauvreté, services de santé, déterminants de la santé, professionnels de la santé

CJNR 2005, Vol. 37 Nº 3, 104–131

Determinants of Health-Service Use by Low-Income People

Miriam Stewart, Linda Reutter, Edward Makwarimba, Irving Rootman, Deanna Williamson, Kim Raine, Doug Wilson, Janet Fast, Rhonda Love, Sharon McFall, Deana Shorten, Nicole Letourneau, Karen Hayward, Jeff Masuda, and William Rutakumwa

Poverty influences health status, life expectancy, health behaviours, and use of health services. This study examined factors influencing the use of health-related services by people living in poverty. In the first phase, 199 impoverished users of health-related services in 2 large Canadian cities were interviewed by their peers. In the second phase, group interviews with people living in poverty (*n* = 52) were conducted. Data were analyzed using thematic content analysis. Diverse health-related services were used to meet basic and health needs, to maintain human contact, and to cope with life's challenges. Use of services depended on proximity, affordability, convenience, information, and providers' attitudes and behaviours. Use was impeded by inequities based on income status. To promote the health of people living in poverty, nurses and other health professionals can enhance the accessibility and quality of services, improve their interactions with people living in poverty, provide information about available programs, offer coordinated community-based services, collaborate with other sectors, and advocate for more equitable services and policies.

Keywords: low income, poverty, health services, consumers, health determinants, health professionals

Canadians who live in poverty have poor health status, whether measured by self-rated health, low life expectancy, health problems, or activity limitations (Federal, Provincial, and Territorial Advisory Committee on Population Health [FPT], 1999; Phipps, 2003; Raphael, 2002; Wilkins, Berthelot, & Ng, 2002). Reducing health inequities resulting from inequalities in socio-economic status was identified as a major health challenge almost two decades ago (Epp, 1986). Poverty continues to be described as the greatest determinant of health, as it influences virtually all other determinants, including accessibility to health care (Canadian Institute of Health Information [CIHI], 2004; FPT; World Health Organization [WHO], 1999, 2003; WHO Europe, 2001). Despite Canada's healthy economic growth in the past decade, the rate of poverty has not declined proportionately and, for some groups, has worsened (National Council of Welfare, 2002). In 1999, 16%

of Canadians were living in poverty, as measured by Statistics Canada low-income cut-offs (LICO). The groups most likely to experience poverty are unattached individuals, lone-mother families, people with disabilities, recent immigrants, and Aboriginal peoples (Lee, 2000; National Council of Welfare, 2002).

Accessibility to health services is receiving increasing attention by health policy-makers, as witnessed by numerous health-care commissions and federal funding of innovative delivery methods (e.g., Federal Health Transition Fund, Primary Health Care Transition Fund) (Ogilvie & Reutter, 2002). Moreover, there is concern about the erosion of publicly funded services, which increases the burden on the economically disadvantaged (Raphael, 2002). A body of Canadian research has examined the effect of income on the use of health services. Most of this research, however, has focused on formal health care, and even more narrowly on medical care. Increased understanding of the broad determinants of health requires attention to use, by those living in poverty, of other services and supports that influence health, many of which lie beyond the formal medical-care and broader health-care sectors. Moreover, little is known about the factors that influence use of a broad range of health-related services and supports from the perspectives of people living in poverty. A deeper understanding of these factors will help nurses and other health professionals to identify the unique service and support needs and utilization patterns of this population, to target and tailor services, and to advocate for policies that will enhance accessibility.

Accordingly, the purpose of this study was to identify the types of health services used, the determinants of health-services use, and the implications for practices, programs, services, and policies from the perspectives of Canadians living in poverty. Health services were broadly defined to include both direct health services (e.g., dental and medical care, prescription medications) and health-*related* services (e.g., food banks, child care, housing) that people living in poverty use to maintain and improve their health and well-being.

Influence of Poverty on Health Status and Personal Health Practices

The debilitating effects of poverty on health have been well documented in Canada. Regardless of how poverty and health are operationalized, the relationship between poverty and ill health has been consistent. Lower socio-economic status in Canada continues to be associated with lower life expectancy (Wilkins et al., 2002). Adults in impoverished households are more likely to describe their health as poor or fair (FTP, 1999) and to experience sleep difficulty, pain, functional limitations, disability days, chronic health conditions such as asthma or stroke, and vision, mobility, and cognition challenges than adults in middle- and high-income categories (Canadian Council on Social Development, 2000; Statistics Canada, 1994). Surveys of Canadian children indicate that poor health (e.g., vision, hearing, speech, or mobility problems) and developmental delays are more prevalent among children in impoverished families (Ross, Roberts, & Scott, 2000).

Poverty influences health status through a variety of mechanisms, including material deprivation, excessive stress, uncertainty, and unhealthy behaviours (Raphael, 2002). Compared to people with higher incomes, those living in poverty have higher smoking rates (FTP, 1999; Health Canada, 2003), are less likely to be physically active (CIHI, 2004; FTP), and are less likely to meet nutritional requirements (Che & Chen, 2001; McIntyre, Connor, & Warren, 2000). These behaviours are influenced by limited incomes and may also be coping strategies to manage the stress and uncertainty that accompany poverty (Raphael).

Effect of Poverty on Use of Health Services in Canada

Canadian studies consistently show that income influences health-care utilization. Low-income Canadians are more likely than other Canadians to use general practitioner, hospital, emergency, mental health, and publicly funded home-care services (FTP, 1999; Glazier, Badley, Gilbert, & Rothman, 2000; Kephart, Thomas, & MacLean, 1998; Lin, Goering, Offord, Campbell, & Boyle, 1996; Mustard, Finlayson, Derksen, & Berthelot, 1999; Roos & Mustard, 1997). This is not surprising given the greater health needs identified above. On the other hand, people living in poverty tend to under-use preventive services such as prenatal care, mammography and cervical cancer screening, and dental services (Bell & Edouard, 1992; Katz & Hofer, 1994; Millar & Beaudet, 1996; Millar & Locker, 1999; Mustard & Roos, 1994; O'Connor, 1993; Snider, Beauvais, Levy, Villeneuve, & Pennock, 1997). Canadians living in poverty are less likely to use health-related services that are not publicly funded such as vision-correction services, dental care (Millar & Locker), and alternative health-care practitioners (Millar, 2001). Research also suggests that people living in poverty may be disadvantaged in terms of specialist and in-hospital care (Dunlop, Coyte, & McIsaac, 2000; Kapral, Wang, Mamdani, & Tu, 2002).

In spite of a publicly funded health-care system in Canada, then, barriers to health-care utilization persist for people living in poverty. Financial barriers are particularly evident for impoverished working families without supplementary health-care benefits (Crowe & Hardill, 1993; FTP, 1999; Williamson & Fast, 1998). Indeed, national Canadian data suggest that unmet health-care needs due to financial constraints are about 10 times greater for members of low-income households than for members of more affluent households (Chen & Hou, 2002).

Other reported barriers to health-services use in Canada reflect availability and acceptability factors (Chen & Hou, 2002). These include discrimination related to ethnicity and poverty, insensitivity of health professionals, negative past experiences with the health-care system, crowded clinics, scheduling difficulties, long waiting times, inconvenient clinic hours, inadequate knowledge of available services, lack of transportation or child care, time constraints, and language barriers (Anderson, Blue, Holbrook, & Ng., 1993; Crowe & Hardill, 1993; Sword, 1999; Waldram, 1990; Williamson & Fast, 1998).

Although the above-cited studies identify gaps in access to health services, they do not delve into the factors that influence the use of services by low-income people and the shortcomings of these services from the viewpoint of those people. Consequently, a study was conducted to investigate factors influencing use of health services and programs from the perspective of people living in poverty. The study was guided by three research questions: What are the perspectives of low-income people on (1) types and importance of health services used, (2) factors determining health-services use, and (3) strategies for enhancing health services.

Methods

This project was conducted in two large Canadian cities — Edmonton, Alberta, and Toronto, Ontario — from 1999 to 2001. At the time of the study, about 21% of the population of these cities lived in poverty (Lee, 2000), as measured by the LICO, the most commonly used measure of low income in Canada. An interdisciplinary team of researchers and staff conducted the study at each site. Communication was facilitated by site coordinators' use of such strategies as e-mail exchange and video- and tele-conferencing. The proposal received clearance from the appropriate university ethics review committees.

Given the paucity of Canadian literature on the lived experiences of impoverished people regarding determinants of the use of a broad range of health services, combined with the sensitive nature of the topic (i.e., poverty), a qualitative descriptive research design was employed (Sandelowski, 2000). Elements of participatory research were incorporated to enhance relevancy, facilitate uptake of the findings, and build individual and research capacity (Green et al., 1995; Green & Mercer, 2001; Mercer, MacDonald, & Green, 2004). For example, community advisory committees (including representatives from service, advocacy, and policy organizations) at each site guided the design and implementation of the project, interpretation of the results at program and policy levels, and dissemination and uptake of the findings. The research team included both academic investigators and community partners (service manager delivering care to low-income people and a member of a poverty advocacy organization). Indeed, the impetus for the study originated with a consumer advocacy organization. Participation of people living in poverty was fostered by hiring and training 13 impoverished interviewers. The interviewers' similar experiences with poverty increased their empathy and credibility with the participants and hence enhanced the validity of the data. This strategy was also used with a view to empowering the interviewers. A more detailed account of the partnership and participation elements of the project is provided elsewhere (Reutter et al., in press).

Phase I Data Collection

In phase I, data were collected from 100 participants in Toronto and 99 in Edmonton; this sample size allowed for an adequate number of participants in various low-income situations with diverse demographic characteristics. Purposive sampling was employed to select people whose incomes were at or below the Statistics Canada LICO and who represented a variety of low-income situations (e.g., working poor, social-assistance recipients, unemployed, homeless) and demographic characteristics (i.e., gender, family size and composition, age, ethnicity, education, occupation) (see Table 1). A sociodemographic data sheet was completed before each interview. Potential participants were accessed through community organizations offering health and human/social services in low-income neighbourhoods throughout each city. Interviewing through agencies was considered most appropriate, to enhance accessibility and safety for low-income interviewers and to provide backup support related to technical use of recording equipment, referral of participants in crisis, and financial reimbursement of participants.

Individual face-to-face interviews were conducted by people living in poverty who had received 14 hours of training in interviewing techniques (e.g., making initial contact, confirming confidentiality, obtaining consent, maintaining interview schedules). The interviewers were recruited from agencies serving low-income people, through word of mouth from community partners, and through the community advisory committee. They were given an honorarium for participating in the training sessions and received payment per interview conducted (plus child care and transportation if required).

Table 1 *Sociodemographic Characteristics of Participants in Phase I*

	Edmonton Sample ($N = 99$)	Toronto Sample ($N = 100$)	Total Sample ($N = 199$) (% of sample)
Gender			
Female	70	65	135 (68)
Male	29	35	64 (32)
Highest level of education			
< Grade 9	7	3	10 (5)
Grade 9–13	57	49	106 (53)
College/trade/technical certificate/diploma	18	26	44 (22)
University undergraduate degree	8	17	25 (13)
University graduate degree	7	3	10 (5)
Missing	2	2	4 (2)
Race			
Caucasian	51	44	95 (48)
Aboriginal/Métis/First Nations	30	6	36 (18)
Other racialized minority	15	41	56 (28)
Missing	3	9	12 (6)
Annual family income (previous year)			
\$0–5,000	12	16	28 (14)
\$5,001–10,000	34	27	61 (31)
\$10,001–15,000	30	22	52 (26)
\$15,001–20,000	15	9	24 (12)
\$20,001–30,000	4	9	13 (6)
> \$30,000	2	4	6 (3)
Missing	2	13	15 (8)
Children < 18 years old			
Yes	57	36	93 (47)
No	40	43	83 (41)
Missing	2	21	23 (12)

The phase I semi-structured interview guide for both sites consisted of fifteen items covering five areas: services that people living in poverty use to stay healthy and to cope when not feeling well, factors influencing use of services/supports, reasons for using services/supports, importance of services in meeting their needs, and suggestions for enhancing services and programs. The interview guide was developed in consultation with the community advisory committee and pilot-tested with low-income people at each site. The individual interviews lasted from 40 to 90 minutes (60 minutes on average).

Phase II Data Collection

In phase II, group interviews were conducted with 52 low-income people at the two sites to validate data from phase I and to focus on specific implications regarding programs, policies, and practices. The most articulate participants in phase I were selected for four group interviews and new participants were recruited for four other group interviews. The same selection criteria were used as in phase I for new participants. The group interviews were facilitated by two investigators. Peer interviewers also contributed to group interviews by relating their experiences in phase I and reporting on the findings. The interview guide for people living in poverty included seven items covering six themes: (1) the fit of findings from phase I interviews with participants' experiences; (2) strategies for improving services and programs; (3) new services needed; (4) required policy changes; (5) potential influence of people living in poverty on services, programs, and policies; and (6) target audiences and approaches for dissemination of results. The same semi-structured interview guide was employed at each site to ensure consistency. The group interviews lasted from 70 to 120 minutes (90 minutes on average).

Participants in the individual and group interviews received payment for their participation in the study, as well as for child care and transportation if needed.

Data Analysis

All individual and group interviews were audiotaped and transcribed prior to analysis. The transcripts were subjected to thematic content analysis using a framework of key concepts and themes derived from the data and were coded by trained research assistants (Cresswell, 1994; Hammersley & Atkinson, 1983). The categories guiding coding were identified via inductive analysis (moving from particular experiences of participants to general themes or categories) and had to meet specific criteria (i.e., inclusive, useful, mutually exclusive) (Cresswell; Morse & Field, 1995). The coding framework was transferred to QSR NUD*IST qualitative data-analysis software to enable data management and coding. The coding process entailed extraction of significant statements from transcripts and classification into appropriate categories. Interrater agreement by the two independent coders across sites was assessed until it reached 80%. Following the comprehensive coding process, a thematic analysis was conducted to classify common themes within the framework into larger clusters (Cresswell; Morse & Field). Investigators and research staff across the sites met regularly to ensure consistency and comprehensiveness of the data analysis.

Findings

In this section we will report the perspectives of the participants on (a) types of health services used by people living in poverty, (b) factors influencing use of services, and (c) strategies for improving services and programs.

Types and Importance of Health Services Used by People Living in Poverty

The participants accessed services for basic health-related needs such as food, shelter, and clothing; community-based services relevant to health promotion such as recreation; and a broad range of health services. Across all three types of services, participants described needs that were met and unmet. Almost all participants reported that they used some form of primary health care such as physicians, community health centres, and walk-in clinics. Sixty-five percent of these people accessed a range of other health-related services, including food banks, addiction counselling, drop-in and job-placement services, and newcomer and recreation services. Many individuals who were homeless or lived in shelters relied upon a continuum of street-based services on a daily basis. Participants identified several reasons for their use of services, the main ones being to meet health needs, to meet basic needs, to make human contact, and to cope with life's challenges.

Meeting health needs. When asked, "What do you do when you are not feeling well — for example, when you are ill or injured?," most participants said they went to a physician, medical centre, hospital emergency room, community service, or church, or talked with friends:

> *When I'm not well I have a physician, yes, I have somebody I see regularly. And if I need to go for the tests, she recommends me for such tests. But I have a physician I see when I'm ill.*

Illness was the most common reason for using health services. Many participants cited illness in themselves or their children as the main reason for using supports and services. Some identified emotional or mental health issues, while others identified physical health problems such as injuries:

> *[I use services] just when the boys get sick or when I get sick myself. Usually I tend to take care of the boys more with the medical services.*
>
> *Just if I'm sick or damaged myself in one way or the other, or the kids…if there is an accident and they have…a broken bone or something.*

In order to stay healthy, participants used a wide range of health services. While many of them visited private physicians, some went to a medical centre or a church and others used support groups or community services/programs, including recreation groups, parenting groups, life-skills programs, programs for psychosocial problems, and child- and family-related programs. Other health-maintenance strategies included counselling and culturally appropriate social groups (e.g., sweats):

> *I wouldn't exist [without health services]…I could never pay for the drugs I'm on, I could never pay the orthopedic, not as it is now. If those things weren't in place I would probably be on the street unhealthy…on the street, it's as simple as that.*
>
> *Those services are very important to me. For example, if there was no [name of health centre] I would have problems to see a doctor, especially the first 3 months when I was in Canada because I did not have [government health-care] coverage… Those services are very important to newcomers. Without those services their lives will be very awful.*

Some participants found that the programs and services helped them to cope and to maintain their health and their positive health behaviours:

> *I wish to get to the point where my body can be flexible and I can have — I likely won't have — but as productive a lifestyle that I can have. That's what my goal is.*
>
> *They [services] help me talk over…, the Sober Meetings have to do with everything. Everything — financial, substance abuse, alcohol abuse — everything. I find they help me lots.*

Meeting basic needs. Accessing services/supports to meet basic needs was the second most commonly cited reason for using services. Many people living in poverty contended that they needed services for survival. Some used supports and services to meet their family's need for food, clothing, and shelter. Supports and services were also means to improve their life and to access financial aid. Services were also used for day-to-day coping. Without services, they believed, their lives would be much more difficult. Many participants stated eloquently that access to food banks, child care, and housing was a matter of life and death:

> *I use the food bank because usually we have used the money to pay bills and stuff, so we are running low on food, so we have to use the food bank.*
>
> *[The services] stop me from going hungry… They put clothes on my back… I'd be dead [without them]… It's a matter of life and death.*

Making human contact. People living in poverty spoke of the importance of social interaction in reducing their isolation. To illustrate, parents described the loneliness of childrearing on their own and the need to connect with other parents. Drop-ins and other health-related services for the homeless relieved the loneliness of living on the street:

> *[At the drop-in centres] I can relax and…collect my thoughts…and socialize with certain people who may have the same problems that I may have…when I get lonely or I [feel]…isolated… [like] I'm not part of the world any more.*
>
> *Because I need support, it really helps me get through the week. I need human contact. I don't have any [family] here… It's my only way of getting contact with people… It gets me through the week. Sometimes that's the only place I go to.*

Coping with life's challenges. Many participants described the impact of health-related services and resources on their ability to cope with personal and family stress:

> *When [I'm] depressed…I can call and go any time [to the community centre] and someone is there to see me…and help me through my problem.*
>
> *[The] parenting program…really empowers me… All the services I got all over, they changed my life. I'm really grateful…. I was an abusive parent and then I got help and I saw that I was an abusive parent and that it was because I was an abused child and an abused wife… I got really good support. For all that I got I'm really grateful.*
>
> *Right now if I didn't have some services I would be stuck at home just taking care of [my child], and I wouldn't be able to do anything in terms of making plans to go back to work or school or do anything with my life.*

Overall, the supports and services available to people living in poverty made their daily lives much easier.

Importance of Services for Survival

When asked directly to imagine what life would be like for them without health supports and services, many participants indicated that they or their families would be unable to cope:

> *I would have some very sick kids and I would be probably digging a hole under my house and hiding in it! It would be terrible. How do you cope if you don't have the things that you need?*

Some participants said their survival would be threatened if they did not have access to resources and services. Others maintained that their families and/or children would experience greater stresses due to their inability to afford children's services such as babysitting and pediatric care, parenting difficulties, family violence, apprehension of children, and poor child outcomes.

Many participants believed that if supports and services were withdrawn they would have to resort to demoralizing and dangerous behaviour such as theft, prostitution, panhandling, or sleeping on the street. Participants also believed that mental health problems would result, as well as suicide and increased crime. The following comments illustrate the importance of services:

> *I don't think I would be alive if I didn't have the help at certain times in my life… I don't know what would have happened. I don't want to think about it.*

> *My children wouldn't survive.… If these services are not provided…these children are going to be on the street. They are not going to know how to deal with it. They are going to have mental problems. They are going to have anxiety attacks. They are going to have depression states.*

Factors Influencing Use of Services

Factors influencing use of services included service-provider behaviours and attitudes, accessibility of services, and self-reliance and readiness.

Service-provider behaviours and attitudes. Service providers had a powerful influence on the reactions to and use of services by people living in poverty. The participants wished to be treated with respect, compassion, and care, and they wanted service providers to spend time with them. Some cited professional competence and trustworthiness as important service-provider qualities. Providers' ability to listen to, understand, and empathize with people living in poverty influenced use of services. Welcoming, receptive staff are very important to the decisions of low-income people regarding the use of services:

> *Just the friendly, non-judgemental attitude of the resource workers. They don't look down their noses at you, or they don't make any judgements.*

> *It's the smallest things [that count]. Just calling me and asking, "How are you today, how are you feeling?" Letting me talk, letting me say what is on my mind or how I slept or what I have eaten.*

Negative provider behaviours deterred some participants from using services and programs. Concerns about the competence of providers and the confidentiality of their interactions with them made the participants reluctant to use services. Negative experiences included poor treatment at health-care facilities and community agencies such as food banks and social-assistance offices. Some participants described provider behaviour as rude, critical, condescending, or controlling — "telling people what they should and shouldn't do with their lives":

> *[In] some places these people can treat you however they want. You can't do anything about it, because you'll either get barred from the place or they'll call the cops on you, and you're not going to be believed, just because you're a street person and the way you look.*

> *I had gone into a drugstore. I had to get a prescription filled, and the pharmacist…said that there was a $2 charge…and I said, "That's fine." He said, "welfare case," and I heard it, and my daughter was standing right beside me… When you come across people like that, that have closed minds and attitudes — they prejudge you — that is so cruel and unfair.*

> *[There is a] longer wait, definitely. Once they see your income or whatever, it's like they kind of push you to the back and the paying customers come first.*

Several participants indicated that they stopped using particular health services because the health professionals did not listen to them or made them feel uncomfortable. One participant's lack of input into his treatment was an important factor in his decision not to use the service:

> *I was told I needed physiotherapy. I accepted that idea but I wasn't given the choice of where to go. And then on top of that, they just kept moving me around to others and it made me unhappy. And then the type of physiotherapy: the doctor who referred me instructed the physiotherapists what type of therapy I needed and didn't let them decide after assessing my needs. They had to go with what the doctor said and they didn't have flexibility to adjust the therapy.*

Participants also explained that negative service-provider behaviours and the attendant poor service resulted from more general inequities.

They believed they were receiving inferior treatment because of discrimination and stigmatization on the basis of their gender, ethnicity, appearance, income status, or neighbourhood of residence. Most participants felt that income status was a factor in the quality of care they received, that they were mistreated because they were poor. Discrimination based on ethnicity is illustrated in the following comment:

> *If you are a Native or a member of an ethnic group [you] are sort of given the lowest of things. I see that. It's hidden. It's very hidden. But I see it.*

According to some participants, gender barriers resulted in inequitable treatment:

> *I found I got more out of [female] nurses after they got to know me than I got out of the [male] doctor.... You are a girl, you are a woman, you know? You are an idiot. They have an attitude.*

> *I think there's always the stigma of people who are single parents, especially single moms.... If you're a single mom you're...classified as this or that, and it's usually not very good. There are lots of really good single moms out there who are working their butts off to get what they got to survive.*

Accessibility. Participants' ability to use services depended on affordability, proximity, convenience, and knowledge of their existence. Financial inaccessibility was a key barrier to health-services use. Almost half of the participants could not use particular services because of lack of public insurance coverage. Not surprisingly, dental care was the most frequently mentioned inaccessible service, given that dental care is not covered by basic health-care plans in Alberta and Ontario:

> *I need to go to a dentist because I have a tooth cavity which has been bothering me for the last 6 months, but I can't afford to go to the dentist so I just put up with it.*

> *I know I need...to get some dental work done, because I have wisdom teeth that need to be taken out and other stuff like that. But I can't do it, can't afford it, so I'm not getting it done. And it won't get done. I mean, I'll have to live through pain. And if it ends up — if those wisdom teeth start coming out...*

The next most frequently discussed professional services that were inaccessible because they were not covered by health plans were chiropractic services, eye and ear examinations, and orthopedic services. Several other services, such as counselling, physiotherapy, and alternative medical therapy (e.g., acupuncture, homeopathy, herbal therapy) were covered only partially if at all:

> *I have a specific physiotherapist downtown. He worked on my back when I was pregnant, and he is the finest in town. I can't afford to go see him to get my back fixed.*
>
> *Well, I could really use the services of a chiropractor right now but there's just no way that it's covered. So, no way.*

Another important factor in the use of services was temporal inaccessibility. Participants expressed concerns about long waiting periods in emergency rooms and physicians' offices. Inner-city residents also spoke of long line-ups and limited hours of operation of some street-based services:

> *It can take forever to get an appointment. You can die waiting to get an appointment.... [At the community health centre] you have to wait 2 weeks to see my doctor.*
>
> *Sometimes I have to wait 4 to 5 hours to see a doctor.*

Many participants identified geographic accessibility as a critical determinant of service use. Lack of transportation or insufficient money for transportation was a key inhibiting factor. Participants explained that transportation deficits prevented them from gaining access to certain services or forced them to accept a lower-quality service in their own community:

> *If it involves taking a bus, forget it...because half the time you don't have money to go to the appointments.*
>
> *There was a situation where — I think it was on a weekend — and my son had fallen and I needed to get to the medical clinic. And there was just no way to get there at all, so I had to wait a couple of days until I had the money to get on the bus and go there.*

Knowledge of available services and familiarity with agency staff and services were considered important determinants of accessibility. Some participants had initially been unaware of services and programs to which they were entitled:

> *Information is very, very important. This Fee Reduction thing...has been lying here but it's like I have not really, really paid attention to it. And I don't know if it's even applicable to me anyway.*
>
> *I didn't know they had stuff like that out there, like food banks and women's shelters for abused women... To me those are big things and nobody ever referred me to any of that stuff.*

Financial, geographic, and temporal accessibility and knowledge of services were perceived as affecting choice and even quality of services. It was not uncommon for participants to report that they used only services and programs that were "available for a low cost or for free." People living in poverty identified an array of services, supports, and programs that they could not afford and therefore did not use. These included extended health care (e.g., naturopathy, physiotherapy, dental care, chiropractic care, counselling, eye care, and home care); vitamins and healthier foods; and treatments and diagnostic services (e.g., orthopedic devices, prescription and non-prescription medications, eyeglasses, magnetic resonance imaging) not covered by government (e.g., public health insurance, Social Services, Indian Affairs):

> *I just take what I can. You can only go by what you can afford.*

> *My income status dictates that I have no choice.*

> *[You use] the services around here because you have to. …you take it because you can't travel to other parts of town where you can, I feel, get better service medically wise.*

Some participants reported inadequate support in times of need. They received poorer-quality services because they had "no choice" due to their inability to pay for uninsured benefits. The following woman's lack of income influenced her use of a variety of services that she needed:

> *There's still more that I have to do that I'm not able to do because I don't have the money. I cannot go to my eye doctor… I have…a little bubble on my eye that was there about a month ago… I can't go to a doctor because it's $55 to walk in. I…can't afford for them to tell me, "You need a new prescription and you have to wear glasses every day"…so why bother? I know there's no point in me going to get an appointment with the chiropractor, because I can't afford to go back… So it's really hit and miss, and if my health deteriorates because of money, so be it. I have no options right now. I can't go to the dentist… In fact I had one tooth pulled because I knew to get it refilled and refilled would mean I would go back and spend much money. And this way I just said, "Pull it," because I cannot afford subsequent visits. I can't go to the doctor because even if they told me something was wrong I couldn't afford to fix it.*

In the phase II group interviews, the participants shared concerns regarding needed services that were unavailable or unaffordable. The participants pointed to a variety of services that were not available to people living in poverty, thus limiting their choices. These included programs focused on children, employment, housing, and education. Concern was expressed that lack of opportunities for children made parenting difficult, especially in the face of limited income and conflicts regarding work.

Self-reliance and readiness. Participants' avoidance of formal health services was sometimes linked to a need for self-reliance. Many reported that even though their incomes were low and use of services was often necessary, they wanted to be self-reliant. Personal readiness to use particular services was also mentioned by several participants as a factor in their use of services:

> *They'll watch [special-needs children] for the weekend for you. I've never had that kind of care where people will take them somewhere… I wasn't ready, I think, to send him for a weekend without me. But he's going on 13 and I think that he's ready. And I'm ready. So hopefully in the New Year I can get him into something.*

Participants described self-diagnosis and treatment, use of informal social supports, adoption of healthy lifestyles, and self-education as viable and often preferable means of managing their health. Despite low income and a need for services, they wanted to be as independent as possible.

Many participants reported that they tried to be self-reliant, particularly when attempting to cope with their day-to-day problems, and used services only as a last resort:

> *I don't like people knowing my personal business… I feel I can handle it.*

> *I work [problems] out on my own. I try to just deal with the problem the best I can. …I don't use any kind of services for anything. Like, that's the last resort.*

> *In general, if I have problems that cannot be resolved on my own I will seek supports and services…. Usually I try to resolve problems by myself first.*

Some participants seemed proud of their ability to deal with issues on their own. For some, pride prevented them from accessing particular services. Others reported feeling ashamed or uncomfortable using specific services:

> *Your pride gets in the way. It makes me feel uncomfortable…. I wish I didn't have to use [the services] all the time.*

> *I feel bad about it, because I wasn't able to deal with it on my own…like, you feel you lose your self-respect and pride.*

Strategies to Improve Health Services and Programs

The individual and group interviews with people living in poverty elicited many recommendations for improving or extending services/ programs and for changing health policies. These recommendations centred on improving accessibility, enhancing sensitivity of service providers, and increasing advocacy with and for low-income people.

Improving accessibility. Suggestions varied from eliminating bureaucratic barriers to access (e.g., easier transfer of records), to providing unlimited coverage without imposed limits, to promoting geographic accessibility. Many participants wished to see geographic accessibility through transportation to services, multiple services at one site, home visits, and outreach programs. They also expressed a need for temporal accessibility through longer hours of service, shorter waits, and weekend services. They were unanimous in their desire for strategies to increase financial accessibility. In the province of Alberta, the full-subsidy threshold for payment of health-care premiums is an annual income of $12,450. An individual with annual earnings of over $15,970 is required to pay the full premium of $528/year. In Ontario at the time of the study, health-care coverage was free for Canadian citizens, landed immigrants, and residents and was not determined by employment or income-tax contributions (this policy has recently changed). Consequently, some participants wished to see more free services, the elimination of health-care premiums, and the public funding of a broader array of health services such as dentistry, mental health counselling, emergency room, specialists, extended health care (e.g., prescriptions, chiropractic, massage, physiotherapy), employment, child care, and recreation. Increased funding would result in an increase in the number of health and other services as well as in the hours of availability. With regard to emergency room and specialist services, increased funding would also help to decrease waiting times. Some participants thought the quality of services could be improved by increasing the number of staff:

> *Actually, there [are] two things that would make the health-care system easier, and that would be getting rid of the…health-care premium. Getting rid of it. I mean, if they are talking about all these tax cuts that they want to make, that would be one area [where] they would actually be doing justice to the poor.*

> *Well, I would like to see…an adequate amount of doctors and clinics and things.*

Some participants wanted to have more comprehensive health-related services, including extracurricular and recreation programs, employment services, and child care, to increase choice. Others suggested that access could be improved if services were increased in number and scope.

As noted, lack of information about available services and entitlements emerged as a major challenge to accessibility. Although services were available, many people living in poverty do not hear about them or know how to access them. Several participants believed that there should be a more concerted effort to disseminate information about available services to potential consumers. Social marketing was suggested as a strategy to promote services:

> *[We need] more information — if there was more information on everything, not having to go into a little book to find it. It should be out in the open, easy to find.*

***Enhancing sensitivity of service providers*.** One common suggestion for enhancing the quality of services focused on service-provider attitudes and behaviours towards people living in poverty. The participants had experienced or witnessed providers conveying a sense of superiority over or disdain for low-income people and also displaying ignorance towards them. In the view of participants, confidentiality, sensitivity, and accountability are important attributes of services. Training and incentives were recommended as strategies for increasing providers' sensitivity to the circumstances and needs of people living in poverty and improving their behaviours towards these clients:

> *Perhaps a training or a retraining of staff…to see what it's like on the other side of the fence, might be an idea…. They need a reality check. These people need to realize that if us as clients stop lining up, you as a person don't have a job any more.*

***Increasing advocacy with and for people living in poverty*.** Participants emphasized the importance of promoting awareness about poverty and creating partnerships between people living in poverty and organizations with the means to communicate their message (e.g., community advocacy groups). They recommended that messages about poverty be targeted at all levels of government. If those living in poverty had adequate information about the system, they would be better equipped to access the range of services available to them. Several participants expressed a need for advocates to disseminate information about available services and help low-income consumers to navigate the system. But while some participants recommended collective action, others favoured advocacy as a means of assisting individuals:

> *I'd love to find a support — somebody, an advocate, who can help me get through all this bureaucracy and red tape to find a place to live that I could afford.*

Limitations

This study had several limitations. Although our findings were similar for two large cities and we used a diverse sample of people living in poverty, the experiences of the participants may not be generalizable to low-income Canadians in other urban or rural areas.

Other limitations relate to the recruitment of participants through agencies, which excluded people living in poverty not currently using services, and the quality of the data collected. The purpose of using peer interviewers was twofold: to put the participants at ease, and to provide training opportunities for impoverished individuals living in the community. Although training was provided, qualitative interviewing is a particular skill developed over time. There was some disparity in the quality of transcripts among the interviewers, with some displaying a greater aptitude than others for probing into important issues around the interview guide. All peer interviewers believed, however, that their participation in the interview process helped to elicit open and honest responses and opinions, thus enhancing the validity of the data.

Discussion

The study bridges a knowledge gap with regard to the determinants of health-services use from the perspective of a vulnerable group. Such knowledge is needed to ensure that policies are inclusive and allow for complete accessibility, to identify the service needs of this vulnerable population, and to target and tailor services. Moreover, the study focused on a variety of supports and services, rather than solely on health care.

In the two large Canadian cities, people living in poverty reported that medical and health-related services were crucial to their survival and greatly enhanced their health and well-being. Services were viewed as a means of coping with stress and alleviating isolation. Stress and isolation have been reported as factors influencing health (Canadian Council on Social Development, 2000; Donner, Busch, & Fontaine, 2002). Participants discussed the importance of both formal and informal health services as well as other human services and supports in managing everyday circumstances related to poverty. The significance of these services and supports in the lives of people living in poverty cannot be overstated; a recent World Bank global study of 60, 000 such people found that "health care services are vital to their survival and livelihood" (Dodd & Munck, 2002).

The main barriers to services use identified in this study were (1) inaccessibility — financial, temporal, and geographic; and (2) negative service-provider behaviours and attitudes. The interviews revealed important factors influencing use of health services related to poverty status.

In each community, people spoke of their struggles living on social assistance or on low incomes, of the need for changes to existing assistance programs, and of the need for increases in the income levels of consumers. Barriers to accessibility relating to socio-economic status, despite the existence of universal health-care coverage, have been reported elsewhere (Morton & Loos, 1995; Williamson & Fast, 1998). Disincentives to seeking services that were found by both the World Bank study and the present study include direct costs of medications, cost of transportation to health services, and time lost waiting for treatment. Temporal and geographic accessibility and perceived quality have also been cited elsewhere as factors determining service utilization and health inequalities (Wagstaff, 2002).

The finding that low-income status reduces accessibility and use of health services confirms the dynamic interaction of health and poverty reported elsewhere (Dodd & Munck, 2002; European Commission on Development, 2000; Wagstaff, 2002; WHO Europe, 2001; Wolfe, 1999). Participants highlighted gaps in coverage of existing services. In addition to identifying services that failed to meet their needs, they described a variety of essential services that were either unavailable or unaffordable. Given the federal and provincial cuts in social and income-security spending in the last decade and a half, this is not surprising (Torjman, 2001). The comments of the participants confirm the finding of previous studies (Dodd & Munck; Wagstaff; WHO Europe; Wolfe) that there is an urgent need to promote awareness of poverty as a grave problem in order to influence health-services utilization and address health inequalities.

The behaviours of service providers emerged as a critical factor in service utilization. The ability of providers to listen to, understand, empathize with, and respect low-income people influenced their use of services. Indeed a World Bank study corroborates this finding, revealing widespread disappointment among poor people in their treatment by health-agency personnel (Dodd & Munck, 2002). Moreover, disadvantage and discrimination experienced by people living in poverty can exacerbate health problems (Shaw, Dorling, & Smith, 1999).

Recommendations for services, programs, and policies across sites reflected the main barriers to service use identified. The recommendations included increased accessibility and range of services, increased health-insurance coverage, staff sensitivity training, and communication of services and entitlements. The six areas requiring greatest attention were dental services, extended health-care services (e.g., prescriptions, chiropractic, massage, physiotherapy), mental health services such as counselling, emergency-room services, physician services, and recreation programs and facilities.

Many of the suggestions articulated by participants concerned policy. These included extended publicly funded health coverage, raised income levels, affordable housing, increased subsidy for basic needs, and consumer participation. Such strategies reflecting broad determinants of health, decreased inequities and barriers to access, and public participation are consistent with the findings of previous research (Donner et al., 2002; Torjman, 2001; Wagstaff, 2002; WHO, 1999). In a Canadian study, Eyles et al. (2002) advise against piecemeal efforts and recommend resource shifting and funding for programs in sectors relevant to health.

The present findings are particularly germane given the climate of concern over the sustainability of Canada's health-care system and the need for increased access for those living in poverty: "This is precisely the reason why Canada's medicare system was introduced — to avoid a situation where wealthy people get access to all the health care services they needed and poor people could not" (Romanow, 2002). This position was reiterated in a recent Speech from the Throne (2004): "The Government's commitment to health care rests on one fundamental tenet: that every Canadian have timely access to quality care, regardless of income or geography — access when they need it."

Implications for Nursing

Despite barriers to access, Canadians living in poverty are, by virtue of their greater health needs, more likely than other Canadians to come into contact with health professionals, to be hospitalized, and to use various health-related services (Reutter, 2000; Sword, Reutter, Meagher-Stewart, & Rideout, 2004). Nurses therefore have a role in ensuring that services and supports for people living in poverty are accessible and sensitive to their unique needs. Accessibility to health supports and services is a principle of primary health care, which Canadian nurses have been advocating for some time (Ogilvie & Reutter, 2002; Stewart, 2000).

The insensitivity to the context and experiences of people living in poverty revealed in this study suggests a need for more education about poverty and its effects both in professional curricula and in-service. Nurses need to critically evaluate their own attitudes towards low-income people, particularly the attribution of poverty and its effects on health. A recent Canadian study found that baccalaureate nursing students would benefit from further content and clinical practice with populations living in poverty (Reutter, Sword, Meagher-Stewart, & Rideout, 2004; Sword et al., 2004). A nursing curriculum that explores the structural causes of poverty, the influence of poverty on health, the negative effects of poverty on society, and strategies to minimize the effects of poverty would enable nurses to re-evaluate their own attitudes towards the poor and would equip them to work more effectively with impoverished people (Reutter, 2000; Sword et al., 2004). A critical social perspective on poverty that explores the psychosocial and socio-economic contexts of individual concerns and problems will lead to more sensitive care (Stewart, 2000). Empowering approaches at the individual level (Labonte, 1993) include listening to the experiences of those living in poverty, acknowledging their constraints as well as their strengths, exploring realistic approaches, and advocating for and with clients regarding access to resources.

Beyond ensuring that clients receive sensitive care on an individual level, nurses have a role to play in working collaboratively with professionals in health and other sectors to advocate for services, supports, and policies that will enhance accessibility to health services. Nurses can advocate for broader coverage of publicly ensured health services, particularly dental care. Given that financial constraints are a major barrier to service accessibility and that people living in poverty use services to meet their basic needs and their health needs, nurses can also advocate for incomes that ensure access to food, shelter, and other essentials. For example, social-assistance rates have never reached the poverty line, for any family type, anywhere in Canada (National Council of Welfare, 2002). The earnings of Ontario and Alberta families working at minimum wage do not reach the poverty line (National Council of Welfare, 2004).

The recent focus in Canada on care 24 hours a day, 7 days a week, and innovative service delivery using a primary health-care framework may enhance geographic and temporal accessibility, particularly if services are provided "under one roof." This may ease some of the transportation barriers faced by people living in poverty. However, there is a need for advocacy regarding affordable transportation services. Advocacy work could also include raising awareness among other professionals and sectors of the effects of poverty on health, which could lead to more positive attitudes towards poor people and reduce bureaucratic barriers to their use of services.

Accessibility of services and empowerment of people living in poverty can be enhanced by egalitarian relationships centred on clients' needs and wishes. This requires nurses and other health professionals to actively acknowledge service users as full members of the collaborative team (Shields & Lindsey, 1998; Stewart, 2000; Whitehead, 2001). As equal partners, people living in poverty would be included in the design of services, thereby ensuring that services are relevant and sensitive.

Nurses can take a leadership role in the development of innovative service-delivery models that facilitate access; reflect the broad determinants of health; incorporate individual, community, and societal interventions; and ultimately promote the physical and psychosocial health of people living in poverty. Nurses are in a key position to advocate for policies that increase accessibility to a broad range of services that meet health-care needs as well as other prerequisites for health.

References

Anderson, J., Blue, C., Holbrook, A., & Ng, M. (1993). On chronic illness: Immigrant women in Canada's work force – A feminist perspective. *Canadian Journal of Nursing Research, 25*(2), 7–22.

Bell, W. G., & Edouard, L. (1992). Reaching out: A community initiative for disadvantaged pregnant women. *Canadian Journal of Public Health, 83,* 188–190.

Canadian Council on Social Development. (2000). *The Canadian fact book on poverty 2000.* Retrieved February 12, 2003, from http://www.ccsd.ca

Canadian Institute of Health Information. (2004). *Improving the health of Canadians.* Ottawa: Author.

Che, J., & Chen, J. (2001). Food security in Canadian households. *Health Reports, 12*(4), 11–22.

Chen, J., & Hou, F. (2002). Unmet needs for health care. *Health Reports, 13*(2), 23–34.

Creswell, J. W. (1994). *Research design: Qualitative and quantitative approaches.* Thousand Oaks, CA: Sage.

Crowe, C., & Hardill, K. (1993). Nursing research and political change: The street health report. *Canadian Nurse, 89,* 21–24.

Dodd, R., & Munck, L. (2002). *Dying for change: Poor people's experience of health and ill-health.* Retrieved February 12, 2003, from http://www.worldbank.org/poverty/voices/reports/dying/index.htm

Donner, L., Busch, A., & Fontaine, N. (2002). *Women, income and health in Manitoba: An overview and ideas for action.* Retrieved February 12, 2003, from http://www.cwhn.ca/resources/women_poverty/summary.html

Dunlop, S., Coyte, P., & McIsaac, W. (2000). Socio-economic status and the utilization of physicians' services: Results from the Canadian National Population Health Survey. *Social Science and Medicine, 51,* 123–133.

Epp, J. (1986). *Achieving health for all: A framework for health promotion.* Ottawa: Ministry of Supply & Services Canada.

European Commission on Development. (2000). *The interaction of health and poverty: Implications for future health, AIDS and population policies.* Retrieved February 12, 2003, from http://europa.eu.int/comm/development/sector/social/1099meeting/backp201.htm

Eyles, J., Stoddart, G., Lavis, J., Pranger, T., Molyneaux-Smith, L., & McMullan, C. (2002). *Making resource shifts supportive of the broad determinants of health: The*

PEI experience. Retrieved February 12, 2003, from http://www.chsrf.ca/docs/finalrpts/2002/funding/eyles_report.pdf

Federal, Provincial, and Territorial Advisory Committee on Population Health. (1999). *Toward a healthy future: Second report on the health of Canadians*. Ottawa: Health Canada.

Glazier, R., Badley, E., Gilbert, J., & Rothman, L. (2000). The nature of increased hospital use in poor neighbourhoods: Findings from a Canadian inner city. *Canadian Journal of Public Health, 91,* 268–273.

Green, L. W., George, M. A., Daniel, M., Frankish, C. J., Herbert, C. J., Bowie, W. R., et al. (1995). *Study of participatory research in health promotion: Review and recommendations for the development of participatory research in health promotion in Canada*. Vancouver: Institute of Health Promotion, University of British Columbia.

Green, L. W., & Mercer, S. L. (2001). Community-based participatory research: Can public health researchers and agencies reconcile the push from funding bodies and the pull from communities? *American Journal of Public Health, 91*(12), 1926–1929.

Hammersley, M., & Atkinson, P. (1983). *Ethnography: Principles in practice.* London: Routledge.

Health Canada. (2003). *Smoking behaviours of Canadians.* Retrieved May 12, 2004, from http://www.hc-sc.gc.ca/pphb-dgspsp/ccdpc-cpcmc/cancer/publications/nphs-sboc/nphs12_e.html

Kapral, M., Wang, H., Mamdani, M., & Tu, J. (2002). Effect of socioeconomic status on treatment and mortality after stroke. *Stroke, 33,* 268–273.

Katz, S., & Hofer, T. (1994). Socioeconomic disparities in preventive care despite universal coverage. *Journal of the American Medical Association, 272,* 530–534.

Kephart, G., Thomas, V., & MacLean, D. (1998). Socioeconomic differences in the use of physician services in Nova Scotia. *American Journal of Public Health, 88,* 800–803.

Labonte, R. (1993). *Health promotion and empowerment: Practice frameworks.* Issues in Health Promotion #3. Toronto: Centre for Health Promotion, University of Toronto, and ParticipAction.

Lee, K. (2000). *Urban poverty in Canada: A statistical profile.* Ottawa: Canadian Council on Social Development.

Lin, E., Goering, P., Offord, D., Campbell, D., & Boyle, M. (1996). The use of mental health services in Ontario: Epidemiologic findings. *Canadian Journal of Psychiatry, 41,* 572–577.

McIntyre, L., Connor, S., & Warren, J. (2000). Child hunger in Canada: Results of the 1994 National Longitudinal Survey of Children and Youth. *Canadian Medical Association Journal, 163*(8), 961–965.

Mercer, S. L., MacDonald, G., & Green, L. W. (2004). Participatory research and evaluation: From best practices for all states to achievable practices within each state in the context of the master settlement agreement. *Health Promotion Practice, 5*(3), 167S–178S.

Millar, W. (2001). Patterns of use – Alternative care practitioners. *Health Reports, 13*(1), 9–21.

Millar, W., & Beaudet, M. (1996). Health facts from the 1994 National Population Health Survey. *Canadian Social Trends, 40,* 24–27.

Millar, W., & Locker, D. (1999). Dental insurance and use of dental services. *Health Reports, 11*(1), 55–67.

Morse, J. M., & Field, P. (1995). *Qualitative research methods for health professionals.* Thousand Oaks, CA: Sage.

Morton, A. M., & Loos, C. (1995). Does universal health care coverage mean universal accessibility? Examining the Canadian experience of poor prenatal women. *Women's Health Issues, 5,* 139–142.

Mustard, C., Finlayson, M., Derksen, S., & Berthelot, J. (1999). What determines the need for nursing home admission in a universally insured population? *Journal of Health Services and Research Policy, 4*(4), 197–203.

Mustard, C., & Roos, N. (1994). The relationship of prenatal and pregnancy complications to birthweight in Winnipeg, Canada. *American Journal of Public Health, 84,* 1450–1457.

National Council of Welfare. (2002). *Poverty profile 1999.* Ottawa: Minister of Public Works & Government Services Canada.

National Council of Welfare. (2004). *Income for living?* Ottawa: Minister of Public Works & Government Services Canada.

O'Connor, A. (1993). Women's cancer prevention practices. In T. Stephens & D. Graham (Eds.), *Canada's Health Promotion Survey 1990 technical report* (pp. 169–180). Ottawa: Minister of Supply & Services Canada.

Ogilvie, L., & Reutter, L. (2002). Primary health care: Complexities and possibilities from a nursing perspective. In J. Ross Kerr & M. Wood (Eds.), *Canadian nursing: Issues and perspectives* (4th ed.) (pp. 441–465). Toronto: Harcourt.

Phipps, S. (2003). *The impact of poverty on health: A scan of research literature.* Ottawa: Canadian Population Health Initiative, Canadian Institute for Health Information. Retrieved October 6, 2003, from http://secure.cihi.ca/cihiweb/dis Page.jsp?cw_page=home_c.

Raphael, D. (2002). *Social justice is good for our hearts: Why societal factors — not lifestyles — are major causes of heart disease in Canada and elsewhere.* Toronto: Centre for Social Justice Foundation for Research and Education.

Reutter, L. I. (2000). Socioeconomic determinants of health. In M. J. Stewart (Ed.), *Community nursing: Promoting Canadians' health* (2nd ed.) (pp. 174–193). Toronto: W. B. Saunders.

Reutter, L., Stewart, M., Raine, K., Williams, D., Letourneau, N., & McFall, D. (in press). Partnerships and participation in conducting poverty-related health research. *Journal of Primary Health Care Research and Development.*

Reutter, L., Sword, W., Meagher-Stewart, D., & Rideout, L. (2004). Nursing students' beliefs about the relationship between poverty and health. *Journal of Advanced Nursing, 48,* 299–309.

Romanow, R. J. (2002). *Building on values: The future of health care in Canada.* Ottawa: Commission on the Future of Health Care in Canada. Retrieved February 12, 2003, from http://www.healthcarecommission.ca

Roos, N., & Mustard, C. (1997). Variation in health and health care use by socioeconomic status in Winnipeg, Canada: Does the system work well? Yes and no. *Milbank Quarterly, 75,* 89–111.

Ross, D., Roberts, P., & Scott, K. (2000). Family income and child well-being. *ISUMA: Canadian Journal of Policy Research, 1,* 1–8.

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

Shaw, M., Dorling, D., & Smith, G. D. (1999). Poverty, social exclusion, and minorities. In M. Marmot & R. G. Wilkinson (Eds.), *Social determinants of health* (pp. 211–239). Oxford: Oxford University Press.

Shields, L. E., & Lindsey, A. E. (1998). Community health promotion nursing practice. *Advances in Nursing Science, 20,* 23–26.

Snider, J., Beauvais, J., Levy, I., Villeneuve, P., & Pennock, J. (1997). Trends in mammography and pap smear utilization in Canada. *Chronic Diseases in Canada, 17*(3), 108–117.

Speech from the Throne. (2004, February 2). To open the third session of the Thirty-Seventh Parliament of Canada (pp. 1–23). Ottawa: Her Majesty the Queen in Right of Canada.

Statistics Canada. (1994). *Health status of Canadians: General Social Survey Analysis Series*. Ottawa: Minister of Supply & Services Canada.

Stewart, M. J. (2000). Framework based on primary health care principles. In M. J. Stewart (Ed.), *Community nursing: Promoting Canadians' health* (2nd ed.) (pp. 58–82). Toronto: W. B. Saunders.

Sword, W. (1999). A socioecological approach to understanding barriers to prenatal care for women of low income. *Journal of Advanced Nursing, 29,* 1170–1177.

Sword, W., Reutter, L., Meagher-Stewart, D., & Rideout, L. (2004). Baccalaureate nursing students' attitudes toward poverty: Implications for nursing curricula. *Journal of Nursing Education, 43*(1), 13–19.

Torjman, S. (2001, December). *Reclaiming our humanity*. Ottawa: Caledon Institute of Social Policy, in partnership with Coalition of National Voluntary Organizations, Canadian Council on Social Development, and United Way of Canada-Centraide Canada.

Wagstaff, A. (2002). Poverty and heath sector inequalities. *Bulletin of the World Health Organization, 80,* 97–105.

Waldram, J. (1990). Physician utilization and urban Native people in Saskatoon, Canada. *Social Science and Medicine, 30,* 579–589.

Whitehead, D. (2001). Applying collaborative practice to health promotion. *Nursing Standard, 15*(20), 33–37.

Wilkins, R., Berthelot, J., & Ng, E. (2002). Trends in mortality by neighbourhood income in urban Canada from 1971 to 1996. *Health Reports, 13* (Suppl), 45–72.

Williamson, D., & Fast, J. (1998). Poverty and medical treatment: When public policy compromises accessibility. *Canadian Journal of Public Health, 89,* 120–124.

Wolfe, B. L. (1999). Poverty, children's health and health care utilization. *Economic Policy Review, 5*(3), 9–21.

World Health Organization. (1999). *Poverty and health.* Report by the Director-General. 105th Session, Provisional Agenda Item 2. Geneva: Author.

World Health Organization. (2003). *The determinants of health.* Retrieved August 13, 2003, from http://www.who.int/hia/evidence/doh/en/print.html

World Health Organization Europe. (2001). *Poverty and health — Evidence and action in WHO's European Region.* Copenhagen: WHO Regional Office for Europe.

Authors' Note

This project was funded by the Canadian Health Services Research Foundation, the Alberta Heritage Foundation for Medical Research, the Boyle McCauley Health Centre, Health Canada (Health Promotion and Programs Branch, Ontario), United Way of Alberta Capital Region, and the Edmonton Community Lotteries Board.

Comments or queries may be directed to Miriam Stewart, Faculty of Nursing, University of Alberta, 700 University Extension Centre, Edmonton, Alberta T6G 2T4 Canada. Telephone: 780-492-6699. E-mail: miriam.stewart@ualberta.ca

---

Miriam Stewart, PhD, is Professor, Faculty of Nursing, University of Alberta, Edmonton, Canada. Linda Reutter, PhD, is Professor, Faculty of Nursing, University of Alberta. Edward Makwarimba, PhD, is Co-director, Social Support Research Program, University of Alberta. Irving Rootman, PhD, is Professor, Faculty of Human and Social Development, University of Victoria, British Columbia, Canada. Deanna Williamson, PhD, is Associate Professor, Department of Human Ecology, University of Alberta. Kim Raine, PhD, is Professor and Director, Centre for Health Promotion Studies, University of Alberta. Doug Wilson, PhD, is Professor, Faculty of Medicine, University of Alberta. Janet Fast, PhD, is Professor, Faculty of Agriculture, Forestry, and Home Economics, University of Alberta. Rhonda Love, PhD, is Associate Professor, Department of Public Health Sciences, University of Toronto, Ontario, Canada. Sharon McFall, MA, was, at the time of the study, Executive Officer, Boyle McCauley Health Centre, Edmonton. Deana Shorten is Secretary-Treasurer, National Anti-poverty Organization, Atlantic, Harvey Station, New Brunswick, Canada. Nicole Letourneau, PhD, is Associate Professor, Faculty of Nursing, University of New Brunswick, Fredericton, Canada. Karen Hayward, MA, is Researcher, Genuine Progress Index for Atlantic Canada, Glen Haven, Nova Scotia, Canada. Jeff Masuda, MSc, is Assistant Director and a doctoral candidate, Institute of Gender and Health (CIHR), University of Alberta. William Rutakumwa is a doctoral candidate, Department of Rural Economy, University of Alberta.

CJNR 2005, Vol. 37 Nº 3, 132–148

Résumé

Les limites sociales et géographiques de l'infirmier-cadre supérieur et des médecins responsables : une application de l'analyse des réseaux sociaux

Elizabeth West et David N. Barron

Cette étude a pour objectif de décrire les limites sociales et géographiques des réseaux d'infirmiers-cadres supérieurs et de médecins responsables et gestionnaires dans les hôpitaux de soins de courte durée au Royaume-Uni. Une enquête téléphonique a été effectuée au moyen des méthodes d'analyse des réseaux sociaux. Un échantillon aléatoire a été sélectionné à partir d'une liste nationale et échantillonné à répétition jusqu'à ce que 100 répondants aient été interviewés. Le taux de réponse obtenu a été de 49,5 %. Les membres des deux groupes avaient tendance à discuter « de questions professionnelles importantes » avec des personnes semblables à eux sur le plan de la profession, du sexe, de l'âge et de l'ancienneté, les médecins affichant une attitude plus marquée à cet égard. Il en ressort que les coupures dans le réseau de liens informels entraveront la dissémination de l'information et de l'influence sociale entre ces deux groupes importants. Les gestionnaires (non qualifiés cliniquement) semblent jouer un puissant rôle de « courtage ». Les réseaux informels sont essentiellement composés de liens locaux. Les auteurs soutiennent que des stratégies de dissémination et d'influence qui prennent en compte les particularités de la structure sociale ont plus de chances de réussir.

Mots clés : réseaux sociaux, dissémination, relations interprofessionnelles, infirmiers-cadres, médecins, responsables et cadres

CJNR 2005, Vol. 37 Nº 3, 132–148

Social and Geographical Boundaries Around Senior Nurse and Physician Leaders: An Application of Social Network Analysis

Elizabeth West and David N. Barron

The purpose of this study was to describe the social and geographical boundaries around the networks of senior nurse executives and physician leaders and managers in acute-care hospitals in the United Kingdom. A telephone survey was conducted using standard social network methods. A random sample was drawn from a national list and repeatedly sampled until 100 respondents were interviewed. The response rate was 49.5%. Both groups tended to discuss "important professional matters" with others who were similar to themselves in terms of profession, gender, age, and seniority, with physicians being more extreme in this regard. The implication is that gaps in the network of informal ties will impede the dissemination of information and the spread of social influence between these 2 important groups. Managers (non-clinically qualified) appear to occupy a powerful "brokerage" role. Informal networks are mainly composed of local ties. The authors argue that dissemination and influence strategies that take features of the social structure into account are more likely to be successful.

Keywords: social networks, influence, dissemination, inter-professional relationships, nurse executives, physicians, leaders and managers

Introduction

The purpose of this paper is to explore the social and geographical dimensions of the social relationships of senior nurses and doctors working in the United Kingdom's National Health Service (NHS). The two groups in our study are Directors of Nursing (DNs), nurse executives who are at the top of the hospital hierarchy, and Clinical Directors of Medicine (CDMs), who lead and manage a clinical team. Our aim is to describe the extent to which these leaders and managers within the hospital interact with those who are similar to or different from them in terms of profession, gender, age, and geographical location. This work is relevant to our understanding of how information spreads through the health system via informal channels as well as how clinical and managerial behaviour might be affected by social processes. An important question is the extent to which managers and leaders in the NHS are exposed to people who may see the world from a different perspective.

The study is founded in social network theory, whose central premise is that "the structure of relations among individuals and the location of individuals in the network have important behavioural, perceptual and attitudinal consequences both for individual units and for the system as a whole" (Knoke & Kuklinski, 1982). Where ties are dense, information and influence can spread rapidly among all those who are in frequent contact. Where ties do not exist, on the other hand, dissemination through informal interaction is impossible.

One of the key aspects of social network analysis is the analysis of the distribution of ties in a network. Often, network ties are grouped into clusters rather than being distributed evenly across all potential contacts. These clusters can be analyzed in many different ways. For example, numerous studies have found that groups are frequently *homophilous* — that is, comprising people who are similar in one or more characteristics (MacPherson, Smith-Lovin, & Cook, 2001), which might include age, highest educational qualification, gender, and social class.

Clusters can also be geographical. It is widely believed that people today experience higher levels of geographical mobility in the course of their careers than did people in past times. It is important to know whether clinicians maintain the geographically dispersed professional ties they accumulate throughout their career, or whether their social networks reflect only their current geographical location. We suspect that, despite the widespread use of e-mail and other boundary-spanning technologies, people's social networks remain strongly influenced by the geographical space they currently occupy. This would be consistent with some recent work in the newly emerging field of the geography of nursing (e.g., Andrews, 2002, 2003). In particular, Andrews argues that geographical space is not something neutral but that certain spaces have particular meanings for people. We think that the "local" space is often particularly important to people, in the sense that it engages feelings of belonging, loyalty, and solidarity.

Rather than attempt to study clinicians of all types, we decided to concentrate on two distinct groups, DNs and CDMs. We selected these two groups because they play key roles in the hospital organization. DNs are full-time managers, often executive directors of the hospital trust, and are often responsible for the quality of care. They have no direct clinical involvement. Because they are at the top of the hospital nursing hierarchy, we thought that we would have maximal chances of finding professional social networks that have significant national or even international components.

CDMs are consultant physicians who are released from direct clinical care for one or two sessions per week to devote time to managing the directorate. Unlike the case with DNs, their job is still primarily clinical and they often have the help of a full-time business manager. Each trust has several clinical directors, each of whom is responsible to the medical director. We selected this group mainly because they are seen as leaders with a role that has important clinical and managerial components and because they are at the mid-level of the medical career hierarchy. Because they are in the middle of the hospital hierarchy, they should be able to make relationships up — to the hospital board — and down — to co-workers in their clinical directorates — as well as to a group of their peers, the other clinical directors in the trust. From this point in the paper we will often refer to these two groups as simply "nurses" or "doctors," respectively, instead of DNs and CDMs; it is important to remember, particularly in interpreting the findings, that this paper focuses on two quite specific occupational groups.

The Nature of Clinicians' Social Networks

Although recently a great deal of emphasis has been placed on the philosophy of multidisciplinarity and working across professional boundaries, the professions are still powerful entities in many health-care systems, including the NHS. Professional background is often an important element of individual identity and determines, to a certain extent, concrete life chances such as job mobility. Professional associations, such as the Royal Colleges in the United Kingdom, benefit members in many ways, such as by providing education and insurance; they also represent the profession in salary negotiations and participate in policy formation.

Since Abbot (1988) published his work on the sociology of the professions, many nurse researchers have adopted his perspective (e.g., Allen, 2001). Briefly, Abbot argues that the professions exist in a system. The evolution of each profession depends on its interactions with other professions. In particular, Abbot emphasizes the fundamentally competitive nature of the relationships among the professions in a given field, where "jurisdictional boundaries are perpetually in dispute, both in local practice and in local claims." Because professional affiliation is important both for the construction of individual identity and for collective action, we expect that professional social networks will be composed mainly of people with the same professional background.

Conjecture 1: Clinicians' social networks will demonstrate professional homophily.

In the past, medicine and nursing recruited almost exclusively from one gender. The 20th century saw the progressive erosion of this pattern, particularly in medicine. As a result, the two professions are now more integrated in terms of gender than ever before. However, when we examine medicine and nursing at the level of specialization, we can see that sex segregation is still the norm (Crompton, 2001). In the United Kingdom, 90% of nurses are female, but as male nurses tend to work in learning disability and mental health, sex segregation at the ward level is even greater than this figure would suggest. Similarly, male doctors predominate in prestigious specialties such as neurology, cardio-thoracic medicine, and renal medicine. Female physicians, by contrast, predominate in dermatology, ophthalmology, and community medicine. This pattern is consistent with much research on sex distribution in other industries, sectors, and countries. Following Marsden (1990), we therefore hypothesize that:

Conjecture 2: Clinicians' networks will tend to be homophilous in terms of gender.

We make similar predictions with regard to age. This is partly because of the correlation between age and rank or status. Social interactions in organizations are more likely to occur between individuals at the same grade, because people tend to encounter their peers more often in the course of their work and because of the importance of peers in the construction of social identities. We share a common history with people who are of the same generation and we share many experiences with people whom we consider our equals. Our expectation is that social network groups will include a majority of members of a similar age and rank.

Conjecture 3: Clinicians' networks will tend to be homophilous in age and rank.

The fact that DNs and CDMs occupy different positions in the nursing and medical hierarchies, respectively, leads us to expect that the two groups may differ in the extent to which they interact with colleagues who are junior and senior to them. The doctors occupy key roles *in the middle* of the hospital hierarchy, whereas the nurses are *at the top* of their profession within the organization. It therefore seems logical to expect nurses' networks to contain more discussion partners who are either junior to them in rank or working in another organization. DNs will have many more opportunities to interact with junior colleagues and fewer opportunities to interact with senior colleagues and peers than will CDMs.

Conjecture 4: DNs will interact with more junior colleagues than CDMs. DNs will interact with fewer senior colleagues and peers than CDMs.

So far we have concentrated on social boundaries, but the geographical boundaries around networks are also interesting. To what extent do doctors and nurses maintain relationships with people who do not live and work in the same area, perhaps people with whom they trained or have met at conferences? We predict that such ties will be in the minority. This is partly because, as we argued above, the "local" is imbued with particular meaning for people. More prosaically, simple frequency of contact is an important factor in the formation and duration of relationships. Trust is more likely to develop between people who interact face to face. There are simply many more opportunities for meeting people who work in the same organization. Nevertheless, the NHS is a national organization, drawing workers from diverse educational institutions spread across the country and further afield. It provides some opportunities for employees to attend conferences and for some access to the Internet. These factors suggest that most health professionals will also have a significant number of national or international ties.

Conjecture 5: Clinicians' networks will tend to be geographically local.

Research Design and Methods

We drew random samples of DNs and CDMs from a national list (*Binley's Directory of National Health Service Management*, 1996). We contacted members of the two groups (DNs and CDMs) to invite them to participate in the study; the acceptance rate was 49.5%. We continued sampling until we had interviewed 50 people in each professional group. Most people we contacted were interested in the study and willing to participate. Those who refused to take part most often cited pressure of work, holidays, being new on the job, or imminent retirement. Nothing in their responses led us to suspect that there might be some correlation between characteristics of their social networks and their disinclination or inability to participate. After a respondent had agreed to participate, information was faxed to him or her in advance of the interview. Responses were recorded on paper and then entered into SPSS by the interviewer, Juliett Dowsett, the research assistant on the project. Data were then checked, cleaned, and analyzed by the second author. At the time the survey was conducted, ethics committee approval was not required for research that did not involve patients.

A key component of social network data collection is the *name generator:* the question used by the interviewer to illicit names of people who are members of the interviewee's social network. We based our survey methodology on that developed for use in the United States General Social Survey special module on social networks (Burt, 1984). Our name generator was: *From time to time people discuss important professional matters with other people. In the past 12 months, who are the people with whom you have discussed important professional matters?*

Data were collected via telephone interviews lasting about 30 minutes. On the phone, we defined "important professional matters" to include both clinical and managerial issues, and asked respondents to give the initials of or otherwise identify every person with whom they had discussed important professional matters in the previous 12 months. Having obtained the long list, we then asked respondents for detailed information on the first five people.[1] This information included demographic characteristics, the nature of the relationship between the respondent and each of his or her discussion partners — known as "alters" in the network literature — and the nature of the relationship between each pair of alters. We also collected personal details about the respondents, including age, marital status, and education, as well as information about relevant professional behaviour, including the number of professional journals read and memberships in professional and social associations.

Findings

The analyses reported below use descriptive statistics to investigate the social boundaries based on profession, gender (and the intersection of profession and gender), age, rank or status, and geography. Throughout this paper we report data on the highest number of responses available and indicate the denominator where appropriate.

The sociodemographic characteristics of the two groups are reported in Table 1. The doctors and nurses in the sample were similar in age (the means of both were nearly 50) but the sex distribution was highly skewed; only 3 out of the 50 doctors were female, whereas 36 nurses were female and 14 were male.

Table 1 *Sociodemographic Characteristics of the Sample*

	Clinical Directors of Medicine	**Directors of Nursing**
Average age	49	46
Males	47	14
Females	3	36
Married	38	27
Single	5	16

---

[1] Burt (1984) discusses the practical and theoretical reasons for limiting to five the number of people about whom detailed information is collected.

1. Professional Homophily

The occupations of all the discussion partners named by respondents were divided into five broad categories — doctor, nurse, manager, kin (including spouse), and friend. Recall that the respondents were asked to give the *current* occupation, rather than the professional background, of their discussion partner. Some of the alters that we have classified as a manager may have begun their professional career as a doctor or nurse, then moved into management at a later date. However, any alter categorized as a doctor is unlikely to have had any other career in the past.

As hypothesized, most discussion partners were in the same profession as the respondent. About 60% of nurses' networks, for example, consisted of other nurses (111 of 184 ties). We expected that the second most common category would be doctors, but we were wrong. Only 20 of the nurses' 184 alters were medically qualified. After fellow nurses, DNs spoke most frequently to managers (44 of 184, or about 24%). As we mentioned above, some of the alters currently working as managers may have had a nursing or medical background. Friends and family were uncommon relationships in these networks: there were only nine assorted relatives in the whole alter pool. Where respondents did select a relative they would often add another reason for choosing the person, over and above family membership, such as working in a related field.

The tendency towards professional homophily was even more marked among doctors. In exact figures, 83 of the 116 alters named were doctors, most commonly "fellow consultants." Managers were the next most common (23) and nurses (7) were third. That means 75% of doctors' alters were medically qualified, 15% were managers, and only 5% were nurses. These results suggest that the boundary around the medical profession is very strong and the preponderance of "fellow consultants" among respondents' discussion partners suggests that the consultant network could comprise a powerful block within the hospital. Like the DNs, this group of doctors had more contact with managers than we had anticipated. Although we hypothesized that in-group association (homophily) would be present, we assumed that nurses and doctors would be important components of each other's networks. They were not, but because both DNs and CDMs include so many managers in their networks, at least some of the communication between the members of these two groups might have been mediated through managers. The last category — friend and kin — together accounted for only seven of the CDMs' alters, which suggests that both CDMs and DNs draw a clear distinction between work life and home life. In sum, the most interesting and robust finding about professional homophily is the lack of doctors in the nurses' discussion networks and the lack of other professions in the doctors' networks.

2. Gender Homophily

Males predominated among the alters of the 30 male doctors who supplied this information. They identified 117 men and 30 women in total — that is, about 80% of the discussion partners of male doctors were also male. This figure is close to Marsden's (1990) estimate of 19.4% of cross-sex ties formed in the workplace. In our study, 21 (out of 30) male doctors had discussion networks that were either entirely male or included one woman, leaving nine whose networks might be described as "mixed," with two or three of each gender. There appeared to be no pattern in the sequence of genders; men and women were equally likely to appear as first, second, third, fourth, or fifth alter. What is striking is the predominance of males across the board.

There were only three female CDMs in this study. Although we cannot generalize from such a small number, it is interesting to note that female doctors also frequently chose males as their discussion partners, naming a total of 10 men and 4 women. In our small sample of female doctors, 73% selected *only* males as discussion partners. If these data are at all representative, then, female doctors are only slightly more likely than their male colleagues to include women in their networks.

At the aggregate level, the distribution of alters across genders was much more even in the social networks of the DNs, with only slightly more females than males in the sample of alters (65 to 59). But gender homophily became apparent when we examined the patterns of association of male and female nurses separately. Female nurses talk to more women than men, at a rate of 54 to 40 (57%). This means that, although their networks are predominantly composed of their own gender, female nurses have a much higher likelihood of forming cross-sex ties at work than either male doctors (who only had 20% cross-sex ties) or the male nurses in this sample (37% cross-sex ties). Again, we have data on only six male nurses so we cannot generalize about this subgroup, but it is interesting that in a female-dominated profession 63% of all male nurses' discussion partners are male. This could be due to male nurses working in clinical areas, such as learning disability or psychiatry, where males predominate, but it may also indicate the preferences of respondents for same-sex ties.

Combining the information we have about gender and profession leads to some loss of data but reveals interesting tendencies. Male doctors' networks are predominantly composed of other male doctors. Male managers are the next most common group. Among the female alters of male CDMs, there were six doctors, six managers, and four nurses.

Table 2 ***Gender and Professional Background of CDMs and DNs by Gender***

Alters	**Male CDMs**	**Female CDMs**	**Female DNs**	**Male DNs**
Male doctors	63	7	8	4
Female doctors	6	1	1	0
Male managers	15	1	10	10
Female managers	6	1	16	1
Male nurses	3	0	14	3
Female nurses	4	0	41	8

Interestingly, then, male doctors speak to as many female managers as they do female doctors, and almost as frequently to male nurses as female nurses, although we would expect female nurses to predominate in acute-care trusts where CDMs are working.

3. Age and Rank

Is age an important social distinction among professions? What we did not anticipate before we began collecting the data was that many of the respondents would be unable to give the exact age of their alters; we had to be content with their estimate to the nearest decade. The average age of respondents was late forties (49 for doctors, 46 for nurses), and most of the alters were also in their forties. There was a tendency for doctors' alters to be older than nurses' alters.

To gain an idea of respondents' subjective assessment of their status in relation to their discussion partners, we asked whether they considered each alter to be "senior," "equal," or "junior" to themselves. Doctors described most of their alters as "equal" (137 of 225, or 60.8%), compared with "juniors" (48, or 21.3%) and "seniors" (40, or 17.7%). DNs showed a similar tendency to select "equals" (119 of 220, or 54.1%), but they included a larger proportion of "juniors" (31.3%) than did CDMs. DNs considered only about 15% of their network to be their "seniors."

4. Geographical Boundaries

Nurses reported the geographical distance between themselves and their alters as ranging from zero to 130 miles, with zero being the most common distance, reported about 47% of the time. Many of the remaining discussion partners were close by; 25.6% were within a 20-

mile radius, so may in fact have been part of the same organization (we did not ask this question specifically). The remaining quarter of the nurses' alters lived more than 20 miles away.

Doctors' networks were even more local, with zero distance between respondent and alter being reported 76% of the time. Only 11.5% of their alters were within a 20-mile radius and the remaining 10.3% were more dispersed. These figures clearly indicate that the networks of CDMs are more locally based than those of the DNs. Whereas 72% of nurses' alters could be described as "in the vicinity" of the respondent, the figure for doctors is 87.5%.

5. Characteristics of Contact

The frequency of contact between respondents and their discussion partners follows from the geographical spread of the alters of the two groups. Doctors' alters are, most frequently, people they talk to every day. Summing the number they talk to either daily or weekly, we account for 73.1% of their alters. Only about 17%, then, are people they talk to less frequently than weekly. By contrast, only about 54% of nurses' contacts could be described as people with whom they are in contact on a daily or weekly basis. This raises some interesting questions. Do doctors simply do more talking about professional problems? Is their work life organized in such a way that contact with other doctors and peers is maximized? Or are doctors simply more able to get advice, information, or support in dealing with professional problems from within their own institution? Perhaps the fact that a peer group is available for CDMs but not for DNs within the hospital contributes to this striking difference in their patterns of relationships.

The data show that face-to-face communication is the norm among CDMs (194 of 233). Only 39 respondent-alter relationships featured communication that was primarily via the phone. Letters and e-mail were not commonly used. The DNs show a similar pattern, with most reliance placed on face-to-face communication (154 of 233). However, more of their relationships were conducted over the phone (69 of 233), which seems consistent with the fact that their alters are more dispersed than those of the CDMs in the sample.

Conclusions, Implications, and Future Research

This paper describes the social and geographical boundaries around the social networks of two groups of senior health-care professionals. Following standard network methods (Burt, 1984), we collected data on the profession, gender, age, rank, and location of the alters of 100 senior nurses and doctors in the United Kingdom's National Health Service, as well as frequency of contact and the most common mode of communication. Consistent with our conjectures, we found that both groups discuss important professional matters with clinicians from a similar professional background and that this tendency is more marked among doctors than among nurses. Perhaps doctors feel that only other doctors can understand and contribute to discussions about the important professional matters that they face. An alternative explanation is that clinicians do discuss professional issues more widely but remember only the conversations that they have with members of their own professional group. Whichever explanation comes closer to the truth, it is clear that professional identities are highly salient and permeate relations in a workplace that, formally, espouses the principles of multidisciplinarity. Medicine and nursing appear to function in parallel, and there is little evidence of integration in the social structure of the hospital. Nurses sometimes complain that doctors do not know what they do, or fail to appreciate the fact that nursing has a different philosophical orientation from medicine, as well as different aims and goals. If these findings can be generalized to other levels of the medical and nursing professions, it may be quite true that doctors and nurses know very little about each other.

We were surprised to find that managers constitute such an important group in the networks of both DNs and CDMs and that nurses and doctors figure so rarely in each other's networks. In the United Kingdom, hospital management grew out of administration and is a relative newcomer to the health professions. These data show that managers are integrated into the networks of both nurses and doctors. Since both nurses and doctors discuss important professional matters with managers and seldom with each other, part of the managers' job may be to facilitate communication between the two groups. Managers may be seen as occupying an important "brokerage" role between the traditional health-care professions, a role that is widely acknowledged in sociological theory as one of the most powerful in a social system (Burt, 1992). Carving out this role, especially over such a short period, must be seen as a real achievement for the profession.

The NHS is highly segregated along gender lines. This is reflected in the social networks we studied. The networks of male CDMs were about 80% male, and although we found that both male and female DNs were more likely to have cross-sex ties at work (approximately 40%), the majority of their ties were also to same-sex alters. This is at least partly a product of gender segregation at the level of the specialty, but our findings suggest that the demography of the professions is not the entire answer. Why, when the ratio of female to male consultants in general medicine is 1:6, are female doctors selected as discussion partners at a rate of less than 1:10? Similarly, recall that female nurse managers outnumber males at a rate of 5:1 in general nursing — so why do male doctors select as many male as female nurses as the people with whom they discuss important professional matters? This tendency to relate to one's own gender, which appears to be particularly marked among men, may be one of the mechanisms perpetuating both gender segregation and gender inequality at work. Women are curiously absent in this study, both from our sample of doctors and from the networks of male and female respondents. Previous research suggests that people who are infrequently selected as discussion partners miss out on opportunities for socialization and for access to important information, which may have a detrimental impact on their careers (Kanter, 1977).

Age and rank also emerged as clear boundaries in the social networks of both professional groups, with the extent of homophily being more marked among the doctors. In fact, all of the findings summarized above show that the doctors' networks are likely to comprise people who are very similar to themselves — in profession, gender, age, and rank. Doctors' networks are composed of people who work in the same institution and with whom they talk, almost daily, in face-to-face interactions. Current theorizing in this area suggests that any network configuration is likely to have advantages and disadvantages (Burt, 1992; Ibarra & Smith-Lovin, 1992). The main advantage of a homophilous network is that the information it conveys will tend to confirm the respondent's perceptions and assumptions about the social world, reaffirming his or her identity and sense of belonging. A homophilous network will also be relatively simple to handle because the behaviour of alters will be predictable and it will provide clear models for the kinds of behaviour that are acceptable to an audience of peers. The main disadvantage of such a network is that the respondent will not have access to knowledge that has been acquired in distant regions of social or geographical space. Such a network will not convey much new information or insight and will tend to reassure rather than challenge the perceptions of members (Granovetter, 1973). For the doctors in this sample, this means that they rarely get the opinion of a woman or of someone whose background is different from their own.

In some ways the respondents in this study, particularly the medical staff in whom all the tendencies to in-group interactions are more marked, might be described as *socially insulated,* which means that they are unlikely to hear through informal channels how other, different, kinds of people see the world. We have long known about the existence of "glass ceilings" that stop some groups rising up the ladder of promotion in some organizations. This study reveals the existence of "glass walls" between some groups of staff in health-care organizations. Although invisible to the naked eye, there are barriers between physicians and nonphysicians, between men and women, and between the generations. It is particularly important that nurses be aware of the informal structure of the hospital, because as (mainly) women and as nurses, they may be excluded from some very powerful groups. Further research is needed to explore the consequences of the lack of diversity in the networks of health-care professionals and the effect this might have in terms of relating to patients and staff at different levels in the hospital organization. It is also important that researchers realize that the formal and informal structures of the organization may differ in some respects. Focusing on the latter when studying social processes such as communication, power, influence, and teamwork could be rewarding.

The results of this study are relevant to a number of other health-policy concerns: how to improve the human resource management of health-care workers and to find better ways to disseminate information through the health-care system and influence the practice of clinicians. These results suggest that we should examine further the relationship between social networks and affective aspects of the quality of work life, such as sense of involvement, participation, and commitment to the organization. Further research is particularly needed on those people who are present in the work environment but are infrequently selected as discussion partners. The outstanding example of such a group in this study is female doctors. We need to ask why female doctors appear so infrequently as discussion partners and what the consequences for them might be in terms of the benefits that can accrue from networks, such as mental and physical health as well as promotion opportunities and job success. In addition, the networks of female nurses seem to be less supportive than those of male doctors — the alters of female nurses are more dispersed and are consulted less frequently, often on the phone rather than face to face. When a nurse in the sample has an important professional issue to discuss, she often has to rely on alters who are probably less familiar with the context of the problem than are the discussion partners of doctors.

The findings of this study support the conclusion of previous authors (e.g., Strong & Robinson, 1990) that nursing and medicine have quite different social structures. In addition, we have identified a gap in the structures of medicine and nursing, where there are few informal ties. This means that information is unlikely to be spread between the two professions by informal routes. This makes formal arrangements for communication all the more important. The role of managers may also be crucial: managers could be in a position to broker relationships between the two professions.

Consistency with the literature increases our confidence in the generalizability of our results. However, we should emphasize that our samples are small and that we concentrated on two distinct, albeit important, groups of doctors and nurses. We cannot be sure that our results would be the same if we had studied doctors and nurses at other grades. Looking for similarities and differences in this regard would be an interesting subject for future research.

The implication of these findings for dissemination and implementation is that quite different strategies are probably required to spread information and influence throughout nursing and medicine. The main benefit of nurses' more dispersed, heterogeneous networks is that nurses are more likely to have access to diverse sources of new information than doctors, who are embedded in closely knit homophilous networks. The latter type of network structure would be much more effective in implementing changes in clinical behaviour through the mechanisms of social control. As a tightly knit clique, however, doctors would also have the power to resist external pressures to change (West, Barron, Dowsett, & Newton, 1999). The implications of our findings are, in effect, hypotheses. Based on what we now know about the social and geographical boundaries around the two professions, we should try to design dissemination and implementation strategies to fit these different network patterns. The effectiveness of different strategies for different groups could then be compared in practice using randomized controlled trials.

Further research could build on, and improve upon, the research tool we have developed to gather network data from health professionals. Future studies could, for example, gather more information about the professional background of alters. This study was hampered by the fact that we cannot distinguish between people who are currently working as managers but come from a nursing background and those who have made their careers in management. Its most robust findings on professional homophily concern the medical profession's dominance of doctors' networks and absence from nurses' networks. Our claims about nurses and managers would have been much stronger had we been able to gather data on their career trajectories. Future researchers might also want to gather data on the institutional affiliation of alters in addition to the geographical distance between respondent and alter. It would also be fascinating to gather more information about the heterogeneity of the organizations and teams that provide the professional context in which social networks are formed. This would enable the analyst to begin to disentangle the roles of choice and opportunity in the formation of social networks. We hope that future research will also pursue questions about the implications of different network configurations for individuals' careers and their experience of work life.

References

Abbott, A. D. (1988). *The system of the professions: An essay on the expert division of labour.* Chicago: University of Chicago Press.

Allen, D. (2001). *The changing shape of nursing practice: The role of nurses in the hospital division of labour.* London: Routledge.

Andrews, G. J. (2002). Towards a more place-sensitive nursing research: An invitation to medical and health geography. *Nursing Inquiry, 9,* 221–238.

Andrews, G. J. (2003). Locating a geography of nursing: Space, place and the progress of geographical thought. *Nursing Philosophy, 4,* 231–248.

Binley's directory of National Health Service management. (1996). (Available on CD-ROM.) Corringham, UK: Beechwood House.

Burt, R. S. (1984). Network items and the General Social Survey. *Social Networks, 6,* 293–339.

Burt, R. S. (1992). *Structural holes: The social structure of competition.* Cambridge, MA: Harvard University Press.

Crompton, R. (2001). *Gender policy, practice and progress in medicine and banking: A comparative cross-national analysis.* Final Report, R000222283. Swindon, UK: Economic and Social Research Council.

Granovetter, M. (1973). The strength of weak ties. *American Journal of Sociology, 78,* 160–1380.

Ibarra, H., & Smith-Lovin, L. (1997). New directions in social network research on gender and organizational careers. In S. Jackson & C. Cooper (Eds.), *Handbook of organizational behaviour*. Chichester: John Wiley.

Kanter, R. M. (1977). *Men and women of the corporation*. New York: Basic Books.

Knoke, D., & Kuklinski, J. H. (1982). *Network analysis.* Beverley Hills, CA: Sage.

Marsden, P. V. (1990). Network diversity, substructures and opportunities for contact. In C. Calhoun, M. W. Meyer, & W. R. Scott (Eds.), *Structures of power and constraint* (pp. 396–410). Cambridge: Cambridge University Press.

McPherson, M., Smith-Lovin, L., & Cook, J. M. (2001). Birds of a feather: Homophily in social networks. *Annual Review of Sociology, 27,* 415–444.

Strong, P., & Robinson, J. (1990). *The NHS: Under new management.* Buckingham, UK: Open University Press.

West, E., Barron, D. N., Dowsett, J., & Newton, J. N. (1999). Hierarchies and cliques in the social networks of health care professionals: Implications for dissemination and implementation. *Social Science and Medicine, 48*(5), 633–646.

Authors' Note

We would like to thank Juliett Dowsett and Viv Crombie for their research assistance and John Newton for his help and advice.

The NHS R&D Executive provided funding for this study.

Comments or queries may be directed to Elizabeth West, Lecturer and Postdoctoral Fellow, London School of Hygiene and Tropical Medicine, 32 Keppel Street, London WC1E 7HT United Kingdom. E-mail: Elizabeth.west@LSHTM.ac.uk

---

Elizabeth West, PhD, is Lecturer and Postdoctoral Fellow, London School of Hygiene and Tropical Medicine, London, United Kingdom. David N. Barron, PhD, is Lecturer, Saïd Business School and Jesus College, University of Oxford, United Kingdom.

CJNR 2005, Vol. 37 Nº 3, 150–159

Résumé

Meilleures pratiques en matière de méthodes de recherche

Facteurs à prendre en considération dans le choix d'une méthode de collecte électronique de données

Karen L. Courtney et Catherine K. Craven

Les chercheurs et les chercheuses sont de plus en plus nombreux à envisager l'adoption de méthodes de collecte électronique de données — lesquelles comportent l'utilisation d'Internet, du courrier électronique ainsi que d'ordinateurs de bureau et de poche — pour les enquêtes, les carnets d'écoute, les instruments de recherche et les groupes de discussion. Se fondant sur les résultats de recherches antérieures sur la collecte électronique de données, les auteures présentent les facteurs clés, qui comprennent les caractéristiques liées à la population, aux données et aux ressources, qui guident les chercheurs et les chercheuses dans le choix de la méthode de collecte de données la plus appropriée à la question de leur recherche. Les facteurs dont il faut tenir compte dans les décisions relatives à la collecte de données sur la population sont l'âge, le sexe, le statut socioéconomique et l'accès aux technologies. Les facteurs clés qui influencent le choix d'une méthode de collecte de données comprennent la sensibilité du sujet, l'importance du facteur temps, les données longitudinales et les données contextuelles. Les décisions relatives à la collecte de données sont aussi fondées sur les ressources en termes d'argent, de temps et de technologies. Les technologies et la démographie vont continuer de modifier les méthodes et les possibilités de collecte de données ainsi que d'influer sur elles. Cependant, par l'examen de ces facteurs clés, les chercheurs et les chercheuses pourront prendre les décisions en matière de collecte de données qui sont appropriées à chaque projet.

Mots clés : Internet, collecte de données, ordinateurs de poche, méthodologie de recherche, informatique médicale

CJNR 2005, Vol. 37 Nº 3, 150–159

Best Practices in Research Methods

Factors to Weigh When Considering Electronic Data Collection

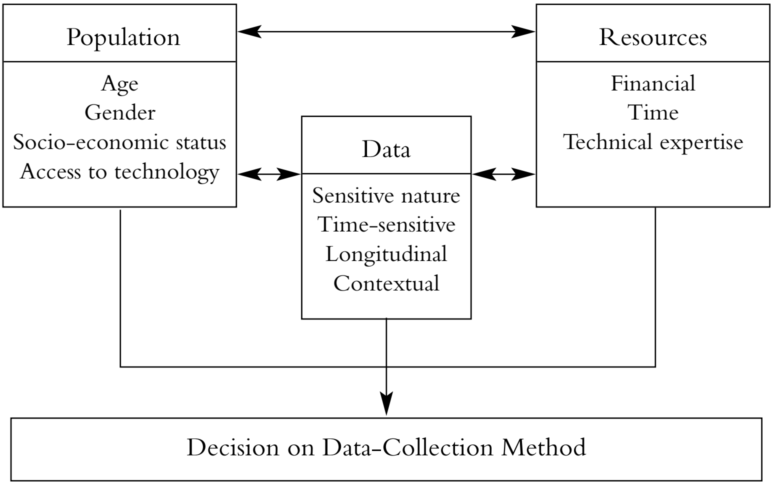
Karen L. Courtney and Catherine K. Craven

Researchers are increasingly considering the adoption of electronic data-collection methods — which entail the use of the Web, e-mail, and desktop and handheld computers — for surveys, diaries, research instruments, and focus groups. Based on prior research findings on electronic data collection, the authors delineate the key factors, which incorporate population, data, and resource characteristics, that guide researchers in selecting the data-collection method most appropriate for their research question. Population factors to consider in data-collection decisions are age, gender, socio-economic status, and access to technology. Key data factors influencing the selection of collection method include sensitivity of the topic, time sensitivity, longitudinal data, and contextual data. Data-collection decisions are also based on financial, time, and technological resources. Technology and demographics will continue to change and affect data-collection methods and possibilities. By examining these key factors, however, researchers will be able to reach data-collection decisions that are appropriate for each project.

Keywords: Internet; data collection; computers, handheld; research design; medical informatics

In the United States, 63% of adults participate in Internet activities such as e-mail exchange, Web browsing, instant messaging, and participation in chat rooms (Madden, 2003). As the number of online participants grows, more researchers are considering the use of electronic data collection (EDC) methods. With EDC methods, the Web, e-mail, and desktop and handheld computers are used for completing surveys and diaries, taking part in focus groups, and participating in other aspects of research. The literature contains numerous articles that partly explore the challenges and opportunities presented by EDC. We found that most health research entailing EDC methods touches on one or more of thirteen issues, three of which are time, cost, and immediacy (Courtney & Craven, 2004). There is a dearth of resources, however, to guide researchers in making decisions about EDC methods. This paper describes factors that can guide investigators in selecting the most appropriate data-collection method for their research question (Figure 1).

Figure 1 ***Data-Collection Method: Factors to Consider***



These critical decision-making factors, identified through an extensive literature review, include population, data, and resource characteristics (Courtney & Craven).

To identify articles on EDC, in spring 2004 we searched the databases MEDLINE, CINAHL, Compendex, and Dissertation Abstracts. Our article-retrieval search strategy comprised keywords, controlled terminology terms, and hand searches. Of the 205 articles identified, 71 entailed the use of EDC in research studies. We reviewed those 71 publications and found that 43 reported evidence-supported findings, 14 were review or concept articles, and 14 were technical or design descriptions.[1] The findings are presented in relation to each factor (i.e., population, data, and resource characteristics) that should be considered in decision-making on data-collection methods.

Population

To determine whether an EDC method is suitable for a proposed project, the researcher must take into account the characteristics of the study population. In the United States there is a potential for sampling bias when EDC methods are used, because only 63% of the population is online (Madden, 2003). Researchers must evaluate access to technology

---

[1] A full bibliography is available upon request.

in relation to the following key population factors: age, gender, socioeconomic status, and race and ethnicity.

Age

Age is an important consideration for methods involving use of e-mail and the Internet, because the majority of those online are young (Greenspan, 2003). Of Internet users in the United States, 61 million are between the ages of 25 and 49 (Greenspan); 87% of youths between the ages of 12 and 17 are Internet users (Lenhart, 2005). Researchers, however, must revisit this generalization regularly, because the demographics of Internet users are changing. One of the fastest-growing segments of Internet users is seniors (those aged 65 and over). Between 2000 and 2004 the number of Internet-using seniors increased by 47% (Fox, 2004); eight million seniors, or 22%, are currently online (Fox). In fact, projections are that 65% of adults aged 50 to 65 and 37% of those over 65 will be online by 2006, so in the future these populations might be more accessible via EDC methods (Greenspan). The use of EDC methods has been successfully demonstrated across the lifespan. These methods have been used with children as young as 8 (Palermo, Valenzuela, & Stork, 2004) and adults as old as 75 (Chang, 2004).

Gender

Although gender is a population characteristic worth considering, data suggest that it is not necessarily a factor in use of electronic methods involving the Internet. Contrary to perceptions that the typical Internet user is male, female users make up more than half (51%) of all Internet users, and their numbers are increasing (Madden, 2003). Despite the difference in the online activities pursued by each gender, researchers have not noted a gender bias in participant recruitment for studies using EDC (Pryor et al., 2002). In their university-campus survey on a conjunctivitis outbreak, Pryor et al. found that Web-based methodology yielded a more representative sample of the campus population than a paper-based survey.

Socio-economic Status

Decisions on data-collection methodology should also include the socioeconomic status of the target population. In terms of Internet-based tools, on a typical day only 37% of US households with an annual income of less than $30,000 are likely to send an e-mail — the most common online activity — compared to 58% of households with a annual income of more than $75,000 (Madden, 2003). A population's level of education also affects online activities: "For example, while 39% of high school graduates were sending e-mail on a typical day in

December 2002, 61% of college graduates were doing so" (Madden, p. 10). Area of residence is another socio-economic factor to consider; only 52% of rural dwellers use the Internet, compared to 66% of suburban and 67% of urban dwellers (Bell, Reddy, & Rainie, 2004).

Race and Ethnicity

Race and ethnicity are potential social factors to consider. Persons with non-white heritage participate in Internet activities less than their white counterparts. In one study, 51% of African-Americans and 62% of English-speaking Hispanics said they were online (Madden, 2003).

Online growth rates are changing for persons with different demographic characteristics. Such factors might be less critical to consider in future decision-making on data-collection methods.

Data

The nature of the data to be collected is another critical concern when choosing a collection method. Data factors that influence this decision include sensitivity of the topic, time sensitivity, longitudinal data, and contextual data.

Sensitivity of the Topic

Prior research indicates that sensitive topics such as intimate-partner violence, substance abuse, psychological state, and sexual behaviour lend themselves to EDC especially well (Buchanan & Smith, 1999; Rhodes, Lauderdale, He, Howes, & Levison, 2002; Turner et al., 1998). For example, researchers have found that electronic screening via a laptop computer can be more effective in identifying potential victims and perpetrators of domestic abuse than face-to-face clinician evaluations (Rhodes et al.). In a study of adolescent male sexual behaviour, illegal substance use, and violence, Turner et al. found substantial differences in highly sensitive data reporting when comparing personal computer-based and traditional paper-based self-administered questionnaires: male adolescents reporting electronically were more likely to report sex with a prostitute (Odds Ratio [OR] 4.24, $p < 0.001$) and specific male-male sexual behaviours (OR ranging from 2.25 to 7.85, $p < 0.05$).

Any discussion of sensitive-topic research must examine the trustworthiness of the data. A number of EDC studies have noted increased sensitive-behaviour reporting, decreased self-revelation, and social desirability bias, which are components of the concept of data trustworthiness (Buchanan & Smith, 1999; Joinson, 1999; Rhodes et al., 2002; Turner et al., 1998). Few studies, however, explicitly acknowledge receiving falsified responses or identities (Cronk & West, 2002; O'Neil, Penrod, &

Bornstein, 2003). EDC methods, subject to some of the same trustworthiness issues as paper-based methods, provide the researcher with additional mechanisms for protecting data integrity. Examples of such safeguards include checking timestamps to verify data-collection time, using cookies in Web-based applications to track the number of responses from one computer, and presenting one question at a time to limit answer changing.

Time Sensitivity

The Internet's relative accessibility to participants makes it a valuable tool for studies that rely on timeliness of data reporting. Likewise, rapid and timely data reporting increases when participants carry data-collection devices with them. As wireless access in a community increases and more people own ever-smaller portable devices such as handheld computers or personal digital assistants (PDAs) and smart phones, more rapid data collection will be possible. For instance, in a conjunctivitis-outbreak study at a university, the speed of electronic methods not only permitted rapid data collection but also allowed clinicians to respond quickly to the local public health crisis (Pryor et al., 2002).

Longitudinal Data

EDC lends itself to longitudinal data collection. In studies of chronic health conditions that require frequent and longitudinal data collection, participants reporting via electronic diaries demonstrated increased compliance. For example, in a study monitoring chronic pain, participants reporting via handheld computers were more compliant in reporting at prescribed intervals, despite a much more stringent definition of compliance for this electronic group, than the paper-based comparison group (Jamison et al., 2001).

Contextual Data

For some research, context is an essential component of data collection. This is especially true for qualitative research. Context is a set of personal, environmental, and socio-cultural factors in which an experience is nested in daily life (Hinds, Chaves, & Cypess, 1992). Collection of contextual data relies on observation and self-reporting. The potential for bias in self-reporting limits the applicability of EDC methods for contextual data without observational confirmation. If a proposed study depends heavily on contextual analysis, non-electronic data-collection methods such as face-to-face interviews or focus groups might be more appropriate. As video phones, Web cameras, and high-speed Internet access proliferate, the potential for the electronic collection of high-quality contextual data will increase.

Resource Characteristics

The availability of resources, always a consideration in planning research studies, is particularly significant in decision-making on electronic data collection. For EDC, it is important that the researcher assesses three types of resources: financial, time, and technological.

Financial Resources

Many studies that compare electronic and traditional data-collection methods focus on the issue of cost. Each study, however, defines cost in a different way, so each reaches a variety of conclusions about the relative costs of electronic and traditional collection methods. Despite these differences, researchers can make some generalizations regarding financial resources. Investigators must consider the technological cost of conducting electronic studies. For example, will the proposed study require the purchase of additional hardware or software? Note that EDC methods usually save personnel time spent on data entry and data cleaning, thereby increasing the speed of data analysis as well. Depending on the nature of the data collected, the personnel cost savings might outweigh the technological outlay.

Electronic surveys can offer considerable additional delivery and response savings in comparison to postal surveys (Raziano, Jayadevappa, Valenzuela, Weiner, & Lavizzo-Mourey, 2001; Schleyer & Forrest, 2000). In the Raziano et al. study, "the cost comparison showed that the average cost was $7.70 for the e-mail group, compared to $10.50 per response for the conventional group." In their study with dental professionals, Schleyer and Forrest's Web-based survey cost $1,916, while a comparable mail-based survey would have cost an estimated $3,092.

Time Resources

Researchers should evaluate time as a resource when selecting a data-collection method. As noted earlier, several studies have demonstrated more rapid data collection using electronic methods. Surveys deployed electronically can reach recipients and be returned more quickly than surveys relying on traditional mail (Raziano et al., 2001; Schleyer & Forrest, 2000). Also, electronic data usually do not require additional transcription and can often be imported directly into statistical-analysis software. Extensive time spent in data collection, especially in studies that require multiple responses from participants over time, is a burden for both participants and investigators.

Technological Resources

As with financial and time resources, technological expertise available to researchers must be weighed in data-collection decisions (Moloney, Dietrich, Strickland, & Myerburg, 2003). Investigators lacking technological resources might find that time and money saved through EDC methods are offset by time and money spent recruiting and paying technological consultants.

Data output from commercial online services must often be manipulated into a useable format. Such transformation requires additional technological savvy. The researcher must be technologically competent in the service selected. For example, if the research will be using the communications of a virtual community, the researchers must be able to confidently use the communications software in their interactions with the virtual community (Moloney et al., 2003).

Conclusions

It would be nice if the EDC points discussed above were reducible to a tidy guideline detailing which data-collection method to use for which type of research question. There are too many scenarios in which such a prescriptive approach might overlook important considerations and guide researchers to inappropriate decisions. Researchers can instead use the population/data/resources decision factors to weigh the advantages and disadvantages and arrive at the optimal choice — likely a compromise — given the particular resources and priorities of the research setting.

The main population factors to consider in decisions about data-collection methods in relation to technological access are age, gender, socio-economic status, and race and ethnicity. The lower likelihood of some groups to be online — seniors, those without a college education, those with an annual household income below $30,000, and, to some extent, rural dwellers and non-white persons — can affect the representativeness of a sample participating in EDC. Online demographics are changing; access to these groups via e-mail and the Internet will likely increase.

Data-collection factors to consider in decision-making are sensitivity of the topic, time sensitivity, longitudinal data, and contextual data. Electronic methods consistently result in greater participant compliance than paper-based methods for longitudinal health data, especially when participants must report frequently. Participants tend to be more self-revelatory about sensitive subjects when reporting electronically. The question remains whether this holds true when the electronic method involves Internet use in a public place. For research relying on contextual data, however, traditional methods remain more effective; this might change as wireless technology improves.

Key factors to assess in data-collection decisions are financial, time, and technical resources. Electronic methods often result in savings of time and money, compared to traditional methods, especially in the data-entry and data-cleaning phases of research and for surveys. Researchers must evaluate their technical infrastructure for available hardware, software, and expertise in order to make an accurate feasibility/cost comparison of data-collection methods.

Technology and demographics will continue to change and to affect data-collection methods and possibilities. By examining the key factors — population, nature of the data, and resources — the investigator will be able to make a data-collection decision based on the research endeavour.

References

Bell, P., Reddy, P., & Rainie, L. (2004). Rural areas and the Internet. *Pew Internet and American Life Project*. Retrieved July 17, 2004, from http://www.pewinternet.org/pdfs/PIP_Rural_Report.pdf

Buchanan, T., & Smith, J. L. (1999). Using the Internet for psychological research: Personality testing on the World Wide Web. *British Journal of Psychology, 90,* 125–144.

Chang, B. L. (2004). Internet interventions for community elders: Process and feasibility. *Western Journal of Nursing Research, 26*(4), 461–466.

Courtney, K. L., & Craven, C. K. (2004, May 21). *Electronic data collection: Advantages and disadvantages*. Paper presented at the American Nursing Informatics Association Spring Conference, New Orleans.

Cronk, B. C., & West, J. L. (2002). Personality research on the Internet: A comparison of Web-based and traditional instruments in take-home and in-class settings. *Behavior Research Methods, Instruments, and Computers, 34*(2), 177–180.

Fox, S. (2004). Older Americans and the Internet. *Pew Internet and American Life Project*. Retrieved July 17, 2004, from http://www.pewinternet.org/pdfs/PIP_Seniors_Online_2004.pdf

Greenspan, R. (2003, November 20). *Senior surfing surges*. Retrieved July 17, 2004, from http://www.clickz.com/stats/big_picture/demographics/article.php/3111871

Hinds, P. S., Chaves, D. E., & Cypess, S. M. (1992). Context as a source of meaning and understanding. *Qualitative Health Research, 2,* 61–74.

Jamison, R. N., Raymond, S. A., Levine, J. G., Slawsby, E. A., Nedeljkovic, S. S., & Katz, N. P. (2001). Electronic diaries for monitoring chronic pain: 1-year validation study. *Pain, 91,* 277–285.

Joinson, A. (1999). Social desirability, anonymity and Internet-based questionnaires. *Behavior Research Methods, Instruments, and Computers, 31*(3), 433–438.

Lenhart, A. (2005). Protecting teens online. *Pew Internet and American Life Project.* Retrieved June 4, 2005, from http://www.pewinternet.org/PPF/r/152/report_display.asp

Madden, M. (2003). America's online pursuits: The changing picture of who's online and what they do. *Pew Internet and American Life Project.* Retrieved July

16, 2004, from http://www.pewinternet.org/pdfs/PIP_Online_Pursuits_Final.PDF

Moloney, M. F., Dietrich, A. S., Strickland, O., & Myerburg, S. (2003). Using Internet discussion boards as virtual focus groups. *Advances in Nursing Science, 26*(4), 274–286.

O'Neil, K. M., Penrod, S. D., & Bornstein, B. H. (2003). Web-based research: Methodological variables' effects on dropout and sample characteristics. *Behavior Research Methods, Instruments, and Computers, 35*(2), 217–226.

Palermo, T. M., Valenzuela, D., & Stork, P. P. (2004). A randomized trial of electronic versus paper pain diaries in children: Impact on compliance, accuracy and acceptability. *Pain, 107,* 213–219.

Pryor, J. H., Martin, M. T., Whitney, C. G., Turco, J. H., Baumgartner, Y. Y., & Zegans, M. E. (2002). Rapid response to a conjunctivitis outbreak: The use of technology to leverage information. *Journal of American College Health, 50*(6), 267–271.

Raziano, D. B., Jayadevappa, R., Valenzuela, D., Weiner, M., & Lavizzo-Mourey, R. (2001). E-mail versus conventional postal mail survey of geriatric chiefs. *Gerontologist, 41*(6), 799–804.

Rhodes, K., Lauderdale, D., He, T., Howes, D., & Levison, W. (2002). "Between me and the computer": Increased detection of intimate partner violence using a computer questionnaire. *Annals of Emergency Medicine, 40*(5), 476–484.

Schleyer, T. K. L., & Forrest, J. L. (2000). Methods for the design and administration of Web-based surveys. *Journal of the American Medical Informatics Association, 7,* 416–425.

Turner, C. F., Ku, L., Rogers, S. M., Lindberg, L. D., Pleck, J. H., & Somenstein, F. L. (1998). Adolescent sexual behavior, drug use, and violence: Increased reporting with computer survey technology. *Science, 280*(5365), 867–873.

Authors' Note

This work was supported in part by National Library of Medicine Biomedical and Health Informatics Research Training Grant T15-LM07089-14.

Comments or queries may be directed to Karen L. Courtney, 324 Clark Hall, Columbia, Missouri 65211 USA. Telephone: 573-882-1625. Fax: 573-882-6158. E-mail: CourtneyKL@health.missouri.edu

---

Karen L. Courtney, RN, MSN, is National Library of Medicine Pre-doctoral Informatics Fellow, University of Missouri – Columbia, United States. Catherine K. Craven, MLS, is National Library of Medicine Informatics Research Fellow, University of Missouri – Columbia.

CJNR 2005, Vol. 37 Nº 3, 161–165

Happenings

Skills Enhancement: Strengthening Public Health Practice in Canada

Carla Troy, Joan Reiter, and Jennifer Lowe

Public health in Canada has recently had intense media attention related to such threats as SARS, avian flu, a potential flu pandemic, contaminated drinking water in Walkerton, Ontario, and North Battleford, Saskatchewan, and preventable chronic conditions including heart disease, cancer, diabetes, and obesity. These issues have highlighted the importance of public health and the need to strengthen the Canadian public health system. There are resounding calls for a renewal of public health in order to build capacity in the Canadian public health workforce (Underwood, 2004). In addition to the concerns expressed in the mass media and in policy reports, federal/provincial/territorial committees and professional organizations are recommending a strengthening of public health systems locally, provincially, and nationally (Campbell, 2004; National Advisory Committee on SARS and Public Health, 2003; Ontario Expert Panel on SARS and Infectious Disease Control, 2004). The Public Health Agency of Canada has been established to strengthen the system nationally. Fundamental to the development of public health capacity is an adequate supply of public health professionals with the knowledge, skills, abilities, and supports to do their jobs (National Advisory Committee on SARS and Public Health; Underwood).

As a leader in public health, the Public Health Agency of Canada, through its online continuing education program, Skills Enhancement for Public Health, offers public health practitioners across Canada an opportunity to develop the skills necessary to carry out effective public health and health surveillance. The application of these skills will result in sound evidence-based decision-making and planning to protect and maintain the health of the public.

What Is the Skills Enhancement for Public Health Program?

The Skills Enhancement program offers continuing education opportunities for Canadian public health practitioners, including public health nurses, inspectors/environmental health officers, nutritionists, health promoters, program managers, and dental hygienists. Its aim is to help practitioners increase their skills in epidemiology, surveillance, information management, needs-based planning, and surveillance database and tool use.

The format is a series of online modules in both English and French. The content is relevant, timely, and specific to Canadian public health. This online distance program is flexible and more affordable than traditional continuing education programs.

Currently five modules are available. A mandatory *Orientation to Online Learning Module* serves as an introduction to the Web-based environment and online learning. Other modules are as follows:

Module 1: Basic Epidemiological Concepts — historical development of epidemiology, use of epidemiology in public health, causation, association, epidemiological triad, surveillance, and ethics

Module 2: Measurement of Health Status — frequency, rates, proportions, ratios, incidence, prevalence, and sources of data

Module 3: Descriptive Epidemiological Methods — study design, confounders, descriptive epidemiology, and basic outbreak investigation

Module 4: Epidemiology of Chronic Diseases — overview of chronic diseases, methods and tools used in chronic disease epidemiology, data sources, the burden and impact of chronic diseases, common risk factors, and control and prevention measures

Learners are placed on a team of 12 to 15 public health practitioners from across Canada. They have access to an online facilitator who is an experienced frontline public health practitioner with content and facilitation training. Facilitators are available to answer content-related questions, encourage discussion, provide feedback on exercises, and guide learners through the material. There are a variety of mechanisms to support the facilitators, including an online training module, a facilitator's Web site, technical and administrative support, face-to-face workshops, and resources on best practices.

A number of modules are currently being developed. The following will soon be available:

Introduction to Surveillance
Outbreak Investigation and Management

Other modules under development include the following:

Basic Biostatistics
Survey Methods
Principles and Practices of Public Health

Introduction to Information Management
Communicating Data Effectively
Applied Epidemiology: Injuries
Evidence-Based Planning

The Skills Enhancement for Public Health program serves to strengthen the Canadian public health system by focusing on increasing public health skills overall, including prevention and health promotion. Future modules will be based on broad public health core competencies that will influence and define future public health research, policy, education, and practice.

Enrolment in the program has been increasing steadily. Since the launch of the first module in May 2002, over 1,500 frontline public health practitioners from across Canada have taken one or more of the modules. More than half of the learners have been nurses: public health nurses, community health nurses, clinical nurse specialists, and program managers.

What Are the Benefits?

Participation in the Skills Enhancement for Public Health program offers benefits to both the learners and their organizations. Learners increase their surveillance and public health expertise and become more confident in their evidence-based decision-making abilities. They have access to a wider range of information and resources, including Help Desk support for technical assistance and online facilitator support for content-related issues. Learners enhance their skills in critical thinking, use of data, computing, and online application and their opportunities to network with colleagues across Canada. The course is flexible and accessible: all that is required is an Internet connection and a browser. Learners who complete the modules receive a certificate from the Public Health Agency of Canada. The program has been endorsed by numerous organizations, including the Canadian Public Health Association, the Community Health Nurses Association of Canada, and the Royal College of Physicians and Surgeons. The Skills Enhancement for Public Health program is working with universities across the country to develop strategies to support postsecondary studies in public health at both the graduate and undergraduate levels.

Well-trained staff members are obviously of great benefit to their employers. The module content equips employees with basic public health tools, as well as enhancing their skills in using data and data sources to interpret the health status of the community. Organizations benefit from staff with superior decision-making and planning abilities and with a basic understanding of epidemiology and surveillance principles as well as public health concepts. Participation in the program is central to the creation of a network of trained personnel and to the building of public health human resource capacity.

The benefits for facilitators are numerous, including an opportunity to network with their counterparts from across Canada and learn new concepts and skills in online facilitation and Web-based learning.

The high quality of this program is a result of partnerships developed between several universities and key public health organizations across Canada. These include the Canadian Public Health Association; the Canadian Nurses Association; the Community Health Nurses Association of Canada; the Ontario Public Health Association; Public Health Research, Education and Development (in Ontario); the Canadian Institute of Public Health Inspectors; the Alberta Dental Hygienists' Association; and provincial epidemiology associations in Ontario and Saskatchewan.

Resources

Several resources are available to help public health departments and health authorities create supportive environments for this continuing education initiative:

The Art and Science of Evidence-Based Decision Making: http://www.phac-aspc.gc.ca/csc-ccs/pdf/epidemiology_e.pdf

Towards Effective Community-Based Action: Using Epidemiological Skills in Public Health Surveillance for Local Public Health Practice: http://www.phac-aspc.gc.ca/csc-ccs/sehs-acss/esphs_e.html

Practical Tips for Implementation of the Skills Enhancement for Health Surveillance Modules: A Handbook for Frontline Managers and Administrators (available upon request)

Putting Skills into Practice: Factors Influencing Individual and Organizational Change (available upon request)

How to Negotiate Time with Your Employer to Participate in the Skills Enhancement for Health Surveillance Modules: http://www.phac-aspc.gc.ca/csc-ccs/sehs-acss/esphs_e.html

Health Surveillance: An Important Tool to Protect and Promote the Health of the Public (under development)

Nurturing Change and New Ways of Learning in Canada's Public Health System (under development)

As in other health-related fields, knowledge and practices in the field of nursing are continually evolving. As the burden of public health threats in Canada increases, nurse clinicians, administrators, researchers, and academics will be required to increase their skill sets and knowledge base accordingly. The acquisition and use of health information is critical to all domains of nursing. The Skills Enhancement for Public Health program is one tool to help public health professionals become expert in and use health information.

More information can be found on the program's Web site: http://healthsurv.net/skills. The Skills Enhancement for Public Health program can be contacted at health_surveillance@phac-aspc.gc.ca or 1-877-430-9995 (toll free).

References

Campbell, J. A. (2004). *SARS and public health in Ontario.* Toronto: Ministry of Health and Long-Term Care.

National Advisory Committee on SARS and Public Health. (2003). *Learning from SARS: Renewal of public health in Canada.* Ottawa: Health Canada.

Ontario Expert Panel on SARS and Infectious Disease Control. (2004). *For the public's health: A plan of action.* Toronto: Ministry of Health and Long-Term Care.

Underwood, J. (2004). Core competencies for public health. *Community Health Nurses Association of Canada National Headlines, 6*(3), 4–5.

Authors' Note

We would like to acknowledge the contribution of Elizabeth Wright, Epidemiologist, Public Health Agency of Canada, in reviewing this article.

Carla Troy, RN, BEd, MHSc, is National Manager, Skills Enhancement for Public Health, Public Health Agency of Canada, Ottawa, Ontario, Canada. Joan Reiter, RN, BScN, MBA, is a Regional Coordinator and Jennifer Lowe, RN, BNSc, MSc, is National Partnership and Evaluation Coordinator, Skills Enhancement for Public Health.

Book Reviews

Long-Term Care: Managing Across the Continuum, 2nd Edition

John R. Pratt
Sudbury, MA: Jones & Bartlett, 2004. 482 pp.
ISBN 0-76-373186-2

Reviewed by Carol Common

Long-term care is coming out of its hidden corner and taking a more prominent and proactive role in the health-care system. This is the theme of *Long-Term Care: Managing Across the Continuum.* While the book's main target readership is current and future administrators in long-term care, it will be useful reading for any health-care professional who deals with aspects of long-term care and wishes to be more informed about it — that is, anyone whose clientele includes persons who are elderly or handicapped.

The book deals with the themes of management and administration. It is also American and, since the issues of administration are often related to the environmental context, such topics as funding, regulations, competition, and market drivers may not be applicable to the single, public-payer system in Canada. Other issues, such as ethics, types of care and their philosophies, trends, and driving forces, can well cross boundaries.

The book offers a comprehensive view of the field as it exists today in the United States, including strengths and weaknesses. Pratt also describes "criteria for evaluation and design of long-term care," acknowledging that the system falls short on many of the criteria. He describes the types of long-term and supportive care for the elderly and handicapped that are included in the long-term-care system, both institutional and non-institutional. For each of these types of care, the author describes the philosophy of care; the consumers; the services provided; the market forces; issues of ownership, regulation, finances, and human resources; legal and ethical issues; management challenges; and current trends and their impact. The types of care described are: nursing facilities (institutional care for a clientele requiring both supportive and specialized care), assisted living (room and board with minimal nursing support), sub-acute care (short-stay clientele with nursing and rehabilitation needs following an acute-care hospitalization), adult day care (offering activities to promote functional autonomy and respite to home caregivers), home health care (support for activities of daily living and specialized nursing care), and hospice care (end-of-life care at home or in an institution).

Since the book's subtitle is *Managing Across the Continuum*, Pratt devotes several chapters to the issues of how long-term-care agencies relate to each other, to other health-care providers in the system, to government agencies, and to the communities they serve. Issues include competition and collaboration as well as various forms of integration among agencies. These chapters focus largely on financial issues and quality of care and, despite the American context, offer management insights that apply to other systems as well.

Other aspects of long-term care that are reviewed in the book include regulations, reimbursement structures, governance and administration, information technology, marketing and community relations, and ethical and legal issues.

The final chapters focus on future trends and actions that managers can take. These are useful and applicable to any health-care system. The trends described include the increasing proportion of elderly in the population, the drive towards more coordination among providers of health care, the variety of delivery systems (e.g., institutional versus home care), outcomes-based quality indicators, advances in information technology, and ethical choices. Pratt outlines the various strategies that managers can use to deal with issues currently impacting the system, as well as to prepare for future trends. The strategies include listening to clients, engaging in integrated care, and building a learning organization.

This book provides useful insights for senior and middle managers in health care, in particular those serving long-term-care populations.

Carol Common, N, MSc(A), is Community Outreach Senior Advisor, McGill University Health Centre, Montreal, Quebec, Canada.

Determinants of Population Health and Well-Being: Controversies and Developments

Edited by Vicente Navarro and Carles Muntaner
Amityville, NY: Baywood, 2004. 570 pp.
ISBN 0-89503-278-3 hardcover; 0-89503-279-1 softcover

Reviewed by Rebecca Hagey

This collection of articles, most having appeared in the *International Journal of Health Services,* is a valuable source of critical scholarship challenging numerous doctrines, myths, and above all policy interventions in recent decades by the World Bank, the International Monetary Fund, and the World Health Organization. The majority of the contributions report on empirical studies drawing on available databases, contesting policy based on neo-liberal ideologies about the benefits of a revived brand of economic determinism. The editors call for a concerted research agenda that builds on the evidence presented to chart public health impacts using integrated cultural, political, and economic understandings of health inequalities. Many of the contributors use such integrated understandings in their critiques. For example, the Nobel laureate for economics Amartya Sen offers a thesis on the relation of democracy and freedom affecting women's reproductive rights and population growth. Vicente Navarro shows that such monolithic concepts as democracy and freedom should be broken down into discrete "political processes" for the purpose of useful analysis. I strongly recommend this book for nursing curricula intent on modelling critical thinking and research that is explicitly argued laying out the tenets of the debate. This is a must-read for those lobbying for the creation of primary health-care infrastructure.

Determinants of Population Health and Well-Being has seven sections. The section on social policy argues for "social democratic policies as the means to reverse the negative impact of growing economic inequality" (p. 11) and includes, for example, Sen's response to Navarro's critique for the reader to weigh. Readers get a clear articulation of the policy reforms that have been introduced under neo-liberalism as well as crisp examples of their impacts on health, such as the consequences for those with chronic illness. Re-entry into employment for the chronically ill is shown to be much more successful in Sweden than in the United Kingdom, which has loosened its regulation of the labour market, reduced the power of unions, reduced the income of the unemployed to prod them to work, and reduced employers' hiring costs. Moreover, the chapter titled "Cross-National Income Inequality" shows that the incomes of low-income Swedes are 24% higher than those of low-income Americans, while American low-income families are better off than those in the United Kingdom.

"Economic Growth, Inequality and the Poor" tests the idea from trickle-down theory that "we can accept higher inequalities providing that those inequalities benefit the worse-off" (p. 61). Member states of the Organization for Economic Cooperation and Development in 1991 (Australia, the United States, Canada, and European countries) showed associations between inequality and economic growth to be negligible, indicating that factors other than inequality explain successful economic performance. The data suggest, in contradiction to trickle-down theory, that "the more equal the income distribution, the better the absolute position of the poor" (p. 58). The author cites studies indicating that poverty is associated more with socio-political factors than with economic prosperity.

The collection includes chapters that deal with decreasing profitability as a predictable phase of capitalism, and the inclination towards political interventions to revive a stagnant economy such as longer hours, lower wages, deteriorating working conditions, and the movement of capital to low-wage countries with minimal enforcement of environmental standards. The section on globalization illuminates compelling political alternatives for improvements in economic and social well-being, establishing political choices as crucial for healthy public policy. Such policy can affect the life expectancy associated with income level, the co-optation of subordinate classes into workplace and community exposure to hazardous wastes, the proliferation of public-sector cutbacks, privatization, and multinational managed-care organizations.

The section on health policy challenges the World Health Organization's recent report *Health Systems: Improving Performance.* It puts to rest the assumption that "health problems our societies now face can be resolved by technological-scientific medical bullets or interventions, without reference to the social, political and economic environments in which these problems are produced" (p. 171). This section challenges "managed competition" policies, seeing them as part of a social movement that has weakened the role of the state, strengthened the role of professionals as "instruments of governmentality," and caused fragmenting of health services. It presents case studies that point to political approaches to administration that may be key to the retention of universality, transparency, accountability, and performance incentives. A case study of the "battle of tobacco" suggests that in the United Kingdom journalists deserve more credit than health practitioners for the (46%) decline in cigarette sales and the 50% reduction in deaths traceable to tobacco use (p. 204).

Evidence cited throughout the book attests to the health-care system being relatively insignificant for mortality and morbidity rates, compared to the socio-economic and political ideological factors that affect population health. The section on health care is essential reading for Canadians confronted with the shift towards a two-tier model of care. I will assign to my undergraduate nursing students the contribution by David Coburn on the historical background of medicare in Ontario. The empirical findings in this section virtually indict the weakened role of the state, privatization, and investor ownership in relation to the comparative findings on deficiencies and adverse events and their negative outcomes for quality of life and quality of care.

Given the global attack on labour unions — which is seen as a political strategy to use inequalities as a means for reversing the worldwide decline in profits — the section on occupational health and unions is important reading for health practitioners. Especially interesting is an empirical feasibility test for a workplace health promotion initiative by unions in Sweden and Finland in relation to preventing cancers, addictions, health problems related to diet and inactivity, workplace carcinogens, and so on. The reader might then turn to the report from Human Rights Watch on the escalation in violations of workers' freedoms and freedom of association among service-sector workers in the United States (pp. 345–384).

I will be using the final two sections in my graduate courses in nursing because of their vibrant treatment of current debates on structural inequalities, especially the theory, research, and ideology pertaining to gender, race, and class. Carles Muntaner and colleagues empirically test two propositions outlined in Navarro's review of the concept of social capital. These are (a) the efficacy of social capital as an indicator of population health, and (b) the significance of social class as a determinant of population health. The authors find that "social capital shows weaker associations with population health indicators than do economic inequality and working-class power" (p. 387). One study with users and non-users of community health centres found that racial and ethnic disparities did not exist among users, a finding that could be related to community health centres' "emphasis on providing ethnically and culturally competent and family centred care" (p. 461).

Most compelling for our journey in nursing to be open and learn about racist phenomena in our midst is the exchange among Nancy Kreiger, Thomas LaVeist, and Paul Stolley. While agreeing that race is an anachronistic term with no scientific basis, Kreiger and LaVeist argue that it should be refined for use in social epidemiology studies that are both biological and social. One application of this view would be for the Registered Nurses Association of Ontario to change its best practice guidelines statement on self-knowledge in relation to therapeutic relationships (www.rnao.org). The term race is included as a factor that has an influence on relationships. Given the backlash described in this section against the need for health professionals to be politically correct, I hesitate to quibble but technically it is racism that impacts on relationships. Race as an attribute of human organisms is a socially constructed concept that conceals group-based dominance. To deny self-knowledge about racism, which divides people into racialized and non-racialized individuals and groups, is consistent with the neo-liberal, individualist idea of health, as pointed out by Muntaner and Marisela Gomez (pp. 523–550). With the notion of individual responsibility, the onus is on the individual to generate healthy responses while contending with unaccounted for racial disparities and relentless intersecting determinants of social inequality.

In their summary chapter the editors remind us that social psychology, environmental science, and transformative behaviour studies will have to be integrated into research programs, in order for the social determinants of health as a discipline to realize its potential to influence policy and practice.

Rebecca Hagey, PhD, is Associate Professor, Faculty of Nursing, and Advisor to the Centre for Equity in Health and Society, University of Toronto, Ontario, Canada.