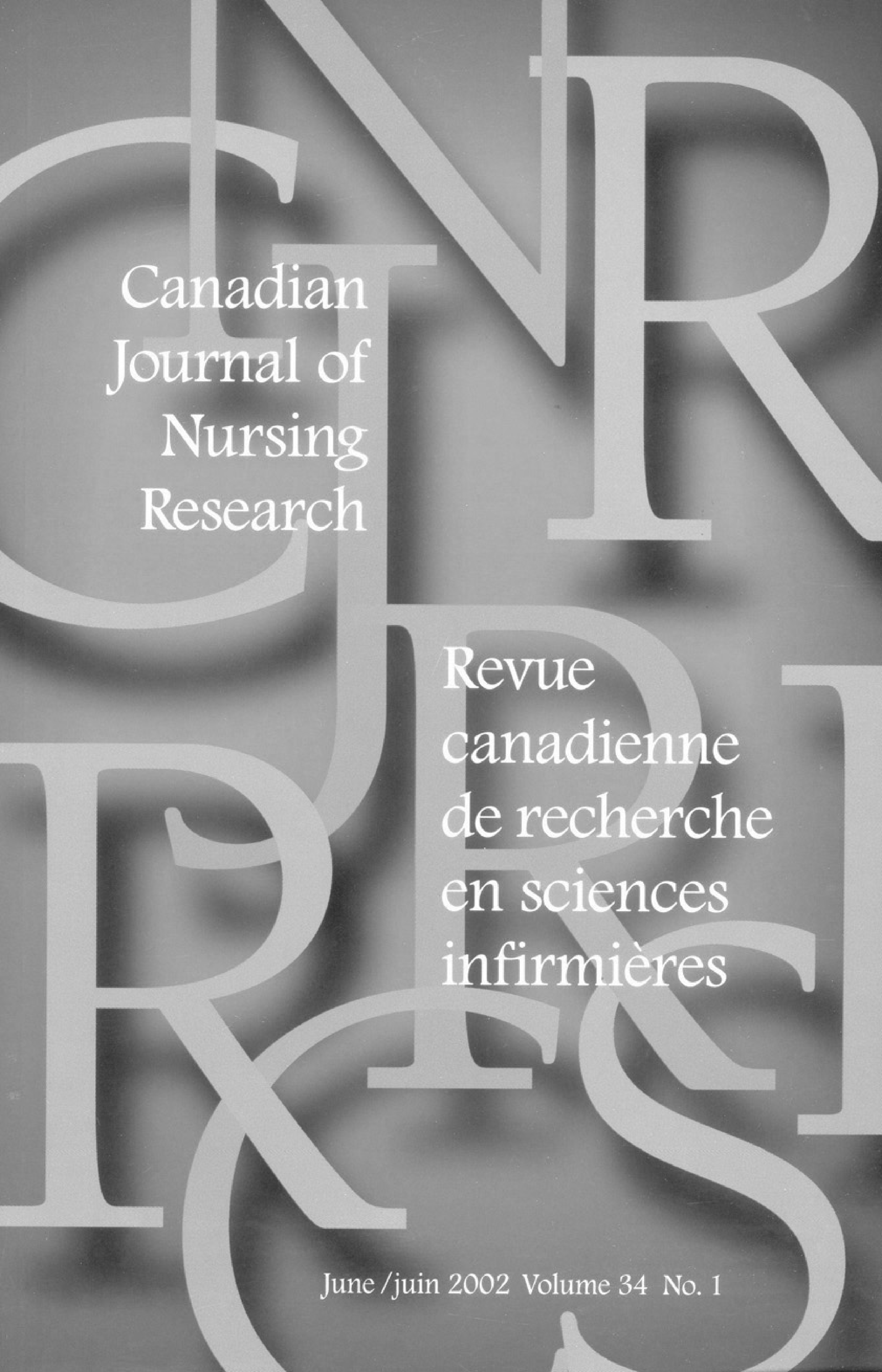

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EDITORIAL

Envisioning the Future: Nightingale Continues to Guide

A sabbatical is a wonderful thing. It provides time to rest the body and the soul, and in so doing enables the mind to revisit ideas and consider new ways of thinking.

I found myself, at the start of my sabbatical year, in London, England, the home of Florence Nightingale and the city where my daughter lives. During the past few years I had become concerned by what I perceived as the increasing "medicalization" of nursing (Gottlieb, 2000). I worried that as a society we would have a world of nurses but a world without nursing. I needed to return to the writings of Florence Nightingale for understanding, direction, and inspiration. I was not disappointed.

Nightingale provided nursing with its basic blueprint: promoting health, supporting healing, alleviating suffering, and helping people to recover from the disruptions caused by illness, disabilities, and the everyday events of life. Nursing, by working with the universal laws of nature, was "to put the patient in the best condition for nature to act upon him" (Nightingale, 1860/1969). What are these universal laws of nature? How well does nursing understand the universal laws governing health and illness and use them as a basis for nursing practice? What does society need now, and what will it need in the future? What type of knowledge does this require of nursing? These were some of the questions I grappled with as I began to work with my husband on identifying the universal laws that Nightingale referred to but never defined (Gottlieb & Gottlieb, under review).

Although every profession must re-interpret and re-think the way it fulfils its mandate in light of new scientific advances and changing societal realities, at the same time it must look to the past to ensure that it is being faithful to its basic principles and values. Continuing from Nightingale's legacy, for example, how does nursing "put the patient in the best condition for nature to act upon him"? A measure of our faithfulness to our principles and values is reflected in the choices we make and the directions we take. What does society require of nursing today, and what will it require of nursing in the future? How are we to address such needs within Nightingale's vision?

To address these questions, I first needed to envision where nursing would be going, and I turned to the past for direction. The names of Lillian Wald and Margaret Sanger immediately came to mind. Recall that Lillian Wald is the mother of public health nursing and founder of visiting nurse services, and Margaret Sanger is the mother of the planned parenthood movement. Both of these nurses, working on the frontlines at the turn of the 20th century, bore witness to the effects of the Industrial Revolution on individual and family lives. They understood the human condition and nursing's contract with society. I believe that today, similarly, nursing needs to find its role at the interface between societal changes and how they impact on people's lives. It requires nurses to have an understanding of its own mandate in society, coupled with a thorough knowledge of the human condition in health and illness (i.e., Nightingale's universal laws) and an ability to effect change.

If I am correct and these *are* the conditions for nursing to flourish, then the present is a fertile time for nursing. Many have compared the technological revolution to the Industrial Revolution in its sweeping effects on society. The nature and rapidity of the current changes brought about by technology and in response to technology are resulting in a world that is, for many, overwhelming, stressful, and taxing beyond the limits which nature intended. We have only to look around us to see the direct and indirect effects of this new revolution: unprecedented increases in mental illness, physical breakdown, violence, and burnout. What is the role of nursing in helping people to deal with the effects of technology on their lives? What is our role as nurses in promoting health and preventing disease and breakdown, using technology but not substituting technology for care?

Insight into these roles was recently heightened for me when my twin sister was diagnosed, during a routine mammogram, with a second breast cancer in 9 years. The advances in mammography in the intervening years have produced a machine that is more sensitive in detecting early changes in breast tissue. Radio Frequency Ablation (RFA), an experimental procedure to eradicate tumours, will, it is hoped, provide a less invasive method for treating breast cancer. Although technology has transformed the way my sister's cancer was diagnosed and temporarily treated, the news of the cancer was more devastating and overwhelming than it had been 9 years earlier. Unlike the first time, however, she was fortunate to be cared for by an outstanding nurse-practitioner who understood how to nurse her. This nurse spent hours with my sister, getting to know her and her many concerns. With this knowledge, the nurse navigated the system and coordinated my sister's treatment so that she could attend the graduations of her two daughters, explained how the new technologies worked, and had everything in place within a few days of diagnosis. Moreover, knowing that this knowledgeable and skilled nurse could be reached 24 hours a day to address a broad range of issues, from physiological and psychosocial concerns to medical treatments to family needs, has been extremely reassuring to my sister. The nurse prevented unnecessary delays in treatment, alleviated my sister's anxiety — which might have exacerbated her mental and physical condition — and enabled her to regain control. This nurse has clearly honoured Nightingale by creating the conditions to support healing.

Clearly, in this age of increasing technological advances, we need the compassionate and knowledgeable services of nursing more than ever before. Ironically, with the new advances in technology we now have ways of measuring the efficacy of nursing acts, acts that until now have been devalued and minimized. For example, technology can now be used to demonstrate that when nurses provide comfort or stay with patients during periods of vulnerability they significantly affect a person's immunological system. Nursing is beginning to integrate these new technologies into its research, and must continue to do so. Again, Nightingale should be our guide. She understood that bringing about change required visible proof, provided in a truly persuasive form. One of Nightingale's greatest contributions was her use of statistical analysis, a novel approach in her time, to influence policy. She made the invisible visible, the trivial relevant and important to those who were in power. Nursing often hides behind "hard" indicators of impact (i.e., mortality rates) instead of tackling the "softer" outcomes of nursing care that may be just as significant to a person's health and well-being. Nursing needs to utilize the available technologies to ensure that it is heard. Advances in technology may be costly, but they may prove to be an important ally, showing that compassionate, knowledgeable, and skilled nursing is what society requires of us now and in a future world transformed by technology.

Laurie N. Gottlieb
Editor

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LETTER TO THE EDITOR

In her paper "Knowledge in Nursing: Contemplating Life Experience," Will (2001) presents and comments on some of my (Kikuchi, 1992) published ideas. She states:

> Kikuchi (1992)...suggest[s] that it is only the body of nursing knowledge that members of the profession are responsible for developing. She dismisses what she calls preclinical knowledge as taken on assumption and outside the discipline. And she dismisses personal knowledge as subjective, incommunicable and *publicly unverifiable*.... Kikuchi's articulate argument against knowledge gained outside the discipline is a powerful barrier to explicit articulation of life-informed knowledge. (p. 111)
>
> Life-informed knowledge is precisely what Kikuchi (1992) argues against. It is knowledge that is intensely personal, private, and subjective... It is knowledge acquired during a lifetime of non-clinical as well as clinical experience, a well-established personal ontology. We cannot disregard it, and it is naive to suggest that we can. (p. 111, 112)

In the above passages, Will omits vital related ideas set down in my paper, and therein gives the erroneous impression that I do not consider preclinical knowledge nor personal knowledge to be important, nor knowledge that nurses use in their practice. Here are my words:

> It is only the body of nursing knowledge that nursing is responsible for developing. Nursing is not responsible for developing the other kinds of knowledge nurses use, such as the preclinical and personal knowledge nurses use to do their work. By *preclinical knowledge* I mean that knowledge that nurses use or take on as assumption, which lies outside their discipline; by *personal knowledge* I mean that knowledge described by Carper (1975) as subjective, incommunicable, publicly unverifiable, and therefore not possessed by anyone other than the one whose direct knowledge it is. Indeed, how could nursing be held responsible for developing such private knowledge? (Kikuchi, 1992, p. 33)

Also, Will states, "Kikuchi (1992) argues that because a nurse's ontological and epistemological perspectives are private, subjective, and exclusively her possession, they cannot be shared, and therefore educators are not responsible for them" (p. 111). Nowhere in my publication do I express these ideas!

In conclusion, erroneous presentation of any author's ideas is problematic because it cannot be undone and expunged from the literature.

Consequently, others, unaware of the errors, may propagate them in their publications.

June F. Kikuchi, RN (ret.), PhD
Professor Emeritus, Faculty of Nursing
University of Alberta
Edmonton, Alberta, Canada

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GUEST EDITORIAL

Coping, Adaptation, and Nursing: What Is the Future?

Judith A. Ritchie

Once again, it has been a pleasure to work with Dr. Laurie Gottlieb, whose knowledge, challenging questions, and creativity contribute so much to this journal. I want to thank Joanna Toti for her skills and her patience with my particular coping strategies! As the call for manuscripts for this issue went out, I wondered what trends in coping and adaptation the manuscripts submitted would reveal. I was not disappointed. This year, all but one of the submissions used qualitative methods, and most of the manuscripts accepted for this issue elicited information from participants over at least two encounters and for as long as 2 years. The studies represented here reflect to some extent the changing knowledge base in coping and adaptation. The issues of the day in this field of research include the discoveries related to the "mind-body" connection, issues of controllability of stressful situations, and the need for innovation in research methods. In my view, nursing, as a practice discipline, should also be considering the "so what?" question: What difference will this knowledge make in our practice and in the outcomes of the people, families, and communities with whom we work?

The field of stress and coping is awash in controversy, resulting, in part, from rapid advances in science. The advances in the science of mind-body connections have major implications for nurses. With more firmly established knowledge about the determinants of health, we have become more alert to the complexity of human function. Advances in neurophysiology and brain imaging have begun to yield new insights into potential additional explanations for the variations in people's differing responses and outcomes in various situations. We have much more evidence now of the impacts of psychosocial situations and our interpretations of and responses to them on brain, immune, and other physiological functions. Huether (1996), for example, has reviewed the research bases that illustrate that the human brain is much more plastic than previously believed, the importance of early experiences and acquisition of coping strategies, and perception of controllability of events. The centrality of controllability to health outcomes was first raised as a hypothesis in the Whitehall studies (Marmot, 1994). This complexity has led to calls for interdisciplinary work in the field, and, while Lazarus (1999) has raised serious questions about the usefulness of bringing the various perspectives together, others disagree. For example, McEwen (2001) states: "The influence of the social and physical environment on the physical and mental health of individual and groups of people can only be understood by the collective efforts of many disciplines." What will be the contribution of nursing to a multidisciplinary effort in this arena? Dr. B. Gottlieb's Discourse helps us to ponder the current issues and questions in this field.

Nursing is an applied discipline that claims a holistic approach and attention to biopsychosocial and spiritual concepts. We often have opportunities for longitudinal encounters with people, their families, and their communities. Given our strengths of enabling people to learn and develop within or to find ways of changing their situation, we have much to offer the research on stress and coping. Adding the biological to our conceptualization and moving to more intervention research in this arena could bring important insights that will extend the understandings of the linkages between the meaning of stressful events, the usefulness of various types of coping strategies, and the health outcomes. Dr. K. Dracup's Designer's Corner helps us to consider the issues of broadening our designs to include biopsychosocial issues.

In relation to methods, Lazarus has for many years called for more innovative methods in the study of stress and coping. Recently, he reiterated his critique and called for studies that are more holistic in their approach, include longitudinal or prospective designs, and include additional methods, such as narratives, to enable more in-depth understandings (Lazarus, 2000). The papers in this issue represent a move in this direction. Drummond and colleagues call for more complex and multi-method approaches, in particular adding "strategic reflective narrative inquiry" to their more quantitative approaches to developing predictive models. Valkenier, Hayes, and McElheran, Kushner and Harrison, and Werezak and Stewart all used such in-depth approaches and longitudinal designs to describe or develop a conceptualization of the situation in which they are interested. Their studies provide important insights into common experiences for nurses.

The situations that are the focus of the studies presented in this issue are increasingly common. Issues of power and controllability are central to situations encountered by the participants in these studies. The findings expand our vision beyond the understandings we gain in our individual lives. They raise important questions about the potential for changing policies that often present more challenges for people rather than facilitiating their coping in difficult circumstances. In all cases, however, we need to ask what is next. How do we use this knowledge to move beyond understanding to the stage in which we are able to find ways of working with people so as to enhance their health outcomes?

The papers in this issue reflect the challenges extant in today's society in the developed world. The issues are related to living with the imbalances in power relationships both at home and at work (Kushner & Harrison), the challenges of in-home respite (Valkenier, Hayes, & McElheran), the early symptoms of dementia (Werezak & Stewart), and the challenges faced by families with young children. In all cases, controllability, the need for diverse coping strategies and resources, and, potentially, major health impacts, are relevant. The challenges in Drummond and colleagues' research program highlight the issues of the complexity of human behaviour within and across situations. It is those complexities that nurses face every day in practice. It seems clear that new and more comprehensive approaches are needed. In Canada, we are fortunate that the Canadian Institutes of Health Research present us with new opportunities for research funding in complex areas requiring multiple perspectives. Dr. D. Alcock's overview of our roles and opportunities with the Institutes provides us with some strategies to consider as we move forward. As we grapple with new approaches to research and developing new multidisciplinary teams of researchers in this area, the potential for important advances to guide our practice is great.

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Judith A. Ritchie, N, PhD, is Associate Director for Nursing Research, McGill University Health Centre, Montreal, Quebec, Canada.

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Discourse

Coping Research: The Road Ahead

Benjamin H. Gottlieb

Research and theory on the topic of coping are undergoing a period of ferment, revision, and elaboration. A number of trenchant critiques of the coping literature have appeared in the past few years, ranging from papers that document the shortcomings of coping checklists to articles that decry the irrelevance of the largely descriptive work on coping to the design of interventions for specific populations (Coyne, 1997; Coyne & Gottlieb, 1996; Lazarus, 2000; Somerfield & McCrae, 2000; Stone, Greenberg, Kennedy-Moore, & Newman, 1991; Tennen, Affleck, Armeli, & Carney, 2000). Collectively, these critiques not only call attention to the many gaps in our knowledge of the nature and effects of coping, but also communicate the disconcerting news that we may not know nearly as much as we thought we knew because of significant methodological and conceptual weaknesses that beset past research. For example, in a simple but elegant way, Stone et al. (1991) have shown that the "extent of use" response categories which appear on the Revised Ways of Coping Checklist (Lazarus & Folkman, 1984) do not make sense for many of the coping items, and that many of the coping items themselves do not make sense when they are applied to a stressor that could not possibly elicit those ways of coping. On the latter score, how could someone endorse the item "Tried to get the person responsible to change his or her mind" when the stressor does not even remotely involve other people? Hence, if there are serious problems with the metric that has been used to quantify people's employment of different ways of coping, and if there are fundamental differences among stressors in the range of applicable coping options, then there is good reason to question the meaning and validity of much of the corpus of our knowledge.

Benjamin H. Gottlieb, PhD, is Professor, Department of Psychology, University of Guelph, Ontario, Canada.

If the next 20 years yield knowledge that is more sound and useful than the knowledge generated in the past 20 years, it will be due to refinements in the very definition of coping, the conduct of more penetrating, hypothesis-driven studies of coping, the integration of knowledge about how people cope with knowledge about the individual differences they bring to the coping process, and the socialization of coping in different social systems at different points in the life course. In what follows I elaborate on each of these forecasted themes.

The Definition of Coping

At least two separate definitional issues need further attention. The first and probably most daunting task is that of distinguishing coping from the rest of human behaviour and cognition. To date, the most widely cited and accepted definition of coping places emphasis on its effortful nature, thereby distinguishing it from automatized behaviours and thoughts. According to Lazarus and Folkman (1984), effortful coping occurs early in the stress process and in response to stressful novelty, but is later superseded by less effortful and less deliberate responses that reflect the learning that has occurred through experience. The crucial element that separates coping from more reflexive or overlearned behaviour is whether or not the behaviour in question occurs in response to demands that tax or exceed the individual's resources.

In reality, however, behaviours that have been assigned to conceptually distinct compartments more often defy than conform to their assignment. Paradoxically, this is especially true in contexts characterized by chronic exposure to hardship, just the sort of contexts in which one might expect to see the more automatized behaviours that result from experiential learning. This is because chronically stressful contexts are rarely unchanging and lacking in novelty. Take, for example, the stress of family care of persons with Alzheimer's disease; there is much evidence that caregivers' stressful demands fluctuate considerably as a function of the vicissitudes of the memory and behavioural problems that plague the sufferer, the caregivers' relationships with the care recipient and other family members, the pressures associated with the use and orchestration of health and social services, and any number of stressful demands issuing from other spheres of the caregivers' lives (Pearlin, Mullan, Semple, & Skaff, 1990). There is little question that even long-term caregivers would admit that the work they do taxes their physical and psychological resources and therefore, by definition, must be considered to be coping. However, contrary to the definition of coping, the caregivers' responses are not necessarily effortful or intentional; when they tell themselves that their relative is not to blame for his/her behaviour, when they compare themselves to peers who have already lost their spouses, and when they engage in wishful thinking about the future course of the disease, they are not necessarily conscious of doing so nor effortfully engaged.

Most likely there are numerous patterns of adjustment to adversity, some marked by entirely effortful responses, some by entirely automatized responses, and some by a combination or cyclical pattern of these two types of responses. Feedback emanating from internal emotional or physiological cues, self-assessment of goal attainment, and the reactions of members of the social network are likely to determine how long different response patterns persist. The challenge is not to formulate a bullet-proof definition of coping, but to discern how people strategically expend and conserve their resources to achieve personally valued ends. To meet this challenge, both idiographic and nomothetic approaches are desirable, the former yielding knowledge about individual differences in the use and impact of coping behaviours, and the latter yielding knowledge about the extent to which there are normative stress appraisals and patterns of coping.

A second definitional issue that requires closer scrutiny is much more specific and concerns one primary axis that is often invoked to describe two contrasting coping orientations, namely approach versus avoidance coping. Numerous studies have found that the employment of such coping behaviours as denial, escape, withdrawal, and distancing is *negatively* correlated with a range of indicators of positive mental health and adjustment. On this basis, researchers have concluded that coping by behaviourally or cognitively avoiding the stressor is maladaptive.

The problem with this conclusion is that it is predicated on an analytic approach that relates discrete or isolated ways of coping to the outcomes of interest instead of examining how a combination of sequentially employed ways of coping relate to those outcomes. Take the examples of physical withdrawal or distraction from a stressor; their widely documented inverse relationship with mental health could be interpreted to mean that, as distress increases, people need a breather from the campaign in which they are engaged; they need periods of disengagement from the stressful demands in order to recover, return to baseline levels of arousal, and regain the energy needed to resume the campaign. Based on several studies of social withdrawal as a coping strategy, Repetti (1992) observes that functionally it may allow individuals to actively analyze the stressful experience and their feelings about it, and to privately formulate a new plan of attack. The point is that withdrawal is only one in a series of coping responses, and it is the series or chain of responses that should be adopted as the unit of analysis, not the isolated use of withdrawal.

More generally, misunderstanding of the adaptive value of temporary disengagement from more active coping efforts stems in part from an analytic convention that involves relating separate coping efforts to the outcomes of interest. To use a cinematic metaphor, it is as though the value and enjoyment of a film is judged on the basis of the events and dialogue occurring in each scene rather than on the basis of the unfolding flow of images, the weave of the story line, and the character development. Moreover, the tendency to define such forms of disengagement as primitive and retreatist, and even to label them with the undesirable connotation of "avoidance," confuses matters further. In short, what is missing in the analysis of coping is precisely its sequential character. Adjustment depends far less on isolated ways of coping than on the cumulative impact of a succession of cognitive and behavioural responses aimed at regaining or establishing a new equilibrium. By examining sequences of coping behaviours, we stand a better chance of learning how mental health and adjustment are related to the relative emphasis and timing of ways of coping that involve intense and energetic engagement and ways of coping that involve disengagement or withdrawal. This analytic approach is also more faithful to a process-oriented investigation of coping; it means abandoning the snapshots obtained from cross-sectional studies in favour of the moving picture yielded by short-term prospective studies. Empirically, it entails shifting to an analytic strategy of relating sequential clusters of coping behaviours to the outcomes of interest while refraining from judging the adaptive value of any single avoidant or approach behaviour.

Focusing the Research: Testing Hypotheses and Investigating Particular Types of Coping

To date, the vast majority of empirical studies of coping have been atheoretical, descriptive, and exploratory. The typical study design asks respondents to identify a current or recent stressor, usually quite global in nature, and then to complete a comprehensive coping checklist and one or more measures of mental health, role functioning, or mood. On either an a priori conceptual basis or by means of an empirical technique, the coping data are then organized into a set of dimensions, such as problem-solving, support-seeking, and avoidance, and dimensional scores are correlated with the outcomes. Studies that are submitted and accepted for publication seem to have one additional element in common: they report one or more significant correlations between the coping dimensions and the outcomes of interest. The discussion section of the paper typically offers post-hoc interpretations of these significant findings, relating them to characteristics of the stressor (e.g., controllable versus uncontrollable), characteristics of the sample (e.g., personality; education), or the stage of stressor exposure (e.g., anticipation; recovery).

These exploratory studies do little to advance our knowledge. Aside from their reliance on analyses that examine coping behaviours individually rather than sequentially, they leave us with a miscellany of disparate findings that are virtually impossible to reconcile with one another even when the studies being compared are conducted among people facing the same stressful situations (Gottlieb & Wolfe, in press). Moreover, in the absence of any theoretical model against which the findings can be evaluated, there can be little progress in our understanding of the psychological and behavioural mechanisms that distinguish adaptive from maladaptive coping in different contexts and among different samples.

A more productive route begins with one or more directional hypotheses about particular forms of coping that are likely to be more and less adaptive as a result of the psychological, social, behavioural, or emotional functions they perform in relation to the stressful encounter. These hypotheses can be derived from an analysis of the particular demands imposed by specific stressors that have particular characteristics during pre-defined temporal periods. More complex hypotheses would include potential interactions between certain personal characteristics of the sample and the focal coping behaviours. For example, an investigator could hypothesize that more extroverted people will engage in more support-seeking and social comparisons or that more conscientious people will engage in less cognitive avoidance of the stressor.

A recent study that exemplifies a clearly focused, hypothesis-driven investigation of coping was conducted with facially disfigured burn victims and limited its attention to two forms of emotion-focused coping, namely emotional venting and mental disengagement (Fauerbach et al., 2002). Drawing on Wegner's (1994) theory of ironic processes of mental control, the authors hypothesized that burn victims who dealt with aversive appearance-related thoughts by cycling back and forth between these two forms of coping would experience greater body-image dissatisfaction than burn victims who relied exclusively on one of these ways of coping or those who used neither form of coping. Wegner's theory suggests that people who engage in both forms of coping are more ambivalent about their motives and goals than those who are motivated either to suppress their feelings about their disfigurement through mental disengagement or to process those feelings through venting. Their ambivalence leads them to this cyclical pattern of emotion-focused coping, which prevents them from either completely processing or suppressing the aversive thoughts, thus perpetuating their distress.

The virtues of this study are that it informs and is informed by a motivational theory of adjustment, restricts its attention to the adaptive value of two specific forms of coping — probing the effects of their joint use versus the exclusive use of each — and examines these ways of coping in relation to a specific stressor and a specific coping period. The study's hypotheses can now be extended to other stressful domains that are likely to prompt these two forms of emotion-focused coping so that broader generalizations can be made about how they operate separately and together. The ultimate goal of studies that are structured to verify (or reject) rather than to discover patterns of relationships among specific forms of coping, specific stressors, and specific outcomes is to gradually accumulate a theoretically founded evidentiary basis for practice aimed at promoting human adaptation in the face of adversity.

A second way in which coping research could become more enlightening is by intensively examining particular modes of coping rather than sampling the entire universe of coping behaviours. When I stated earlier that we know less than we believe we know, I was referring in part to the fact that we have not delved very deeply into each of the various modes of coping in order to understand its varied forms of expression, its functions, and the personal and situational factors that condition its use. Perhaps this is due to the fact that the measurement of coping has preceded its understanding. Once batteries and checklists of coping appear, along with the standard validation work they require, researchers seem to assume that the phenomenon of interest has been fully specified. As studies using the instrument begin to appear in scholarly outlets, a cascading effect occurs, generating even greater consensus about the infallibility and utility of the measurement device. Moreover, since scholarly journals accept only papers that report significant findings, the findings themselves further buttress the instrument's credibility, leading to an exponential increase in the instrument's dissemination.

To date, only a select few modes of coping have been subjected to intensive scrutiny, but the yield has been impressive. Social comparison processes have been quite thoroughly investigated by Buunk and by Taylor (e.g., Buunk, Collins, Taylor, Van Yperen, & Dakof, 1990; Taylor, Buunk, & Aspinwall, 1990; Taylor & Lobell, 1989), coping by drawing positive meaning and benefits from adversity has been carefully researched by Affleck and Tennen (Affleck & Tennen, 1996; Affleck, Tennen, Croog, & Levine, 1987), and the delivery as well as the miscarriage of social support have been addressed by numerous investigators (e.g., Coyne & Smith, 1994; Coyne, Wortman, & Lehman, 1988; Gottlieb, 2000). However, these represent a small fraction of the many modes of coping whose forms and functions are only dimly understood.

For example, despite its high prevalence as a way of coping, the stress-relevant functions of spirituality are only now beginning to be investigated (Koenig, George, & Peterson, 1998), and its relations with other constructs such as social support, locus of control, and causal attributions are being probed. Spirituality can be the basis for a more hopeful outlook, or it can represent a way of bargaining with a higher power, or achieving a state of tranquillity through surrendering control. People who find new faith when adversity strikes may reap benefits different from those accruing to people who intensify longstanding reliance on their spiritual beliefs. Moreover, the functions of religious and spiritual experience may differ in accordance with the demands and threats that arise at different stages of the stress process. Perhaps spirituality plays an important role in sustaining morale and life quality when there are few options for exercising primary control, and performs these functions by promoting other forms of coping such as acceptance and optimism. Reliance on spirituality may also have beneficial or adverse social repercussions, either attracting the support of like-minded peers or repelling would-be supporters who view this way of coping as capitulation to the stressor and therefore believe their aid would be poorly invested. By conducting careful, programmatic studies of spirituality, coping checklist items that tap this mode of coping will come to be seen as windows that open onto a landscape containing diverse expressions and effects of spirituality. Surely, the canvas on which we portray coping must be more faithful to the richness, variety, and complexity of human adaptive strivings.

Situational, State, and Trait Influences on Coping

To date, much evidence has accumulated in support of Lazarus and Folkman's (1984) view that coping is best understood in light of the specific situational demands individuals confront at any given point in time, and in relation to their cognitive appraisals and reappraisals of these exigencies and their own resources for handling them. However, this evidence does not mean that coping is entirely determined by the interaction between objective situational factors and the cognitive appraisals that are made. In fact, in a carefully documented theoretical paper, Caspi and Moffitt (1993) have shown that personality dictates the dominant response in situations marked by a high degree of novelty, uncertainty, and ambiguity — conditions that define contextual threat. Moreover, even in less stressful contexts, stable individual differences have been found to be relatively strong predictors of adaptive outcomes, both independently and through their interaction with particular modes of coping. For example, in Affleck and Tennen's (1996) exploration of the dispositional bases for the use of benefit-finding as a way of coping, they discovered that the personality factor of extroversion was strongly associated with benefit-finding, particularly with the tendency to report that relationships improved as a result of the adversity encountered. They also found that dispositional hope was associated with benefit-finding and argue that it is also likely that people characterized by cognitive complexity engage in more of this coping strategy due to their superior ability to pursue alternative goals.

Another example of the growing recognition that coping is shaped in part by more stable dispositional variables comes from Miller's (1987) work on the distinction between a monitoring and a blunting attentional style. When exposed to a stressful event, such as an invasive medical diagnostic or treatment procedure, monitors tend to selectively seek information about threatening aspects of the event and focus on negative potential outcomes, thus magnifying the threat both cognitively and emotionally. Blunters tend to avoid threatening information and they psychologically dull threat-arousing cues. These two styles can promote contrasting coping patterns; because the monitors tend to worry more and experience more negative intrusive thoughts, they tend to engage in more avoidant coping behaviours such as denial and withdrawal. In contrast, the blunters simply tend to keep threatening information out of consciousness, and therefore engage in more distraction as a way of coping.

Since it is highly unlikely that coping responses are newly devised in each stressful encounter, it stands to reason that there are certain central tendencies that stem from people's stable perceptual styles, personality characteristics, and other dispositional assets and liabilities. These trait-like properties may narrow the range of coping responses people employ, or they may shape the appraisals and reappraisals that people make, or they may exercise both functions (Major, Richards, Cooper, Cozzarelli, & Zubek, 1998). To illustrate, self-esteem and perceived support, both relatively stable cognitions about the self and social environment respectively, may condition a less stressful primary appraisal of the stressor while also steering coping towards the use of more active problem-solving efforts and help-seeking behaviours (Holohan & Moos, 1987). In short, appraisals and coping behaviours are likely to mediate the relationship between stable dispositional variables and the outcomes of interest.

What is presently unknown, however, is the extent of correspondence among these variables, a question that is most fruitfully addressed by formulating hypotheses based on available theory. To use a relatively simple example, attachment theory predicts that people who are securely attached would differ from those insecurely attached (both ambivalent and avoidant types) by virtue of their propensity to trust and depend on others. Accordingly, securely attached people would tend to make less threatening primary appraisals of the stressor due to their sense of security about the reliability of the support they could gain, as gauged by measures of perceived support. In their coping, securely attached people would also tend to disclose their feelings and needs to others more and welcome the nurturing and guidance of others (Mikulincer, Florian, & Weller, 1993). Having benefited from the support they gained from their earliest caregiver, these securely attached people would tend to value and reinforce (through expressions of appreciation and reciprocation) the support received from their current close associates. The effect would be to prolong the receipt of support, a distinct advantage in chronically stressful contexts. This is only one example of a more general line of investigation that begins with a set of theoretical propositions about the pathways from personality and other psychological dispositions to the appraisals and coping responses that mediate the outcomes of the stress process.

The Socialization of Coping Over the Life Course

Although personality and other relatively stable individual differences play an important part in shaping the kinds of coping that people employ, the manner in which people deal with stressful events is also influenced by key members of their social networks. There are two main aspects of the social environment's influence on coping, one being the direct influence exerted by people who are in a position to constrain, sanction, or commend and shore up the individual's coping efforts as they unfold, and the other being the indirect influence that arises from exposure to associates' coping behaviours and norms relevant to coping. Relatively little is known about both of these aspects of coping's socialization.

Direct social influences on coping go far beyond support-seeking and include social behaviours and messages that communicate disapproval or approval, solidarity or disengagement, and protectiveness or indifference. To take an extreme example, if observers see someone coping in a manner that they believe is injurious to the individual's physical health, they are likely to communicate this and perhaps even advise a safer way of coping. The same applies in a more subtle way to observations of others coping in ways that are deemed to be psychologically damaging; if an associate is perceived to be coping by denying the existence of a problem or by denying the emotional distress it has occasioned, then the observers are likely to either attempt to make the individual "face up to reality" or to withdraw as a way of registering their disapproval and dealing with their own discomfort. When two individuals are confronted with a common stressor, there are likely to be reciprocal attempts to influence one another's coping behaviours. For example, in a study of parents dealing with their child's serious chronic illness, Gottlieb and Wagner (1991) recorded numerous ways in which the partners pressured one another to cope in particular ways, their principal goal being to privilege and safeguard their own ways of handling the threat they faced. Ultimately, the parents found themselves battling over the question of who employed the superior coping efforts, with the husbands championing the superiority of stoicism and the wives being forced to adopt that way of coping in order to appease their husbands and keep them involved. Whether dyadic coping takes a collaborative, complementary, or adversarial trajectory, the degree of synchrony between the parties has a substantial impact on their emotional lives and the strength of their relationship.

The indirect influences of the social network on the process and outcomes of coping are also dimly understood. A handful of studies have examined the ways in which parents socialize their children's coping, mainly concentrating on the parents' coaching strategies. But children may learn as much or more about coping by observing how their parents resolve conflicts and deal with stressful life events (Kliewer, Sandler, & Wolchik, 1994). If a child is repeatedly exposed to one parent who typically vents his emotions and blames others when stymied by stressful events, and if the child sees the other parent responding sympathetically to these coping behaviours, then the child is likely to conclude that this is an acceptable and even effective way of emotion regulation, and is more likely to emulate it in similar stressful contexts. To an extent that is yet unknown, the intergenerational transfer of maladaptive coping, including the transmission of interpersonal violence, is based on children's observations and interpretations of parental coping patterns, as well as their perceived costs and benefits. Moreover, when parents themselves suffer from impairments in their coping skills, due to substance abuse or mental illness, the children are likely to be at increased risk of learning maladaptive styles of problem-solving and emotion regulation (Chassin, Barrera, & Montgomery, 1997; Hammen, 1997).

The socialization of coping does not, however, occur exclusively within the confines of the family, in the context of the home, or during childhood. As children come into contact with peers in the classroom, on the playing fields, and in their neighbourhoods, they are exposed to a variety of models of coping. Imitative learning may be hastened by the motive to gain peer acceptance and approval, and if this is the case for children it is likely to hold for adults who enter new social systems and are eager to learn the rules of conduct and the definitions of misconduct. The process of adjusting to a new work setting requires learning about the norms that govern interactions among co-workers, between subordinates and supervisors, and between employees and their customers, clients, or patients. The socialization process also entails learning about how problems at work are addressed. Is it acceptable to disclose problems originating at home to one's manager and workmates? Can job-related difficulties be handled by calling on the resources of co-workers, or does the organization place a premium on autonomous problem-solving? Does the organization's unwritten performance evaluation grid reserve its greatest rewards for those who have the cognitive flexibility to minimize and positively reframe setbacks, or does it award its trophies to the tough realists who force recognition of the bumps and potholes in the road? Anyone who has worked in different organizations, or even in different units of the same organization, will acknowledge that there are vast differences in the norms and social climates for coping. Indeed, people take decisive action to change their jobs when they realize that they can no longer function effectively in a setting that either constrains or prohibits them from drawing on the personal and social resources they value. Employees also gravitate towards organizations that offer them a broader range of resources and greater flexibility for managing personal and job demands. Witness the evidence showing that people are willing to forego higher financial compensation and promotions in favour of greater flexibility in their schedules and access to a range of family-friendly services and benefits (Gottlieb, Kelloway, & Barham, 1998).

Conclusion

The topic of coping covers a vast landscape, but to date it has been investigated like a tourist who has time only for a helicopter excursion and therefore never gets a close-up look at the fauna and flora. Coping researchers have barely penetrated the diverse ways in which people come to terms with the alarms, transitions, and setbacks of life. This is partly owing to the fact that coping has been ill-defined, its measurement has preceded its understanding, and the contingencies affecting the forms it takes are poorly comprehended. In the future, depth should take priority over breadth, and a more dynamic process orientation should replace fruitless study of the relations between isolated bits of coping and the outcomes of interest. Instead of searching for evidence that certain strands of coping have adaptive value, we need to ask how clusters and sequences of coping foster progress towards the goals people strive to attain. To address this question, measurement will need to probe behaviours and cognitions far more deeply than can be revealed by the blunt checklist tools that have been employed to date. Measurement should also be capable of discerning how differences in the duration and intensity of coping sequences are related to the outcomes of interest, and at what cost. Although some progress has recently been made in developing more valid and ecologically sound records of daily coping and mood (e.g., Stone et al., 1998), analyses of the resulting data have not yet shifted from a single-stranded to a clustered, sequential focus.

Finally, this paper has been silent about matters related to coping interventions. This is not because there is a paucity of research on that topic but because there is such a vast distance between the descriptive literature and the information needs of clinical and community practitioners. Coping researchers rarely ask practitioners what they have learned from their observations of clients and patients, much less what practitioners need to know in order to serve their clients better. Even more disconcerting, coping researchers are rarely involved in dissecting the process through which clinical and community interventions designed by practitioners achieve their intended effects or fail to do so. This is highly regrettable, because programs that aim to improve people's problem-solving skills, augment or specialize the social support they receive, or modify their cognitions about themselves or their stressful situation offer golden opportunities for learning about the mechanisms and contingencies that govern changes in the coping process. Working alliances between those seeking to research coping and those seeking to optimize its expression and utility are likely to be mutually instructive.

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The Family Adaptation Model: Examination of Dimensions and Relations

Jane Drummond, Gerard M. Kysela, Linda McDonald, and Brenda Query

Le présent article a comme but de résumer les fondements théoriques du modèle d'adaptation de la famille (Family Adaptation Model) et de présenter les analyses qui servent à son élaboration et à son évaluation. La théorie de la résilience et ses composantes de sécurité et de vulnérabilité sont à la base du modèle en question. Les auteures présentent une analyse des données provenant de deux échantillons soumis à des techniques d'enquête et à un plan d'expérience post-test seulement. Les résultats appuient modérément les dimensions linéaires du modèle. Lorsqu'on a testé les tendances prédites par le modèle, les résultats obtenus étaient non significatifs. On s'est fondé sur les études récentes en matière d'adaptation et de recherche pour explorer le sens de ces résultats non concluants en rapport avec l'utilité avérée du modèle dans l'élaboration des approches pratiques axées sur la famille.

The purpose of this paper is to summarize the theoretical underpinnings and present the model analyses used in the development and evaluation of the Family Adaptation Model. Resilience theory, with its components of protective processes and vulnerability processes, underlies the assumptions of the model. Data analyses are presented from 2 samples in which survey methodology, post-test only experimental designs were implemented. There is moderate support for the linear dimensions of the model. When the paths predicted by the theory were tested, insignificant results were produced. Recent expert reviews of adaptation concepts and research approaches were used to explore the meaning of the null findings when testing the paths of the model in contrast to the success of the model when used to develop practice approaches with families.

Jane Drummond, PhD, is Professor and leader of the Child and Family Resilience Research Program, Faculty of Nursing, University of Alberta, Edmonton, Canada. Gerard M. Kysela, PhD, is a Child Development Specialist practising in Vancouver, British Columbia, Canada, Professor Emeritus, University of Alberta, and a former leader of the Child and Family Resilience Research Program. Linda McDonald, PhD, is Professor, Faculty of Education, University of Alberta, and a founding member of the Child and Family Resilience Research Program. Brenda Query is a PhD student in the Faculty of Nursing, University of Alberta.

The Family Adaptation Model is the product of research carried out by a multidisciplinary team at the University of Alberta. The model functions successfully to direct the development and testing of practice approaches used with families that have young children (Drummond, Kysela, McDonald, Alexander, & Shank, 1995; Drummond, Query, McDonald, Kysela, & Shank, 2002; Fleming, McDonald, & Drummond, 2001; Letourneau et al., 2001; McDonald, Kysela, Alexander, & Drummond, 1995; McDonald et al., 1997). The Family Adaptation Model is historically grounded in previous research and carries with it important theoretical considerations relevant to health professionals who work with young families. The principles of parsimony, practice utility, and empirical support have guided the choices made by the researchers during the evolution of this model.

In this manuscript the following are presented: a recounting of the assumptions underlying the model, a brief review of published data that describe the linear relations within the model, a presentation of new analyses that test causal relations hypothesized among the dimensions of the model, and a discussion of the implications for the future of this research program.

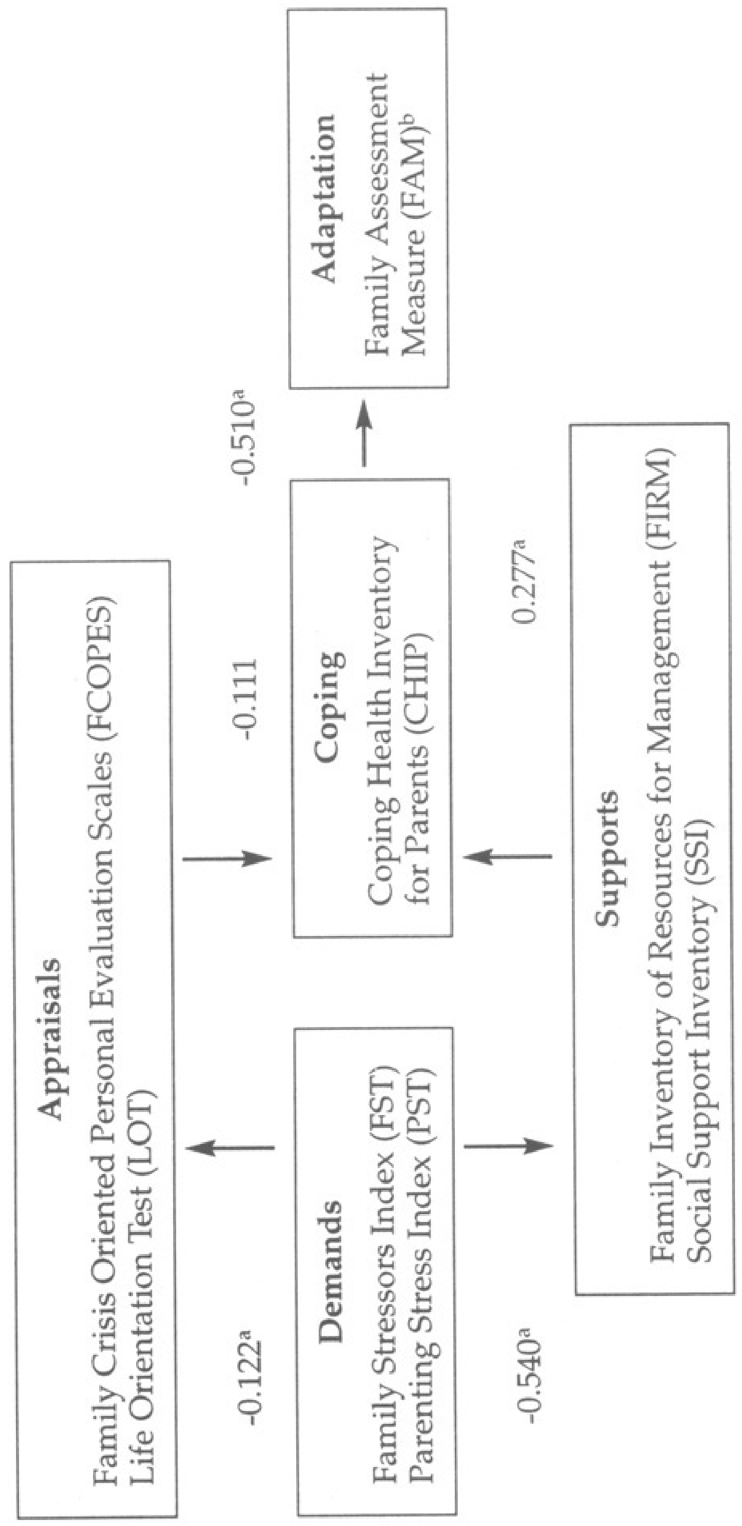
Theoretical Considerations

Concepts of resilience are foundational to the Family Adaptation Model (Drummond, Kysela, McDonald, Alexander, & Fleming, 1996/97). Recent examinations of the concept are consistent with our own. Resilience is defined as maintenance of positive adjustment under challenging life conditions (Luthar, Cicchetti, & Becker, 2000). It consists of an interaction between protective processes and vulnerability processes. This notion of resilience alerts us to the possibility that positive adjustment processes may differ according to environment (Luthar, 1999). The following two theoretical assumptions follow: family adaptation is the outcome of ongoing development and successful use of protective family processes; and the presence of vulnerability processes in family life, such as those initiated by the presence of a family member with special needs, *may* create demands on the maintenance of protective processes and/or provide opportunities for the development of more successful protective processes.

An established principle of early human development is to view the child within the context of family life (Bronfenbrenner, 1974; Dunst, Johanson, Trivette, & Hamby, 1991; McCubbin, McCubbin, Thompson, Han, & Allen, 1997). The need for a model of family adaptation that takes the unique nature of family into consideration has been historically driven by the need to move away from child-centred towards family-centred programming (Achenbach, Phares, Howell, Rauh, & Nurcombe, 1990; Barrera, Rosenbaum, & Cunningham, 1986; Belsky, 1985; Davis, & Rushton, 1991; Singer & Powers, 1993). Family functions targeted in successful family intervention programs include stress management, coping and problem-solving, parent-child interactions, and family resource building. At a minimum, any comprehensive model of family adaptation should delineate key dimensions that facilitate the inclusion of these and similar family-centred practice approaches (Murphy, Lee, Turnbull, & Turbiville, 1995). The third theoretical assumption of the Family Adaptation Model, therefore, is that the dynamic between protective and vulnerability family processes can be adequately captured in its five dimensions (adaptation, demands, appraisals, supports, and coping).

Our first conceptualization of the relations in the Family Adaptation Model is depicted in Figure 1. An ongoing process of family adaptation that includes response to demands of varying magnitude and intensity is hypothesized. Demands affect family adaptation through family coping processes. This is in keeping with the reported need for increased coping when confronted with the demands placed on the family unit by the presence of a child with special needs (Beckman, Newcomb, Frank, Brown, & Filer, 1993; Beckwith, 1990; Zeitlin & Williamson, 1988). It is also consistent with the research finding that family coping strategies are among the main predictors of resilient outcomes for children living in adverse conditions (Masten et al., 1999; Reynolds, Mavrogenes, Bezruczko, & Hagemann, 1996; Rutter, 1979). In the Family Adaptation Model, adaptation is seen as the development and maintenance of protective processes through the use of the strengths or capacities of supports (Dunst, 1993) and appraisals (Bandura, 1997; Lazarus & Folkman, 1984) to attenuate the effects of demands of the family on coping. There is one simple iterative process of family adaptation, rather than two phases that represent resilience processes and vulnerability processes separately (McCubbin & McCubbin, 1991; McCubbin et al., 1997). This emphasis on ongoing adaptation eliminates the tendency to categorize family life into the typical poles of usual/normative and reactive/ recovery. It also serves the specified need of the research team for parsimony and practicality. The purpose of the study presented here was to evaluate the adequacy of the relations among the five dimensions of the Family Adaptation Model.

Figure 1 *Dimensions of the Family Adaptation Model, Instruments Selected to Measure Them, and Path Coefficients of the First Test of the Model*



Note: chi square value = 189.52 (*df* = 44).

[a] t-value = 2

[b] FAM is scored negatively.

Family Adaptation

In the Family Adaptation Model, adaptation is conceptualized as successful implementation of six protective family processes: commitment to flexibility, coherent response to crisis, maintenance of stability, development of support, responsibility outside the home, and effective parenting (Drummond et al., 1996/97). These processes were distilled from two sources. The first was a study in which the prevalence of 16 family styles was determined in a large sample of military families (McCubbin & McCubbin, 1988). The second was a literature review commissioned by Health Canada to delineate the important resilient capacities of individuals, families, and communities (Mangham, Reid, McGrath, & Stewart, 1994). The processes and their sources are described in Table 1.

McCubbin and McCubbin (1988) found three family styles to be significant. Resilient military families are committed to a meaningful family unit that is responsive to the need for change (commitment to flexibility), have a shared sense of strong family control over life events (coherent response to crisis), and value the rhythm of family life (maintenance of stability). Resilient family capacities outlined by Mangham and colleagues (1994) could be categorized into five processes: good family coping, effective parenting, effective structure, presence of supports, and responsibilities outside the home. In our synthesis, these eight processes of family life were collapsed into six. Coherent response to crisis, development of supports, commitment to flexibility, effective parenting, and responsibilities outside the home were unique. Good family coping seemed vague and was eliminated since its attributes were contained in the remaining six resilient family processes. Maintenance of stability was common in both sources. Table 2 categorizes the attributes of the protective family processes into the appraisal, support, and coping dimensions of the Family Adaptation Model.

Dimensions of the Family Adaptation Model

Demands, appraisals, supports, and coping are easily traced to the T Double ABCX model (McCubbin & Patterson, 1981) that was an extension of Hill's (1958) classic family stress theory and the ABCX family crisis model. The dimensions continue to be represented in the more recent Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1991). Support for the dimensions is also present in the separate bodies of literature that represent each of them. A brief overview of each dimension follows.

Table 1 *Protective Family Patterns and Associated Attributes That Define Adaptation in Families*

- **Commitment to flexibility of the family unit**[a]
  - willingness to change
  - interdependent family members
  - fluid assignment of responsibilities
  - sense of efficacy
  - positive expectations for family members
- **Coherent responsiveness to crisis**[a]
  - active family problem-solving
  - cooperation among members
  - acceptance of life situations
  - sense of being in control
  - maintenance of trust and calm
- **Maintenance of stability**[a,b]
  - involvement of relatives in family activities
  - effective family structure
  - family rules and routines
  - responsibilities for all family members
  - detachment from conflict in family of origin
- **Effective parenting**[b]
  - warmth and affection
  - father involved in child care
  - positive parent-child interactions
  - secure attachment
- **Presence of supports to the family**[b]
  - supportive spousal relationships
  - strong extended-family network
  - supportive network beyond the family
  - supportive professionals
- **Responsibilities outside the home**[b]
  - employment
  - community involvement
  - extracurricular activities
  - positive school experience

[a] McCubbin & McCubbin, 1988.
[b] Mangham et al., 1994.

Table 2 *Attributes of Protective Family Processes Categorized by Mediating Dimensions of the Family Adaptation Model*

Mediating Dimension	Attributes of Protective Family Processes
Appraisal	Willingness to change Sense of efficacy Positive expectations Sense of control Maintenance of trust and calm Acceptance of life situations Detachment from conflict in family of origin Attachment
Support	Spousal relationships Extended family Network beyond the family Employment Community and school involvement Supportive professionals
Coping	Warmth and affection Active problem-solving Cooperation Responsibilities for all Positive interactions Effective rules and routines Father involved in child-rearing Community involvement Leisure and social activities Involvement in the schools

Demands are commonly conceptualized as discrete major life events or stressors (Holmes & Rahe, 1967). Another approach is to conceive demands as "daily hassles" (Delongis, Coyne, Dakof, Folkman, & Lazarus, 1982). Chronic difficulties, such as poverty, are seen as vulnerability processes (Luthar, 1999) or as an amalgam of daily stressors (Gottlieb, 1997). Pile-up of stress is also likely (McCubbin & McCubbin, 1991) and has been linked to psychiatric and physical disorders, as well as to broad adjustment and social competence difficulties (Compas, 1987). There is growing recognition that multiple risk situations are hazardous, because their effects may be multiplicative rather than simply additive. Two landmark studies highlight the phenomenon. Werner and Smith (1982) investigated the effects of perinatal stress in conjunction with aspects of environmental disadvantage such as chronic poverty, family discord, parental psychopathology, or other poor rearing conditions. Overall, rearing conditions were found to be more powerful determinants of later maladjustment than perinatal trauma. Similarly, Rutter (1979) reported on the importance of rearing conditions and identified six factors associated with developmental disorder in a large sample of 10-year-old children: severe marital distress, low social status, overcrowding or large family size, paternal criminality, maternal psychiatric disorder, and admission into care of local authorities.

The accommodations induced by demands on family life define the process of *coping* (Compas, 1987) in families. Coping has two major functions (Lazarus & Folkman, 1984). The first is instrumental and is described as problem-solving, a cognitive enterprise with behavioural components. The second, emotional regulation, consists of *appraisals* that function in the evaluation of the balance between demands and availability of resources. An overview of studies on family resources (Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Dunst, Trivette, & Deal, 1994) found that parental social *supports* have both direct and indirect positive effects on child development, family stress, and family adaptation. It is further known that families of children with special needs that utilize the resources of their social network and the community are more able to cope with daily stressors, demands, and strains (Dunst, 1993).

In our research, demands are addressed at two levels. First, families likely to be living in different vulnerable situations are studied separately through the use of different samples. Second, accumulation of daily stressors within these situations operationalizes our understanding of *demands*. In the Family Adaptation Model, as in the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1991), appraisals and supports are separated from coping. This conception serves to prompt both researchers and clinicians. For researchers, a separate appraisal dimension necessitates the search for adequate measurement of important appraisal elements such as positive reframe, sense of efficacy, and optimistic attitude. For clinicians, the presence of *appraisals* ensures that an assessment of family beliefs, values, and approaches to the presence of demands is explored and that practices supporting positive appraisal are implemented. Social *supports* are conceived as an inventory of tangible relationships and resources. Thus the *coping* dimension is a process that is largely reserved for the "cognitive and behavioural efforts" (Lazarus & Folkman, 1984, p. 141) of problem-solving or "actions that help."

Linear Relations Within the Family Adaptation Model

To date, two convenience samples of parents have participated in studies to determine whether the dimensions of the Family Adaptation Model adequately conceptualize the components of adaptation. The first sample comprises 113 families of children with special needs. The second sample comprises 57 families of children enrolled in Head Start. Self-report measures common to family-studies research with adequate psychometric properties are used. Detailed descriptions of the specific measures, their subscales, and their psychometric properties have been published elsewhere (Drummond et al., 1996/97).

Both samples of families were found to have normative adaptation in the face of significant demand. Families of children with special needs had significantly better appraisal and perceived significantly less support than the norm. With respect to the linear relations within the Family Adaptation Model, the data from both samples lent support to the notion that demands do not directly account for adaptation. It is the resilient capacity to develop supports that accounts for the variance in the adaptation of both samples. In the sample of families of children with special needs, appraisals also accounted for a smaller but significant amount of variance in adaptation (Drummond et al., 1996/97).

Causal Relations of the Family Adaptation Model

Having attained moderate support for the dimensions of the Family Adaptation Model, it was decided to examine the causal relations hypothesized by the model. The larger of the two data sets was chosen for this exercise. Because there was dependency between mothers' and fathers' responses on the self-report measures used with the 113 families of children with special needs, only mothers' data were used in these structural equation modelling analyses.

Participants

The 113 families were recruited from agencies associated with the provision of child and family preventive health-care services in the province of Alberta. The families resided in either rural or urban settings. Children with special needs between birth and 5 ½ years of age were included. A special need was defined as a delay of 12 months or greater in one domain of early development or a delay of 6 months or greater in two or more domains of early development. Young infants with any special condition that has potential for these levels of delay were included. The domains of early development evaluated included cognitive, motor, social, emotional, speech, and language development. The presence of delays was identified through the clinical judgement of professional nursing or health-care staff, parental report, formal screening procedures, or, in some cases, formal diagnostic procedures.

Measurement

Eight self-report measures represent the dimensions of the Family Adaptation Model. The measures include the Child Characteristics Domain of the Parenting Stress Index-PSI (Abidin, 1986); the Family Stressors Index-FSI (McCubbin, 1991a); the Family Inventory of Resources for Management-FIRM (McCubbin & Comeau, 1991); the Social Support Inventory-SSI (McCubbin & Thompson, 1987); the Reframing and Passive Appraisal Scales of the Family Crisis Oriented Personal Evaluation Scales-FCOPES (McCubbin, Olson, & Larson, 1991); the Life Orientation Test-LOT (Scheier & Carver, 1985); the Coping Health Inventory for Parents-CHIP (McCubbin, 1991b); and the Family Assessment Measure-FAM (Skinner, Steinhauer, & Santa Barbara, 1984). Many of these measures are designed by McCubbin and colleagues and are utilized because they address the measurement of the dimensions of the Family Adaptation Model from a family context.

Data Analysis

Correlation was used to examine the patterns of relationships among the measures representing the dimensions of the model. Multiple regression analyses were performed to predict family adaptation. These analyses are summarized above and published elsewhere (Drummond et al., 1996/97). The path analyses conducted for the Family Adaptation Model pictured in Figure 1, testing the mediating effects of appraisals, coping, and supports between demands and adaptation, are reported first.

Findings

The mothers' ages ranged from 16 to 53 years (*mean* = 30). Most mothers reported having completed high school and being largely involved as full-time caregivers (88), with 16 mothers reporting some type of current employment. The majority of the mothers were either married or in partnerships; 19 indicated that they were separated, divorced, or single.

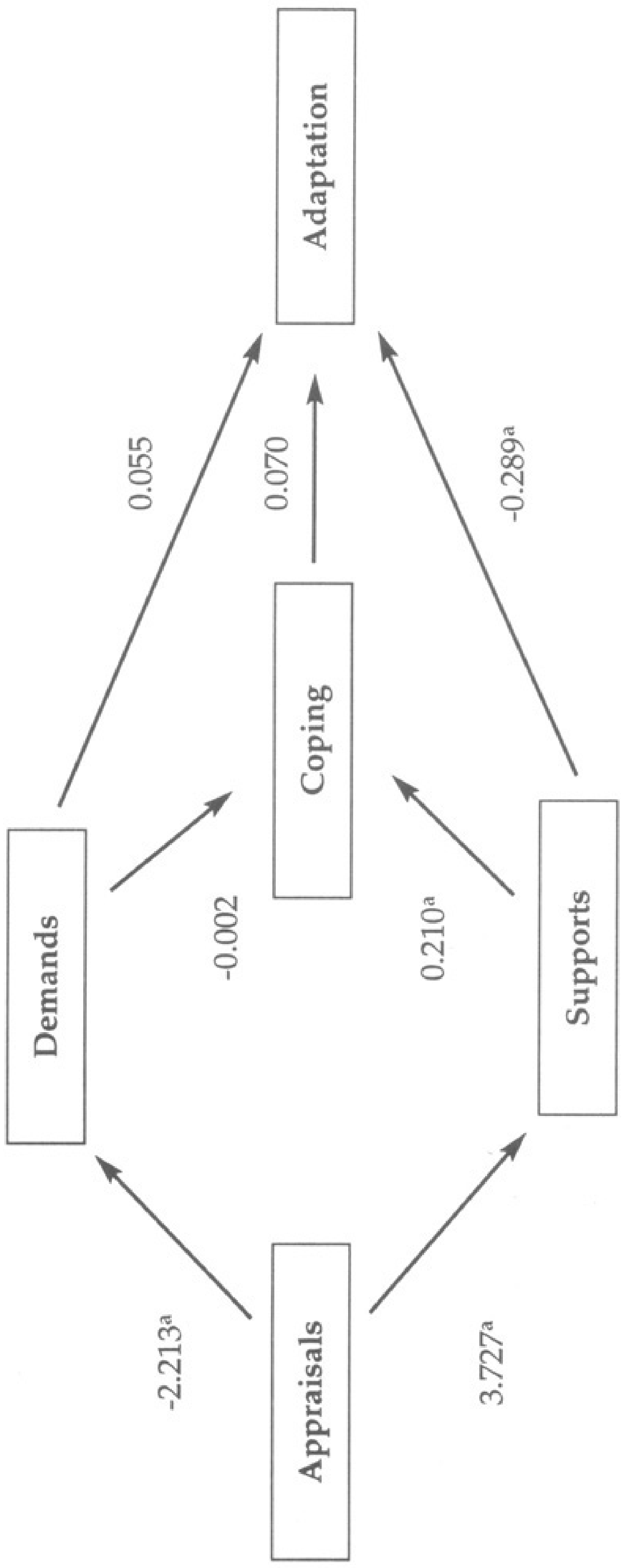
The mean age of the children with special needs was 39.11 months (*SD* = 18.4). The special needs most frequently identified by parents were: speech/articulation, physical/motor, cognitive/behavioural, and developmental delays. Formal diagnoses were available for 86 children. These diagnostic conditions generally coincided with the areas of need identified by the parents.

The best predictor of family adaptation for each dimension was set at 1.00 in order to test the path. The path coefficients of the relations between the dimensions of the Family Adaptation Model are shown in Figure 1. They indicate that the effect of demands on adaptation is best mediated by supports through coping — that is, every unit increase in demands was followed by a half-unit decrease in supports; further, every unit decrease in support was followed by a one-third-of-a-unit decrease in coping; finally, every unit decrease in coping was followed by a half-unit decrease in adaptation. The chi-square value of 189.52 (*df* = 44) is significant, indicating that the hypothesized paths of the Family Adaptation Model do not conform to the data set of mothers of children with special needs.

After a re-visitation of the literature, a second model was hypothesized that places appraisals at the beginning of all other dimensions of the Family Adaptation Model. This placement is supported by those authors (Lazarus & Folkman, 1984; Zeitlin & Williamson, 1988) who suggest that parents use coping and social supports as directed by their appraisals of family situations and that the meaning ascribed to a stimulus is a result of two forms of appraisal. Primary appraisal occurs before the conclusion that a stimulus is a stressor or demand. Secondary appraisal is carried out on the resources available.

This theory was partially tested in the model seen in Figure 2, wherein both demands and supports mediate appraisals ahead of coping and adaptation. This configuration is also an insignificant fit for these data. Some support for these theoretical postulations is indicated by the further lowering of the chi-square value by 100 to 88.53 (*df* = 43). Nevertheless, the effects of appraisals on demands and support are significant, as are the effects of supports on coping and adaptation. Insignificant effects include the effect of demands on coping and adaptation and the effect of coping on adaptation. While the effect of demands on adaptation is not significant, it is in the direction postulated. The effect of coping is the opposite of that expected. It is assumed that the greater the number of coping mechanisms one can access, the better one's family will adapt. As expected, large amounts of the variance of support (83%) and of adaptation (74%) are due to concepts in the model, while 21% of the variance in demands and 31% of the variance in coping are accounted for by the model.

Figure 2 *Dimensions of the Family Adaptation Model and Path Coefficients of the Second Test of the Model*



Note: chi square value = 88.53 (*df* = 43). Adaptation is scored negatively.
[a] t-value = 2

Summary of Evidence and Methodological Issues for the Family Adaptation Model

The objective findings from the linear analysis of the model with two samples of vulnerable families (families of children with special needs and families of children in Head Start) validate the presence of greater than normal demands in both family situations. Normative adaptation is managed mostly through the use of supports in both samples and through positive appraisals in the families of children with special needs. The finding that the model can make some differentiation between adaptive processes in samples representing two different family vulnerability processes is promising. It may demonstrate the sensitivity of the model's dimensions to accommodations made by families in different vulnerability situations. Analyses of hypothesized paths of mediation were insignificant but do highlight the possibility that appraisals underlie the other mediating dimensions of demands, supports, and coping for families with children who have special needs.

The usual important methodological solutions need rigorous application to this research program. First, the model's dimensions must accurately reflect up-to-date conceptions (Lazarus, 1999). The separation of appraisals from coping is helpful clinically, and when placed before all other dimensions in the model and tested provides a better fit to the data. However, the aspects of coping beyond problem-solving, including such things as support seeking/maintenance and connectedness to the community, are not well represented in this conception and are therefore not well measured. Second, it is necessary to find or develop and match appropriate objective measures of the model's dimensions to their conceptions. For instance, in the work described here, the coping measure did not adequately operationalize the intended focus of the concept in the model on problem-solving. It is also desirable to find a truer measure of the resilient family processes that were chosen to conceptualize family adaptation in the Family Adaptation Model. Third, data-analysis techniques that account for the family unit of analysis must be developed and applied. Before these methodological corrections are incorporated into the Family Adaptation Model research program, the broad and foundational issue concerning the systems/transactional approach to providing context to family adaptation must be examined.

According to recent expert reviews of stress and coping research (Lazarus, 1999; Somerfield & commentators, 1997), the essence of an adaptational transaction is that the whole system changes from moment to moment and from one situation to another. The authors of these reviews admit that diagramming this level of changing complexity obscures more than it clarifies and is difficult to test completely. Two different overarching methodological approaches are advanced as solutions to the complex nature of studying adaptation within the systems approach.

Most conservative of all (Somerfield & commentators, 1997) is the proposal that a traditional microanalytic strategy of centring attention and resources on high-frequency, high-stress problems — for example, family adaptation in the presence of a child with special needs — would reveal conceptually sophisticated and generalizable, clinically informative analysis. This approach presents difficulties (Lazarus, 1999). It is known that each type of stress and each family context produce distinctive demands, constraints, and opportunities. In this regard, Luthar (1999) shows that effective middle-class parenting strategies, when employed by families in situations of extreme inner-city poverty, are not protective of children. Further, the use of traditional objective scientific approaches, even in a longitudinal fashion, will not likely add to our understanding of such a complex system as family adaptation. The results from the causal modelling of the Family Adaptation Model lend support to this conclusion. It is an example of a microanalytic approach that breaks family adaptation into its constituent parts with their cause-and-effect relations identified. These parts and relations are not the whole of family adaptation, and the microanalytic approach does not provide an obvious way to re-synthesize it.

A systems analysis of family adaptation would more profitably consist of building objective understanding of the important variables in combination with individual families' construal of what counts for them (Lazarus, 1999). For the Family Adaptation Model, the dimensions of demands, appraisals, supports, coping, and family adaptation are the proposed important variables. The data analysis that best supported these dimensions was that obtained with families of children with special needs while they used the dimensions of the Family Adaptation Model with researchers skilled at implementing family-centred practice (McDonald et al., 1997). We plan, therefore, to continue objective examination of the dimensions of the model, but to also validate those conceptions through strategic reflective narrative inquiry in the context of individual families.

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Comments or queries concerning this article should be directed to Jane Drummond, Professor, Faculty of Nursing, 3rd Floor, Clinical Sciences Building, University of Alberta, Edmonton, Alberta T6G 2G3 Canada. Telephone: 780-492-6410. Fax: 780-492-2551. E-mail: jane.drummond@ualberta.ca

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Employed Mothers: Stress and Balance-Focused Coping

Kaysi Eastlick Kushner and Margaret J. Harrison

Ancré dans une perspective féministe critique, le projet de recherche dont cet article fait l'objet visait à analyser comment les mères réussissent à concilier les multiples responsabilités liées à la famille, à la santé et au travail rémunéré. Pendant une période de deux ans, 20 mères travaillant comme employées de soutien dans un établissement public ont participé à une série d'entrevues individuelles menées en personne et par téléphone, ainsi qu'à un groupe de discussion. Les entrevues ont été transcrites et analysées au moyen de méthodes comparatives constantes. Les exigences continues liées au travail rémunéré et au bien-être des membres de la famille sont une source de stress pour les femmes, une condition exacerbée par les contraintes de temps, les attentes inflexibles ou contradictoires, les concessions relatives aux ressources personnelles et l'insuffisance des moyens de soutien. Dans la plupart des cas, les stratégies d'adaptation sont individuelles, comme celle qui consiste à se concentrer sur les priorités; certaines femmes recourent toutefois à la prise de décisions partagée en famille. Les résultats appuient les théories courantes sur le stress et l'adaptation en lien avec l'individu et la famille, tout en soulignant la nécessité d'expliciter l'incidence de facteurs socioécologiques tels que les relations de pouvoir. L'article fournit à l'intention des infirmières qui travaillent auprès des femmes et des familles des stratégies visant à rehausser le degré d'adaptation et à réduire les facteurs de stress.

This critical feminist grounded theory study examined how employed mothers coped with the stress of managing multiple responsibilities in family, health, and paid work. Over a 2-year period, 20 mothers employed as support staff in a large, publicly funded institution participated in repeated individual in-person and telephone interviews and in a focus group. Interviews were transcribed and analyzed using constant comparative methods. The women experienced stress from continuous demands in paid and family health work compounded by time constraints, inflexible expectations, conflicting demands, compromised personal resources, and inadequate support. Most of their coping strategies were individual, such as focusing on priorities, but some women used shared family decision-making. Findings support both individual and family stress and coping theory, yet underscore the need to explicate social-ecological influences such as relational power. Strategies that can enhance coping and reduce stress are described for nurses who work with women and families.

Kaysi Eastlick Kushner, RN, PhD, is Assistant Professor, Faculty of Nursing and Perinatal Research Centre, University of Alberta, and Assistant Director, CIHR Institute of Gender and Health, Edmonton, Alberta, Canada. Margaret J. Harrison, RN, PhD, is Professor, Faculty of Nursing and Perinatal Research Centre, University of Alberta.

The inequitable division of paid and family labour between women and men as partners and parents remains problematic for women trying to create work-family balance (Higgins, Duxbury, & Lee, 1994). Even as women are expected to make commitments "just like men" in the workplace (Duxbury & Higgins, 1991), they are normatively expected to make priority commitments to family caregiving roles. Their acceptance of social ideals about women's caregiving work may limit their use of social support (Neufeld & Harrison, 2000; Wuest, 1997). When women are socially disadvantaged by greater exposure to stress and lower education — for example, women in non-professional positions such as clerks and factory workers — they may limit health-promoting self-care (Woods, Lentz, & Mitchell, 1993). Yet, in investigations of individual and family stress and coping, researchers have not routinely focused on these conditions or critically examined their social construction.

The health and social science literature reveals two perspectives on stress and coping: an individual perspective and a family perspective. Antonovsky (1987) proposed a salutogenic model of individual stress and coping based on an inherent uncertainty in daily life and a potential for the health-promoting consequences of stress. The central concept, a sense of coherence, reflected an individual's confidence in his or her ability to anticipate, find meaning in, and cope with life challenges. Successful coping resulted when the individual selected appropriate strategies to deal with stressors or experiences that were seen as unpredictable, overwhelming, or difficult to resolve. A family perspective on stress and coping (McCubbin, Thompson, & McCubbin, 1996) assumes that families have patterns of behaviour that promote growth and development and enable family members to respond to stresses such as illness of a member or inadequate financial resources. Family coping reflects coordinated behaviour within the family system and synergistic efforts of individual members to secure and use resources to maintain individual and family well-being.

Women's health research has focused predominantly on individual coping. Coping skills such as asking for and accepting help or altering self-expectations are described as important factors in women's health (Woods et al., 1993). In a study with employed and at-home women, Killien and Brown (1987) found substantial diversity in patterns of stressors, experiences of stress, and coping strategies. Employed mothers, both lone and partnered, tended to take action to "fix the problem," whereas unemployed mothers tended to "talk out the problem" with someone other than their spouse. Both of these types of coping were individual strategies. Killien (1999) advocates the use of a role-resilience perspective in "women, work and health" research to support an integrated focus on beneficial and harmful effects of multiple social roles. This perspective, however, still focuses on individual coping. Implicitly, the family is viewed as a recipient of care by women rather than as a partner with women in coping with life stress.

Much of the research that uses a family perspective on coping has focused on families in crisis due to chronic illness of a child or parent, immigration, or war trauma (McCubbin et al., 1996). Family coping with everyday demands in employment and family roles has received limited attention. Anderson (1998) used a family perspective on stress and coping to study family quality of life after a diagnosis of chronic illness in an adult family member. Maintaining a stable family sense of coherence supported family quality of life. Antonovsky (1998), however, contends that the concept of a family sense of coherence remains problematic as data have reflected aggregated individual family member experience rather than family processes. For example, Gottlieb (1998) studied family coping in lone-mother families of a child with a disability. A strong sense of family coherence was associated with a greater frequency and variety of coping strategies used by mothers; larger, more helpful support networks; higher maternal education and economic stability; and more cohesive mother-child relationships. Although this study was conducted to examine family coping, in reality individual coping strategies used by the lone mothers were identified.

The purpose of this study was to describe how employed mothers cope with the stress of managing multiple responsibilities in family, health, and paid work. The research questions were: *What types of stress do mothers employed in support positions have? What coping strategies do these mothers describe using on an individual basis and/or as a family?* This study was part of a larger study of meanings and social contexts in personal and family health decision-making.

Research Design

A critical feminist grounded theory method was used in the study. Recent discussion among feminists of the need to consider sociocultural as well as gender influences on women's circumstances (Marshall, 1994), and the discussion among critical theorists that gender has been neglected (Morrow, 1994), supported the integration of feminist and critical social theory inquiry. Critical analysis of social pressures in the workplace and society was integrated with an understanding of action and interaction in a woman's social world. The use of grounded theory methodology was based on the compatibility between grounded theory and feminist theory (Keddy, Sims, & Stern, 1996; McMahon, 1995; Wuest, 1995; Wuest & Merritt-Gray, 2001). A critical feminist perspective promoted development of a non-hierarchical "friendly stranger" (Cotterill, 1992) research relationship between the first author and the women in the study, and a focus in the interviews on the experiences of each woman through her eyes (Reinharz, 1992; Seibold, Richards, & Simon, 1994).

Data Generation and Analysis

Data were generated with employed mothers who described individual and family health, stress, and coping experiences relevant to their everyday decision-making about family, health, and paid work. Obtaining family-level data from an individual family member, typically a parent, is an accepted strategy (Patterson & Garwick, 1998), and mothers' reports on family health and activities have been found to be consistent with family reports (Denham, 1999).

The sampling strategy focused on women who worked as support staff in clerical, laboratory assistant, or janitorial positions with a large, publicly funded employer. These women may experience greater stress than women employed as professionals or managers, as they have less control over working conditions and fewer economic and social resources (Meleis, Norbeck, & Laffrey, 1989). Following approval by the Ethics Review Board, union and employer support was secured. Notices describing the study were distributed through the union newsletter and administrative offices. Women who cared for at least one child under 18 years of age were recruited. Theoretical sampling following preliminary data analysis guided the selection of women, who varied in their hours and type of paid work, their family income, the number and ages of their children, and whether a partner contributed to their family work.

Twenty women participated in the study. All but one, who withdrew due to serious family illness after the initial interview, agreed to follow-up interviews. All women held support positions that were considered working-class (McMahon, 1995). Most women held full-time clerical positions. A few were employed in laboratory or janitorial work. During the study, two women changed jobs. The women ranged in age from 27 to 45 years. The majority cared for two or more school-aged children. Three women were lone mothers. The rest were partnered with men employed in trades or professions. Most women managed chronic personal and family health concerns such as asthma and caring for a child with developmental problems or for an aging parent. Social-class differences among women were of interest in the study, but class description is complicated in Canadian society by the lack of widely accepted criteria. Based on education and occupation, five women were considered working-class (McMahon). All women, however, had family incomes above the Statistics Canada (2001) low-income cut-off and the low-income measure.

Repeat interactive, in-person and telephone interviews were conducted over 2 years. In keeping with the women's preferences, most interviews were held in the workplace after working hours or during scheduled breaks. During the initial interviews, the women were asked to describe a "typical" day including their family, health, and paid-work responsibilities and how they made decisions to cope with these responsibilities. In subsequent interviews, the women were asked to describe changes in their circumstances and coping methods. Consent was obtained in writing prior to the initial individual interview and reaffirmed verbally at the end of each interview. All women were asked if they would like to join a focus group at the end of the interviews, and four women consented. In the focus-group discussion, the women were asked about workplace policies, benefits, and conditions such as supervisor or co-worker relationships that supported coping or contributed to stress. Interpretive summaries of data were presented to the women for their review and feedback prior to the follow-up interview and the focus-group discussion. The women developed a shared awareness about their experiences that stimulated further reflection and helped develop data interpretations.

All in-person interviews and the focus-group discussion were audiotaped and transcribed verbatim with pauses and emotions. Pseudonyms were chosen by the women or by the researcher with the women's verbal consent. Field notes recorded telephone interview data. The interviews, focus-group discussion, and field notes were analyzed for themes using constant comparative techniques (Glaser, 1978), and the analysis was guided by a critical feminist questioning of underlying values and social conditions that affected women's experiences (Campbell & Bunting, 1991). Information about employer-provided benefits and policies such as personal and family leave and health-promotion programs was provided by the union and was publicly available. Gender-sensitive strategies (Status of Women Canada, 1998), focused on the impact of workplace policies and social conditions on women's lives, were used to analyze information about employer-provided benefits and policies. Reflective memo-writing was used to document researcher responses that were relevant to but not necessarily specified in the data. Concurrent data analysis guided the topics explored in subsequent interviews. Theoretical sampling, data generation, and analysis continued until new data no longer contributed to further theoretical development.

Findings

Sources of Stress and Unbalanced Solutions

The women faced multiple sources of stress: time pressures, inflexible expectations, conflicting demands, compromised personal resources, and difficulty accessing support from the family, the workplace, and health and social services. Because of the constraints of their situations, they frequently were unable to find solutions that decreased their stress and benefited their family. As a result, the women felt a sense of imbalance between what they believed they *should* do and what they found they *could* do in any given situation.

All women acknowledged stress imposed by time pressures. They experienced conflict between concurrent demands and time to deal with those demands. Lea reflected: "Time constraints are a major factor in decisions on when to take care of things and how. I would like to not have everything compressed in such a tiny ball where you have to make decisions based on the clock, rather than practicality or necessity." Lea attended to her son's health but neglected self-care. Under time pressure, the women coped by making ill-considered decisions that satisfied immediate demands without reducing the stress from multiple demands.

Many women experienced stress related to inflexible expectations of themselves, particularly as mothers and employees. They felt guilty when they did not meet these expectations and responded by placing priority on family and paid work. The women felt pressured to be available to their children, to support their social and emotional well-being and be seen as a good mother. Leandra, a lone mother, said, "The work and the children are going to come first and what little time there is left…there's not going to be a whole lot of time for me." Leandra's struggle to take care of her own needs was common to many women, who believed that family and work responsibilities should take priority over their personal needs. At times, the women faced intense stress from these multiple demands. Lea noted, "I fell into the superwoman trap way early. I never learned about boundaries and it's hurt me really badly. It's hard when you're getting different messages from all around you." Several women had accepted idealized views of women's work and habitually minimized self-care to cope with family and job demands.

Conflict between family and job responsibilities increased the women's stress. This stress was compounded by high personal expectations and guilt. Daria said, "There's a lot of guilt in not getting things done to a certain specification. I don't want anybody else to pick up my job partway through. There's guilt when it comes to the pressures of everyday life and being tired and wanting to be by yourself.... There's guilt in wishing I could be more involved with my kids' school. I should maybe be doing more things for my grandmother [and] visiting my parents more often. I should be doing more around the house. My biggest guilt is from falling asleep. And there's guilt that you don't spend enough time with your husband." Daria's catalogue of guilt reflected her stress from expecting she should do more in each aspect of her life. Stress from continuously attending to paid, personal, family, and volunteer work was a recurrent experience for many women.

For several women, stress arose from compromised personal resources such as their need to conserve energy to deal with chronic health problems. Daria talked about the stress of an extended convalescence: "It's very, very hard for me right now because I am doing so many medical things myself that I don't have the time for medical things for my kids unless they are sick-sick." Daria had always "saved" her sick time for dealing with family health issues but now felt pressured to delay their less serious concerns. This pressure increased her guilt and stress. Other women faced stress from inadequate financial resources. For example, Lea said, "One of the biggest balancing acts for me is between what I need and what I want, because what I may want is to pay a sitter so I can get out and what I may need is to not spend any money."

The women experienced stress from trying to manage with inadequate support from their family. Ilana said, "We don't really have any extended family here. We have to basically rely on our little family to cope one way or the other." Ilana acknowledged the stress this created when her partner or adolescent children did not provide support. "Everybody assumes that it is the mothers that have to do all these things. I don't think there is going to be any change unless society [plays] some part." Ilana's partner was frequently unavailable due to work requirements and her children were inconsistent in providing requested support. Haley also talked about pressures on women: "I think we end up doing more because our husbands don't worry so much. How our kids turn out is still a reflection on us. I try to delegate to my husband, who then delegates to my son. It's cooperation as long as it's not interfering with anything he [husband] needs to do." For a few women, stress was compounded by negative actions from family members. Diana had an adolescent with recurrent behavioural problems: "I find it's harder for me to deal with a situation when he's [husband] saying, 'Well, it's your fault'." Diana felt blamed and betrayed by her partner when he made these comments, even though she excused them as an expression of his frustration with parenting. Such negativity effectively limited the women's choices in securing support and increased their stress.

Inadequate support in the workplace, such as lack of relief from co-workers and difficulty using personal or family leave to deal with family issues, created stress. Rose noted, "We've got people away at work, we've got one less supervisor than we did last year, we've got people retiring." Rose, like several women, felt that continual staff issues limited her opportunities to secure workplace support to manage personal and family health concerns. Whereas employer policies provided for personal and family leave and group health-benefit entitlements, the women found that their access to entitlements was limited by supervisor or co-worker attitudes. Cass recalled, "The supervisor, she's got kids herself, but she has a way of saying things...you feel guilty that you left because your child was sick." Cass limited her use of family leave because she believed her supervisor was not supportive. She, like other women in the study, expected employed mothers to be supportive in the workplace but found that this was not always the case. Male supervisors, co-workers, and written policies were seen by a few women as reflecting an orientation in the workplace of relative freedom from family responsibilities. Dol said, "In the last 5 years we have had four different managers. The majority of them wanted you here when they're here in the morning and to stay until they were ready to go home, which wasn't always comfortable to make a home life." Naomi said, "Both my supervisors are males and don't have children themselves. I believe they truly don't understand the entire involvement of that. They don't want to give me extra responsibility [at work]." These women were concerned that acknowledging family responsibilities compromised their position in the workplace and could threaten their job unless they restricted their use of personal and family leave.

Difficulty securing health and social services frequently contributed to time pressures and put additional strain on the women's personal coping resources. Some women expressed frustration with trying to identify resources and dealing with unsupportive professionals or agency personnel. Leandra recalled her frustration when trying to identify child-care alternatives: "I phoned the City to see if I could qualify for some type of subsidy for daycare, and I phoned 4 days in a row and left messages every day and I never ever heard from anybody. I kind of gave up." In addition to increasing her stress, the time spent seeking child care had conflicted with her workday and raised tensions with her supervisor. Other women experienced similar problems with the education and health-care systems; accessing information and services required extended effort and time.

Balance-Focused Coping Strategies

All the women believed that they would be able to achieve a balance between the demands they faced and their resources if they made use of successful coping strategies. The women used multiple coping strategies directed at meeting expectations and demands, using available resources and working around situational constraints.

Meeting expectations and demands. As illustrated by the women's descriptions of everyday stresses, family and social expectations of the caring, good mother and the productive, good worker were embodied in the women's self-expectations and their family and job demands. The three coping strategies that were used to meet expectations and demands were: focusing on priorities, being fair, and letting go of expectations and demands.

The women described the importance of focusing on priorities in personal and family responsibilities so that immediate health demands could be met without persistently subverting other responsibilities. Although the two priorities of being a good mother and being a good worker were not considered inherently conflictual, the women faced many situations in which they needed to choose between the two. Scarlett said, "It's learning to take that time for your own health, because if you don't, you can't do it with everyone else."

The women were concerned about being fair to themselves and their families. Naomi, who tried to consider her partner's perspective in her decisions, said, "Sometimes when you're doing the balancing stuff it's not so much about you. Sometimes it's about the other person... You have this whole thing going about your time, your work, your schedule, your kids, your husband, but then he has this whole other circle that includes everything but in sort of a different world." The women considered how their decisions might affect others in their family and their workplace. They felt less stress when they believed they were being fair by meeting personal and social expectations of good mothers and good workers.

Letting go meant moderating their self-expectations, particularly in family and volunteer work. Mora said, "I'm doing the best I can. What can I say? I can't say I am perfect, no." Unlike Mora, most women were reluctant to let go of their self-expectations even to relieve persistent stress. Haley said, "I want to take care of my own myself. We are supposed to be able to solve all these things ourselves." The women had high self-expectations, particularly in situations of intense social pressure such as dealing with an ill child or a new supervisor. Focus-group participants agreed with one woman's comment: "You kind of hope when you start a new job nothing goes wrong at home for a while, that the kid doesn't get sick or the school doesn't call, so you have time to prove yourself."

Using available resources. The women used a range of personal, family, social network, workplace, and health- and social-system resources. Coping strategies included accepting support, asking for help, sharing decision-making, emphasizing self-rewards, using spiritual support, choosing work with flexibility and benefits, and securing satisfactory health and social services.

The women were comfortable accepting support from partners, family, and members of their social network who were willing to share family responsibilities. Scarlett recalled an important family decision: "We just said, 'We're gonna do it.' Because we all have to buy into it. It's going to affect us all." Among the women with supportive family and social networks, Dol's comment was typical: "If you have the right network, they will help you and they will support you in your decision, whether they agree or disagree." The women appreciated family and friends who made themselves available without being asked. A global view of reciprocal support enabled the women to accept support without feeling an immediate sense of obligation. The women in the focus group agreed: "You do pay back one way or the other. There is always something that the other person needs. Sometimes it's simply the friendship." Recognition that reciprocity could occur over time and through diverse actions promoted women's comfort in accepting support.

When support was not offered, asking for help was an important strategy. Geri said, "I ask for help. I don't like asking, and it's neither pleasant nor easy." Geri sometimes asked another adult to help balance demands on her as a lone mother. To be able to ask for help, the women had to let go of self-expectations and recognize their need for support.

Half of the women, however, resisted asking and sometimes refused help if they felt they could not "pay back" the support. Leandra reflected: "A lot of friends have extended their support. It's hard for me to take it because I probably know I am not going to give back."

The influence of power in the partnership on shared decision-making was evident in the situations described by several women. Aryn commented: "I have always said to my husband, 'My job is as important as your job. We are in this together'." Women like Aryn, who found that their partners were committed to sharing family and paid-work responsibilities, described a comparative balance in decision-making power within the family. In contrast to other women in the study, Haley talked forcefully about power in the partnership: "You have to start to delegate more to your spouse, but that means you have to give your spouse information and you don't really want his opinion." Haley described her partner as selectively involved in family responsibilities. She and several women saw partner support as a resource qualified by tensions over decision-making and responsibilities, particularly in family work.

Many women spoke of self-rewards such as the satisfaction they derived from their multiple activities, particularly in their paid work. Diana stated, "I've always felt that work has actually been healthy for me. I think it's good to get away from the kids, the husband, and the housework." Although paid work complicated everyday demands on women, it provided time out for them and relief from constant family demands. Women also used individual and social activities for time out. Diana said, "I think this is really important, to be able to disengage from the everyday happenings in your life and say, 'OK, this 2 hours is *my* time and I am going to do with it what I want to do'." These women were able to remove themselves from the stress of demands and maintain a sense of personal balance, which strengthened their resources.

A few women talked about using spiritual support. Dol said, "There are some days you just feel overwhelmed and you say, 'It's time to pull in the big guy, this is up to You.' And it seems to take the load off your shoulders." The sense of connection to life beyond their particular experience supported Dol and other women through very difficult decisions.

Employment with flexibility and benefits provided needed workplace support for the women. Most of the women were employed full-time and valued flexibility in work demands and supervisors and co-workers who supported the use of family-leave policies. Analysis of employer-provided benefits and policies supported the "progressive workplace" reputation of the employing institution. Women in the study had access to family and personal leave, diverse family medical and alternative health benefits, and family assistance and wellness programs. They valued their employee health benefits. Lea said, "I am very grateful for all the different health-care coverage, because I have options without worrying about, 'How can I afford this?'" In several cases, the woman's employment provided family health coverage.

A few women had secured employment flexibility through altered working hours, typically starting and finishing earlier than regular business hours. This allowed them to be home with their children after school and alleviated child-care concerns. Some women had secured flexibility informally by "making up time" taken for family work or by completing paid-work tasks at home. Aryn was one of the few women with flexible working hours and the opportunity to work at home occasionally: "Where I work they know that even if I am at home and my child is sick, my work gets done and maybe I will take some stuff home at night." The women attributed their ability to obtain support to their good workplace relationships, their reputation as good workers, and their infrequent use of flexible conditions.

All the women described having secured satisfactory health and social services, including access to supportive health and social programs and trusted care providers. The women sought to establish supportive relationships with medical and alternative health providers. Scarlett recounted dealing with a serious illness: "My doctor said, 'We got two ways of treating this.' We did start to treat it with meds and I got very sick. I said, 'I am going to do this holistically'." The physician's willingness to consider available medical and alternative treatments enabled Scarlett to include her preference for various therapies. Women also secured quality child care as an essential support. Aryn recalled, "I had a wonderful babysitter for 5 years and I never worried." The women felt less stress when they knew that their children were in a caring and safe environment.

Working around constraints. The women needed strategies to work around constraints from conflicting demands, time pressures, inadequate available support, and limited access to health and social resources. Their coping strategies included delaying, planning contingencies, using alternatives, and persisting.

To work around inflexible working conditions such as fixed hours, the women selectively used the strategy of delaying their response to family demands. Emily commented, "We have a rule in our house that you do not phone me at work unless you're dying. The 1% of the time they do call, very calmly I'll say, 'We'll discuss it when I get home'." When demands could not be delayed, she requested leave and hoped her supervisor would support her decision. Emily limited such requests because of inconsistent supervisor support despite the existence of a family-leave policy.

Women used contingency planning to resolve conflicting demands, such as if they had to be at work when a child was ill. All the women acknowledged that the support available from their partners and social network was less than optimal. Geri's response in such situations was typical: "I try to handle things most of the time." The women used contingency planning and their own resources before asking for help.

By using alternatives the women were able to work around limited access to needed resources or services. Alternatives, however, were a compromise. Ilana reflected: "Unfortunately, your choices are kind of limited. You can't often just take time off work even if you are sick. So it leaves me the options that I go back to the doctor and I also try to improve in the other areas, like more rest." To deal with her chronic asthma, Ilana used alternatives because she did not have supervisor support for recurrent use of personal leave. Lea described a similar strategy in dealing with her son's medical needs as she considered "whether or not I will drive across town to the doctor we'd normally see or go to the medi-centre behind our place where I don't trust the diagnosis." Alternatives provided relief but did not ensure resolution of concerns.

Persistence helped the women to work around stressful family situations or difficulty accessing needed resources. Geri said, "Some things are easy to access and others are not." She described her approach as "putting on armour and doing battle." The women identified needed services and persisted in their requests for access until they succeeded. Persistent attention to constraints was stressful, however, even when a sense of successful coping was achieved.

The women developed routine decision and coping strategies that gradually changed in response to their children's development or focal events that raised their awareness of inadequacies in their routines. All the women described changes in their coping as their children matured. Whereas women with young children coped by taking responsibility for their well-being, women with school-aged children included them in decisions about family and health issues. In contrast, women with older children focused on facilitating their adolescents' independent health decision-making. Olivia, the mother of adolescent twins, recalled these changes: "It's really neat, because there are stages. You could probably graph it with the age of the kids." Many women also described changes in their coping routines, particularly in relation to self-care, when faced with a crisis or cumulative events that revealed inadequacies in established routines. Ilana considered the impact of a personal-health crisis: "I was at a point physically and mentally that I could take no more than I was already handling. After that, I kind of reviewed my practices." Women knew that their coping routines changed as they obtained greater support, typically from partners and children, in managing multiple responsibilities.

Discussion

In this study, social expectations that define caregiving as women's work reinforced women's sense of obligation to manage family, health, and paid-work demands on their own. These findings are consistent with other research on women's use of social support (Harrison, Neufeld, & Kushner, 1995; Neufeld & Harrison, 2000; Wuest, 1997, 1998, 2000). Social ideals continue to orient women towards nurturing and caring for others over themselves, implicitly supporting a hierarchy of caring that fosters self-neglect among women. The ideal of "the good mother" as selfless and self-sacrificing remains a powerful influence on women in Western cultures (Villani, 1997). Although family social and public policies in Canada are framed within an individual model of responsibility (Eichler, 1997) that is overtly gender-neutral (i.e., both mothers and fathers are assumed to be responsible for family well-being), the social ideal of motherhood effectively holds women responsible. When faced with inconsistent support from an uninvolved partner, an unreliable adolescent, very young children, or an unsupportive work supervisor, women reasonably rely on individual coping strategies that are under their control.

Unlike most research with employed mothers, this study focused on women in support-staff positions. Their stress increased with inflexibility in working conditions and lack of supervisor support for taking family leave. This finding is consistent with stressors identified in studies with women clerical workers in California (Meleis, Norbeck, Laffrey, Solomon, & Miller, 1989) and Brazil (Meleis, Messias, & Arruda, 1996). From a feminist perspective (Tronto, 1992), women's differential access to power, both in family relationships and in the workplace, is a major constraint on their coping decisions. A lack of power in relations within the workplace makes it difficult to challenge supervisor or co-worker attitudes. Women are expected to work within an employment mentality that centres paid work in employees' lives and marginalizes family responsibilities (Baker, 1995). Women who are members of support staff may be doubly disadvantaged, since their positions often are structured so that workers are easily replaced and have little job control, inflexible hours, and limited opportunity for promotion (Armstrong & Armstrong, 1994).

Except for shared decision-making, the coping strategies used by the women in this study were individual strategies. These strategies support Antonovsky's (1987) proposed theoretical constructs of instrumental and emotion-focused coping strategies. Asking for help and choosing employment with flexibility and health benefits fit within instrumental focused coping, while emphasizing self-rewards and letting go of expectations and demands are types of emotion-focused coping. In contrast, shared decision-making is a family-level coping strategy, similar to family problem-solving and coping, one of the main concepts identified by McCubbin and colleagues (1996). Shared decision-making occurred within families where women were able to share authority with their partner. Such power-sharing may depend on men seeing themselves as partners in family work, rather than as "helpers" with women's work (Coltrane, 1996; Pyke & Coltrane, 1996). An imbalance of family and job responsibilities between men and women in North American families persists despite a shift towards men making a greater contribution to family work (Duxbury & Higgins, 1991; Higgins et al., 1994; Hochschild, 1997). Women have assumed paid-work and family-provider roles like men, but men have not assumed a proportionate contribution to family caregiving (Eichler, 1997). Disproportionate contributions to family caregiving by men and women are grounded in gender-role ideology and compounded by men's typically higher wages (Pyke & Coltrane; Tiedje & Darling-Fischer, 1993).

Social-ecological influences, including power in family and workplace relationships, have been inadequately examined in stress and coping research. There is a need to examine power differentials in order to extend the relevance of coping theory to women's and family experience in everyday life. Failure to do so may result in support for individual models of stress and coping that inadequately reflect family dynamics and the influences of gender inequities on everyday experience and action.

The focus of this study with mothers employed in support positions extends previous research typically focused on women in professional positions. The study, however, was limited by the exclusion of non-English-speaking women and by recruitment from a large, publicly funded institution. The demonstrated influences on women's experiences, their sources of stress, and their coping strategies need to be examined under conditions of greater socio-economic and cultural diversity and in other workplace environments. Employed mothers who are immigrants may experience greater stress, as they frequently work in low-paying jobs that are not consistent with their qualifications or experience and may lack the English-language skills needed to access resources (Ng, 1993). Women in low-income circumstances such as those returning to work after receiving social assistance may have limited employment and family resources to support coping with multiple responsibilities (Heymann & Earle, 1998). Mothers employed in smaller organizations or self-employed mothers may have access to fewer workplace resources than women in this study (MacDermid & Williams, 1997). The coping methods of such women warrant examination. Another limitation of the study was the use of only one family member to describe family coping strategies. Although Patterson and Garwick (1998) suggest that one family member can provide insight into family coping, further insight into shared decision-making and family use of supports might be gained if other family members were interviewed.

Nurses have opportunities to explore stress and coping strategies with employed women and their families. Women in the current study found that talking about their everyday experiences promoted reflection on their coping decisions and contributed to their awareness of a wider range of coping and stress-reduction strategies. Encouraging reflection may be an effective intervention to enhance coping skills (Collins & Tiedje, 1988). Nurses, however, should be aware of Denham's (1999) caution about speaking only with women about family issues, as this approach implicitly pressures women to fulfil a primary role as family caregiver. Nurses who work with women and their families also need to help them identify ways to share responsibility within the family, to develop realistic expectations, and to use appropriate support from workplace, health, and social systems as well as their extended families.

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Comments or queries about this article should be directed to K. E. Kushner, Assistant Professor, Faculty of Nursing, 700 UEC, University of Alberta, 8303–112 Street, Edmonton, Alberta T6G 2T4 Canada. Telephone: 780-492-3656. Fax: 780-492-8045. E-mail: kaysi.kushner@ualberta.ca

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Learning to Live With Early Dementia

Leona Werezak and Norma Stewart

Les études sur la démence précoce se concentrent en grande partie sur la perspective des prestataires de soins, si bien que l'on sait peu de choses sur l'expérience des personnes atteintes aux stades débutants. La présente étude a été conçue dans le but de découvrir comment elles apprenaient à vivre avec cette maladie durant cette période. On a mené des entrevues auprès de 6 participants (3 hommes et 3 femmes) âgés de 61 à 79 ans. On a élaboré un modèle théorique sur la base d'une approche qualitative et d'une théorie à base empirique. On a ensuite établi un cadre théorique préliminaire à partir des données obtenues : les sujets s'apprivoisent à la démence selon un processus en cinq étapes, commençant avec les antécédents et se poursuivant avec les stades de l'anticipation, de l'apparition, de l'assimilation et de l'acceptation. Cette démarche évolue à mesure que la perception des sujets sur eux-mêmes et le monde extérieur se transforme. En définitive, les implications découlant de cette recherche sont nombreuses pour les cliniciens et les chercheurs qui interviennent auprès des personnes atteintes de démence aux stades précoces.

Much of the literature on early dementia is focused on caregiver perspectives, while little is known about the perspective of persons with early-stage dementia such as what it is like to live with this syndrome. This study was conducted to explore the process of learning to live with early-stage dementia. Interviews were conducted with 6 early-stage participants (3 men and 3 women) ranging in age from 61 to 79 years. Theory construction was facilitated using a qualitative approach and grounded theory. A preliminary theoretical framework was developed from the data which outlines a 5-stage process of learning to live with dementia that begins with various antecedents and proceeds through the stages of anticipation, appearance, assimilation, and acceptance. This process evolved as participants' awareness of themselves and their outer world changed. Ultimately, the findings of this study have several implications for clinicians and researchers working with persons in early-stage dementia.

Context of the Study

The term *dementia* refers to a clinical syndrome comprising a wide range of neurological diseases that typically occur with increasing age and are distinguished by progressive memory loss, impaired judgement, and a decreased capacity for abstract reasoning (Langston Lind, 1995). The most common cause of dementia is Alzheimer's disease,

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Leona Werezak, RN, MN, is a nursing instructor at the Saskatchewan Institute of Applied Science and Technology, Kelsey Campus, Saskatoon, Saskatchewan, Canada. Norma Stewart, RN, PhD, is a Medical Research Council Scientist and Associate Professor, College of Nursing, University of Saskatchewan, Saskatoon.

with an overall prevalence rate of 5.1% in Canada for people over the age of 65 (Canadian Study of Health and Aging Working Group, 1994). In order to provide effective care and services for people with dementia, health-care providers have to understand the needs and issues facing this client group. Unfortunately, though, the views of people with dementia have been conspicuously absent from the literature until recently. At present, most of the information about the needs and concerns of dementia clients has been obtained from family members (McWalter et al., 1998) or formal caregivers (Gordon, Carter, & Scott, 1997). The few existing studies from the perspective of persons with dementia suggest that their views may differ from those of their caregivers (Cotrell & Schulz, 1993). Consequently, there is growing recognition in the literature that the perspective of persons with dementia must be sought out, particularly in the early stages of the disease process when language skills are relatively intact (Cotrell & Schulz).

To address this gap in the literature, we designed a study to explore and conceptualize the process of learning to live with memory loss in older adults with early-stage dementia. Through the use of grounded theory methodology, participants' experiences were examined and a broad theoretical framework evolved that outlined how persons with dementia gradually learned to live with early memory loss (Werezak, 2001).

Persons With Dementia as Research Participants

An extensive literature review revealed little research that included self-reports by persons with dementia as research participants. As one might expect, the paucity of information in this area is due to methodological problems of self-report reliability as cognitive decline occurs (Ballard et al., 1991; Burgener & Dickerson-Putman, 1999). Therefore, most of the literature is focused on caregiver needs (Luscombe, Brodaty, & Freeth, 1998; Nankervis, Schofield, Herrman, & Bloch, 1997) and level of caregiver burden (Freyne, Kidd, Coen, & Lawlor, 1999; Schneider, Murray, Banerjee, & Mann, 1999) rather than on the perspective of persons with dementia.

The studies that have included persons with early-stage dementia as participants have addressed the issue of reliability and staging of the disease in various ways. In the study by Burgener and Dickerson-Putman (1999), participants were "mostly in the early disease stages" (p. 35), as assessed by a diagnosis of Alzheimer's disease or related disorder within the previous 12 months and a Mini-Mental State Examination (MMSE) score between 12 and 26 ($M = 20.5$) — with a maximum score of 30 representing no cognitive impairment. Although no specific reliability testing was conducted, consistency was found in participants' responses from baseline interview to 6-month follow-up. Other researchers have also begun to demonstrate that information provided by persons with early-stage dementia is reliable (McAuslane & Sperlinger, 1994) and "insightful" (Keady & Nolan, 1995, p. 1338); hence, the importance and feasibility of continued research in this area with persons in early-stage dementia have received increasing support.

The Experience of Living With Dementia

In order to better understand the issues related to living with dementia, researchers have outlined two preliminary models that conceptualize the experience of persons with dementia on a continuum with identifiable stages or phases (Cohen, Kennedy, & Eisdorfer, 1984; Keady & Nolan, 1994). Cohen et al. delineate six psychological phases in the cognitively impaired individual based on several hundred clinical interviews with dementia sufferers. These phases are: prediagnosis — recognition and concern; during diagnosis — denial; post-diagnosis — anger, guilt, and sadness; coping; maturation; and separation from self. Similarly, Keady and Nolan (1994) propose a preliminary nine-stage model defining the experience of dementia from the perspective of persons with the disease. The nine stages are: slipping, suspecting, covering up, revealing, confirming, surviving, disorganization, decline, and death. Both of these frameworks suggest that persons with dementia undergo a process beginning with initial memory impairment and ending with terminal disability. However, what has yet to be determined is how individuals progress through the early stages of the disease, and it is during these stages that they may be most involved in their own care and planning for the future. Although the above-noted authors propose two different models that explicate the entire process of dementia from diagnosis to death (based on research in the United States and the United Kingdom), the model proposed in this paper is unique in that it describes the early stage of dementia exclusively while offering a Canadian perspective on this devastating syndrome.

Methods

Design and Sampling

A qualitative grounded theory approach was used to explore the subjective experience of persons with early-stage dementia (Strauss & Corbin, 1998). Theoretical sampling was carried out to obtain six participants (three men and three women) with early-stage dementia (five with Alzheimer's disease and one with vascular dementia). Participants ranged in age from 61 to 79 years. All participants were in Global Deterioration Scale (GDS) (Youngjohn & Crook, 1996) stage 3 out of seven possible stages, with Modified Mini-Mental State examination (3MS) scores (Teng & Chui, 1987) ranging from 79 to 91 out of a possible 100. All participants were living in their home communities with their spouses. Four participants stated that they had participated in a support group for persons with early-stage dementia. Each participant was assigned a pseudonym. To ensure anonymity, the pseudonyms were assigned alphabetically in the order in which the participants were interviewed (e.g., participant #1: Mr. A. = Mr. Arnold). Inclusion criteria were: (1) diagnosis of Alzheimer's disease or related disorder, (2) early stage of dementia, and (3) all ages of onset of dementia (< 65 and > 65 years). In addition to meeting the above criteria, participants were selected on the basis of their ability to provide data relevant to the development of emerging conceptual categories.

Ethical Considerations

When recruiting people with dementia as research participants, the investigator should consider three issues: competence, ability to provide informed consent, and use of proxy consent. Resau (1995) notes that "a diagnosis of dementia is not necessarily synonymous with incompetency," since a person with mild or early-stage dementia may still be able to perform relatively simple routine tasks such as handling small sums of money (p. 57). The current consensus in the literature is that many individuals with dementia, particularly those in the earliest stages of the disease, are still capable of making numerous decisions competently, including the decision whether or not to participate in research (American Geriatrics Society Ethics Committee, 1998; Resau).

With regard to proxy consent, there is recent evidence that proxy decisions in favour of research participation do not always match dementia persons' decisions to participate in research (Sachs et al., 1994). As a result, the current best practice is to obtain informed consent from both the potential dementia participant and that person's proxy (Sachs et al.). The present study was approved by a university-based ethics committee and received consent from all dementia participants and their proxies.

Recruitment and Screening

In order to recruit participants from various agencies, the researchers supplied the agency contact persons with a one-page letter describing the study. Agency personnel distributed the letter to potential participants and then provided contact information for the study. The first author then phoned potential participants to arrange a meeting in their homes to further inform them about the study. Participants who provided signed consent (with their proxies) were interviewed during this first visit.

The first level of screening was the clinical assessment of early-stage dementia by the agency contact person. Interviews were conducted based on this initial screening. After the first interview, two screening instruments were used to confirm the participant's degree of cognitive decline (3MS; Teng & Chui, 1987) and stage of dementia (GDS; Youngjohn & Crook, 1996). Two potential participants were excluded from the study because their 3MS scores fell below the cut-off of 78 (McDowell, Kristjansson, Hill, & Hebert, 1997). Finally, participants' family physicians or specialists were contacted by mail in order to confirm the diagnosis of dementia. The authors did not ask participants the length of time since diagnosis, since their possible inability to remember due to dementia could cause undue stress and anxiety during interviewing. Neither was this information sought from physicians, since frequently a definitive diagnosis is not made on a specific date, but rather the diagnosis is made over time as the symptoms worsen and various tests rule out other possible diagnoses.

Data Collection

Data were initially collected from participants using a semi-structured interview format based on previous research (Keady & Nolan, 1995). Each participant was interviewed twice. Proxies were allowed to be present during the interview process but were informed that the purpose of the interview was to elicit the perspective of the person with dementia. Once transcripts from the first interviews were coded and analyzed, a preliminary theory comprising six categories was identified. A second interview was conducted with each participant for the purpose of verifying and clarifying the emerging theory. During this second interview (1 to 3 months later), the interview process evolved and became more unstructured and open-ended as clarification was sought on issues that emerged in the previous interview.

Data Analysis

Data were analyzed using constant comparison analysis to identify core concepts that described the experience of living with dementia from the perspective of the person with early memory loss (Strauss & Corbin, 1998). Negative case analyses were also carried out by including participants who had different types of dementia (i.e., Alzheimer's disease and vascular dementia). Data analysis was conducted using three types of coding: open coding, axial coding, and selective coding (Strauss & Corbin). Coding was facilitated by the use of Nvivo qualitative analysis software. During the process of coding the first interviews, five preliminary categories emerged from the data, which the first author "validated" and expanded on based on the second interviews (Strauss & Corbin, p. 159).

Findings

The theory that emerged from the interviews can best be described as a *continuous process of adjusting to early-stage dementia.* The process consists of five core categories or stages that evolve over time, namely *antecedents, anticipation, appearance, assimilation,* and *acceptance* (see Figure 1). The participants described a process of adjusting to early-stage dementia beginning with various *antecedents* and progressing through the next four stages of the model with differing levels of *awareness* connecting each stage to the next. The findings that follow explicate the sub-processes of these stages in greater detail based on the information obtained from the participants. Negative case analyses did not reveal any differences among participants.

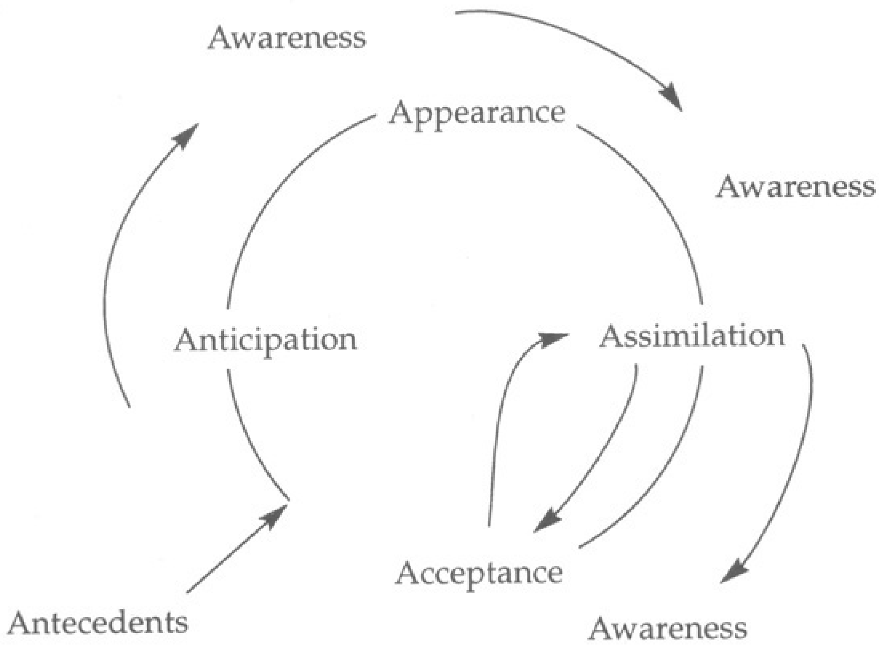
Antecedents

There were several sub-processes that preceded participants' being diagnosed with dementia. These made it difficult for participants to obtain a diagnosis of dementia.

Recognizing that a problem exists. At the beginning of the interview process, participants were asked what they first noticed when they began experiencing difficulties with their memory. Not surprisingly, five of the six participants responded that they were not aware that they even had a problem with their memory when the dementia began. The following statement illustrates this point:

> *Actually, I don't think I really realized at the beginning that I had memory loss. I'd say, "I can't think of it right now," if somebody asked me something, and I didn't realize I had memory loss.*

Figure 1 *The Continuous Process of Adjusting to Early-Stage Dementia*



This initial reaction appeared to be due to the insidious onset of symptoms that the participants with Alzheimer's disease referred to, which some attributed to benign forgetfulness or stress at work. Unlike the other participants, who described an insidious onset of symptoms, one participant described experiencing an acute onset of what she said her physician called "vascular dementia." She described the beginning of her memory loss as follows:

> *I was crocheting this one day and all of a sudden it was just like if somebody had taken something sharp and just jabbed it into here [pointing to her forehead] and it cracked, and I just yelled, "Ouch!"*

The other five participants cited various reasons for deciding to seek medical assessment, most commonly due to the progression of their memory loss.

Recalling previous memory quality. When participants discussed the onset of their memory loss, many inevitably spoke about what their memory was like before the dementia began. During the first interview, one participant suggested that his memory was not good even before he was diagnosed with Alzheimer's disease:

> *Remembering at any time in my life, I mean, playing bridge was never a big thing, and any card game for that matter, you had to remember...memorize your numbers.... It wasn't my bag.*

In sharp contrast, one participant remarked that her memory was excellent before the onset of dementia. Because the change in her memory was so drastic, both she and her husband were initially quite upset about her memory loss:

> *I feel I'm very forgetful, and I think that bothered [my husband] so much...because I've never been like that. I've always had an excellent memory. But that was a very hard, hard thing for me, to not be able to remember things, because I just never had that experience before.*

Identifying family members with and without dementia. Another issue participants raised in relation to being unaware, initially, of their memory loss was whether any family member had ever been diagnosed with dementia or Alzheimer's disease. Participants who had a family history of other diseases such as cancer or heart disease often said they expected to develop one of these diseases rather than dementia:

> *I was thinking I'd maybe [get] cancer or heart disease or some damn thing, because that's what was in my family. My dad died of...angina, and my mother had cancer.... I expected one of them anyway [laughs] ...not this one.*

Confounding health problems. Finally, some participants described facing other complex health problems prior to being diagnosed with dementia, which made it difficult for them to identify which disease process was causing the memory loss, decreased attention span, and fatigue. For example, one participant explained that he had suffered from attention deficit since childhood and initially attributed his memory problems to his attention deficit disorder rather than dementia. Another participant, who was receiving radiation treatment for prostate cancer, voiced the following concern:

> *I'm overly tired, but I don't know whether that has anything to do with Alzheimer's or whether it's something else.*

In summary, the sub-processes of the *antecedents* stage were precursors to participants seeking medical attention and subsequently obtaining a diagnosis of dementia.

Anticipation

Once participants recognized that they were experiencing difficulties with their memory and sought medical help for this problem, they described moving to the next step, *anticipation.* They discussed *anticipating* the diagnosis, their reactions to learning that they had dementia, and speculating about possible causes. Many participants recalled *anticipating* what losses they might face in the future, how they would become dependent on others for their basic needs, and how others would react when they learned that the participant had memory loss.

Obtaining a diagnosis. Although they used different words and phrases to describe their feeling when they learned they had early dementia, the participants' common reaction could be described as shock, horror, and disbelief. The following excerpt vividly describes one participant's response to the news:

> *That was quite an experience...because he did all these tests. He sat down and he said, "Well, I think you've got Alzheimer's." Like, there was no...nothing else but... No, he didn't say, "I think"; he said, "You have Alzheimer's." Well, I was just devastated.*

Some participants also tried to determine what might have caused their dementia. One participant wondered whether having his eardrum punctured accidentally by a physician and needing to have it surgically repaired could have caused his memory loss. Another participant described consistently waking up with severely reddened eyes, which she thought might be related to her memory loss.

Considering future losses. After the initial reaction to their diagnosis, the participants soon wondered what restrictions the dementia would impose on their lives. The issue of "becoming a burden" to their spouses became central as they anticipated slowly losing the ability to care for themselves. One participant described her reaction to being diagnosed with Alzheimer's disease as follows:

> *I think maybe I could probably handle somebody telling me I had whatever, but when it's your mind it's just really devastating, because you think, oh, how long is it going to be until I'm going to be a burden? That's one of the first things you think of...like, how long is it going to be before I'm a...I'm not able to look after myself and I have to have [my husband] doing everything for me.*

Other participants expressed concern about losing the intellectual and social abilities and skills necessary to function as productive members of society: "I'm staying in contact with everybody, just so I don't just become a blob."

Some participants remarked that they expected to need help as their disease progressed. Indeed, some pointed out that they were already relying on the assistance of others, especially their spouses, to serve as a memory aid. Most participants were observed doing this during the interviews. For example, when asked if he was still working, one participant replied, "Oh, I retired," and, after pausing for a few seconds, turned to his wife, who was sitting in the adjoining room, and asked, "What year did I retire?"

Telling others. Finally, in the anticipation stage, participants unanimously recalled feeling anxious about how others would respond if and when they discovered that the participant had memory loss. Two primary factors they considered when contemplating whether to disclose their memory loss were how people might react if they knew about the dementia and how people had reacted when they discovered the participant had memory loss. One participant explained why she had not disclosed her memory loss:

> *I haven't really told anyone else, because I figure if they know they're always watching for you to do things that are not what you should be doing. [chuckles]*

Appearance

Telling others was closely linked to the next stage of the process, *appearance,* in which participants began to consider that others were *noticing* their memory impairment, how others viewed them in light of their memory impairment, and how they saw themselves as persons with memory loss.

Noticing the sufferer's memory loss. Two different components of this category became evident in the data. Looking back at the onset of their dementia, the participants recalled slowly becoming aware that family members, friends, or co-workers were "noticing" their memory loss although they themselves were not aware or were only beginning to become aware of their memory deficits. Similarly, as participants became increasingly aware of their memory impairments, they became greatly concerned that others were also noticing these deficits.

Most of the participants recounted hurtful situations in which others were insensitive or indifferent to what the dementia sufferer was experiencing as a result of the disease process. Perhaps most unsettling was the fact that often these painful situations occurred at the hand of a family member, friend, or co-worker. For example, when the first author asked one participant how she knew that members of her women's group were "gossiping" about her memory loss, she replied, "Well, because they'll go and talk to themselves…and then look at me." As a result of this experience, the participant and her husband decided not to tell anyone about her memory loss when they moved to a large city. She said, "I just cover it up and no one knows."

Seeing self as the "same person." Finally, the participants also addressed how they viewed themselves since being diagnosed with dementia. All the participants described feeling that they were "still the same person" despite the memory impairments they faced. When asked what she thought other people should know about living with memory loss, one woman eloquently summarized what other participants expressed in different words:

> *Maybe it's important that, although you have a memory loss, you haven't lost your mind completely, you know.... You've lost your memory but you haven't lost your mind. And you're still the same person, and you do make mistakes when you're...when you repeat yourself, but you're still knowledgeable, you're still the same person, and I think it's important that people realize that you don't change. I mean, things...your life changes, of course, but you're still the same person inside...at least I think I am. [laughs]*

Assimilation

The fourth stage in the process of adjusting to early dementia was a sub-process called *assimilation. Assimilation* refers to the process of "fitting the dementia" into one's life, similar to the way one might learn to adapt to a physical disability such as adult-onset blindness. First of all, the participants described assimilating the disease into their *inner world*, which included their personal feelings and thoughts about the disease, the need to educate themselves about memory loss, and some of the physiological changes that occurred as a result of the disease. When asked if he had any concerns at the time of diagnosis about things he eventually might not be able to do, one participant replied:

> *When we walked out from [the physician's office] we were handed a brown envelope about it.... And that's what you got from [the physician], and he is a specialist...I didn't feel that they really gave us anything to guide us. I mean, he said, did we know ourselves. Well, we didn't know. I mean, we were looking for answers. So we finally said, hey, something's got to happen here. I mean, we hear about things in brochures, we hear about things on the radio and stuff like that, and we are not getting any smarter here, which is when we sort of decided to drop in to [the Alzheimer's Society].*

Secondly, participants described assimilating the disease into their *outer world*, which included incorporating lifestyle changes related to their memory loss, interacting with supportive and unsupportive significant others, and relating to other persons with dementia. Referring to the support group she attended, one participant explained:

> *...there's people that are about in the same stages as I am, and I think that's important.... And we talk back and forth about things we do and things we do wrong and stuff, and I think that helps a lot. It doesn't make you feel so isolated.*

Discussions with participants revealed that, like the larger process of adjusting to early memory loss, this sub-process of *assimilation* was cyclical and continuous, the end result being increased *acceptance* of the disease. The transition from the *inner world* to the *outer world* was facilitated by *positive mediating experiences* such as feeling supported and accepted by significant others, retaining certain skills and abilities that gave life meaning and purpose, and being able to relate to others who were experiencing memory loss or other conditions. *Negative mediating experiences* such as progression of the disease, feeling unsupported or unaccepted by others, feeling unable to function in social or work situations, or simply having an unexplained setback and wanting to "give up" or "quit" resulted in participants "retreating" or "withdrawing" into their *inner world*. Retreating into their *inner world* served as a coping mechanism whereby participants were able to deal with the negative experience internally and decide how they wanted to proceed with their life from that point on.

Acceptance

The last step in the process of adjusting to early dementia was *acceptance*. Throughout the interviews, participants discussed various aspects of *acceptance* in relation to having dementia. Clearly, the most salient step in the process of adjusting to dementia was learning to *accept* the disease as an integral, albeit unwelcome, component of one's life. One woman summarized her acceptance of her memory loss as follows:

> *I think I am very fortunate. I have really managed to accept it and to say that I'm a lot luckier than a lot of other people. I could be a lot worse. I still can do my [lay ministry work], I still can see my kids, I can still do things that I like doing, and I think you have to sometimes just be grateful for what you have.*

Participants recounted a number of factors in their acceptance of memory loss, notably others' acceptance of the disease, using humour to cope, maintaining hope, and, finally, wanting to help others. Alluding to his sense of hope, one participant confessed during the second interview:

> *In my mind I still feel like I'm going to beat this, but then after reading about it I know there's no cure.*

Later in the interview, the first author tried to determine whether he believed this was his way of maintaining some hope about his illness, to which he replied:

> *Yeah, yeah. And it helps me in a way, because I think I am accepting the fact but I still have a bit of hope that it may not be actually Alzheimer's.*

Having adopted a variety of these coping methods, the participants unanimously described having achieved a degree of acceptance of their disease, which permitted them to focus on enjoying the remainder of their lives rather than dwelling on their illness.

Awareness

Awareness was a common link connecting each stage of the adjustment process to the next. It became readily apparent after all the first interviews had been completed that the participants' *awareness* had gradually developed and changed. Reflecting back on her reaction to the news that she had Alzheimer's disease, one participant described her thoughts as follows:

> *One of the things I thought of right away was, oh, I hope I live to see my grandchildren graduate. But I think that was quite normal because I just...of course, being a grandmother, you always do adore your grandchildren, and I always thought it would be so wonderful to see them graduate and get married and...all of a sudden I thought I might not ever be able to do that. And that would really bother me.*

As the participants discussed moving through the various stages in the process of adjusting to their memory loss, they demonstrated considerable insight and awareness about themselves, their disease, and, finally, those around them. An example of this insightfulness is one participant's description of his family as treating him "like a leper" upon learning he had Alzheimer's disease. When the first author asked how he currently felt about his family's attitude towards him and his dementia, he replied:

> *It doesn't bother me any more, but it did at first...I had the concept that, well, "he's not all there," and [I was] very seldom asked for an opinion or anything of that nature.*

As participants became more comfortable living with their memory loss, their awareness began to change from highly introspective to more outwardly focused, particularly in their interactions with others.

Discussion

Theoretical and Clinical Implications

Support for the various components of the proposed model are found interspersed throughout the literature on early dementia, chronic illness, mental illness, and stigma. One of the concerns Phinney (1998) identified through interviews with dementia sufferers was that the unpreditability of changes in symptoms left them "with a feeling of uncertainty" (p. 11). In other words, escalating anxiety and uncertainty during the *anticipation* stage may be the result of participants perceiving their memory loss as a threat to their sense of order and personal control (Bahro, Silber, & Sunderland, 1995; Gwyther, 1997; Nygard & Borell, 1998). Nurse-clinicians and researchers should be cognizant of the emotional strain endured by dementia sufferers and seek to minimize any further emotional distress that may result from the interview process during a nursing assessment or research study. One means of minimizing distress may be to conduct assessments or interviews in the dementia sufferer's home, as was done in this study and recommended by Cotrell and Schulz (1993).

Although denial has been identified as a common coping method among individuals with early memory loss (Bahro et al., 1995; Cohen et al., 1984), evidence of denial did not surface in this study. On the contrary, participants demonstrated a striking openness and willingness to talk about their memory impairment and its effects on their lives. However, some participants did describe employing avoidance and conscious detachment in response to negative events (e.g., gossip), as opposed to unconscious defence. Intellectualizing the disease (e.g., by educating oneself about it) was another conscious means used by participants to assimilate it into their lives.

One of the factors participants saw as instrumental in the assimilation process was connecting with and learning from other dementia sufferers in support groups. The literature cites numerous ways in which self-help and support groups help people to adapt to chronic illness. In a phenomenological study with chronically ill adults, Michael (1996) found that "seeking support helped people feel connected/less isolated and helped them understand what others had done to deal with their illness" (p. 261). Similarly, Collins, Hooton, and Thirkettle (1999) found that participants who were members of a support group appreciated the opportunity to talk with other dementia sufferers about their life situations, feelings, and experiences. The participants in the current study who attended a support group identified all of these benefits. These findings clearly indicate that more support groups should be established for persons with early-stage dementia. Research into the design, function, and efficacy of such groups, once established, could serve to ensure maximum benefit for participants and to secure funding to staff them with educated personnel such as nurses.

Many of the participants in the current study indicated that lack of support from family and friends hindered them from accepting their dementia. Collins et al. (1999) report similar findings. These researchers also found that family members treated the person with dementia "very differently," which contributed to the sufferer's stigmatization and negative self-perception (p. 98). In the current study, supportive family and friends played a key role in enabling participants to come to terms with their memory loss. Based on this finding, nurses can play a role in educating family members and others in the importance of learning to understand and support persons in the early stages of the disease.

Another implication concerns the clinical approach of health-care professionals who work with people with early-stage dementia. For example, one participant explained that the insensitivity of her physician in blurting out to her the news that she had Alzheimer's disease had discouraged her from asking the physician questions about the diagnosis. Michael (1996) found that the insensitivity of health-care professionals contributed to feelings of loss among chronic disease sufferers: "In seeking health care, patients had hoped to be seen as more than their illness and to find help in living with their illnesses. Instead participants felt insignificant and misunderstood" (p. 263). Participants in the current study shared similar feelings about their experiences with health-care professionals. These findings suggest that nurse clinicians and researchers must become aware of the impact of their verbal and non-verbal communication on early-stage sufferers. Clinicians and researchers should adopt an individualized, unhurried approach in working with early-stage sufferers, and should demonstrate their recognition of and respect for the unique difficulties and concerns of these persons.

Research Implications

Some of the participants commented that they received insufficient information from their physician at the time of diagnosis. Research into this area could look at the kinds of information that newly diagnosed sufferers want, who they would expect to dispense such information, and the form that such information should take. Based on the participants' comments as well, an equally important area of dementia research concerns the issues of stigmatization and its effect on self-esteem, adaptation, and acceptance of the disease. As persons are being diagnosed earlier in the disease process, it is becoming increasingly important to identify the coping methods that early-stage sufferers employ and whether they facilitate or hinder adaptation to early dementia.

Limitations of the Study

Several factors may influence the transferability of these findings. First, it should be noted that saturation was reached relatively quickly in the study, with a sample size of only six due to the homogeneity of the sample. For example, these participants represented a relatively well-educated group (all had completed Grade 10 and several had some post-secondary education), which would account for their ability to articulate and describe their experiences in living with the disease. In addition, all of the participants were married, financially secure, and retired from work outside the home. Second, the participants volunteered to take part in the research, which suggests that they had achieved a measure of acceptance of their disease before enrolling in the study. As a result, the findings of this study should not be generalized to all early-stage sufferers but rather be used as preliminary findings that may shed some light on the issues to consider when sampling early-stage sufferers for dementia research.

Another factor to consider is that four of the six participants had attended or were attending a support group for persons with early dementia. The support of and contact with other sufferers was instrumental in their adjustment to early dementia. Dementia sufferers who do not have contact with other sufferers may in fact experience greater difficulty in adjusting to their memory loss. Because support-group participation significantly influenced the findings of this study, it would not be appropriate to generalize the results to early-stage sufferers who have not been part of an early-stage support group.

A final possible limitation concerns the technique of negative case analysis as used in this study. Many factors, such as the stigmatization of the disease and the fact that the disease is often not diagnosed until it has progressed, made it difficult to obtain a sample of early-stage sufferers. Because of this difficulty in obtaining a sample, true negative case analyses could not be conducted by selectively sampling participants to expand on emerging categories. Nevertheless, some negative case analyses were performed indirectly by sampling participants based on characteristics such as age, gender, type of dementia, and age of onset.

Conclusion

Although the current study began as a general exploration of the process of learning to live with early dementia, the depth and breadth of insight revealed in the interviews permitted the development of a preliminary theoretical framework of how persons with early-stage dementia learn to live with their memory loss. Theory development from the voice of the person with dementia makes this study unique. Previous studies have been almost exclusively descriptive in design (Bahro et al., 1995; Phinney, 1998) and have focused on caregiver perspectives (Freyne et al., 1999; Luscombe et al., 1998; Nankervis et al., 1997). From a nursing perspective, the proposed framework offers a base of valuable information to nurses working with persons who have early-stage dementia, while the core concepts provide a foundation for future research to test the applicability of the model in the larger population of persons with this devastating syndrome.

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Mothers' Perspectives of an In-Home Nursing Respite Service: Coping and Control

Beverley J. Valkenier, Virginia E. Hayes, and Pamela J. McElheran

Quelles sont les expériences des mères relativement aux services de relève à domicile qu'elles reçoivent pour les aider à soigner un enfant à la santé fragile ou qui souffre d'un problème médical complexe? Le présent article met en lumière les conclusions d'une étude exhaustive de deux ans qui visait à évaluer les retombées d'un programme canadien de soins infirmiers de relève. Des données ont été recueillies à trois reprises aux domiciles des 27 familles participantes, au moyen de méthodes quantitatives et qualitatives. Les auteurs présentent un concept élaboré à partir des entretiens non structurés et de leurs observations, à savoir apprivoiser le système. Un sous-ensemble de 10 mères a été choisi pour effectuer une analyse comparative constante de leurs points de vue, laquelle a permis de déceler un processus en 4 étapes : *intégration, perte de la maîtrise, prise en charge* et *gestion efficace en fonction des contraintes imposées par des règles rigides.* Ces résultats devraient permettre d'approfondir les connaissances en matière de soins de relève, dans le but de répondre adéquatement aux besoins des mères qui soignent un enfant aux prises avec un problème médical complexe.

What are mothers' experiences of receiving in-home nursing respite care for their children with medically fragile or complex conditions? This paper highlights selected findings from a comprehensive 2-year study designed to evaluate the impact of a Canadian nursing respite program. Data were collected at 3 time points in the homes of 27 families, using both quantitative and qualitative methods. This paper reports on 1 construct arising from unstructured interview and observational data: *learning to manage the system.* A specific subset of 10 mothers was chosen for constant comparative analysis of their perspectives of receiving in-home nursing respite, revealing a 4-phase process: *taking in, losing control, taking charge,* and *managing effectively within the constraints of inflexible rules.* These findings contribute to nursing knowledge about meeting the in-home respite needs of mothers of children with complex medical conditions. Implications for nursing include how to better support maternal coping, decrease uncertainty, and foster more effective relationships with mothers of children with complex conditions.

Beverley J. Valkenier, RN, MSN, is Lecturer, University of British Columbia, Vancouver, Canada. Virginia E. Hayes, RN, PhD, is Associate Professor, School of Nursing, Lower Mainland Campus, University of Victoria, British Columbia, Canada. Pamela J. McElheran, RN, MSN, is Acting Program Director, Sunny Hill Health Centre for Children, a part of the Children's and Women's Hospital of British Columbia.

Children with medically fragile conditions, including those who are dependent on life-sustaining technological equipment, are increasingly being cared for in their communities, usually in the family home (Kirk, 1998; Kohrman & Kaufman, 1997; Perrin, Shayne, & Bloom, 1993). It is believed that home-based care is better for children's social, emotional, and psychological development than long-term institutional care (Thompson & Gustafson, 1996), but possibly at a cost to community-based caregivers, usually their parents. Although care for children with chronic conditions, disabilities, or special needs is demanding for each family member and for the family as a whole (Hayes, 1992; Knafl, Breitmayer, Gallo, & Zoeller, 1996), in most cultures the primary responsibility for home care falls to the mother. Due to the complex nature of care demands, parents of such children frequently experience high levels of stress, burnout, and mental and physical exhaustion (Eiser, 1993; Kirk, 1998; Perrin et al.; Wade, Taylor, Drotar, Stancin, & Yeates, 1998). In addition, mothers are uncomfortable leaving their child with friends or relatives due to the complexity of the care required and the need for high-level skills and knowledge (Diehl, Moffitt, & Wade, 1991; Kirk, 1998).

The Canadian Association for Community Care (1996) defines respite care as "a service whose main function is to relieve the parent/family/primary caregiver for a specific period of time while facilitating a positive and rewarding experience for the child with a chronic illness" (p. 5). There is evidence that technology-dependent children usually require the services of registered or licensed practical nurses because of the specialized knowledge needed to manage the complex equipment (Olsen & Maslin-Prothero, 2001; Sherman, 1995). The literature suggests that while attempts have been made to put appropriate and comprehensive services in place for families to safely care for their children at home, there are some oversights and service gaps that significantly contribute to family members' stress and inability to cope with the child's care demands. Notable among the service gaps is the lack of *nursing* respite care (Bamford, Griffiths, Long, & Kernohan, 1997; Robinson, Jackson, & Townsley, 2001; Spalding, Hayes, Williams, & McKeever, 2002; Wegener & Aday, 1989; While, Cornish, & Citrone, 1996).

To date, there has been little published research that has looked specifically at the benefits of nursing respite programs for caregivers of children with complex care needs (Breckbill & Carmen, 1999; Hazlett, 1989; Olsen & Maslin-Prothero, 2001).

This article reports on one component of a comprehensive evaluation of nursing respite services. The findings reported here address, in a subsample of mothers in the overall study, the question: *How do mothers who are primary caregivers of children who are dependent on technology at home view the role of nursing respite in managing their stress and increasing their coping ability?*

Literature Review

Children Who Are Technology-Dependent

Since the early 1980s there has been a rising trend towards parental in-home care of children who are dependent on ventilators, oxygen therapy, and parenteral nutrition. Common sources of stress identified by the families of such children are: persistent gravity of the situation, fears about their own medical/nursing incompetence, inadequate respite care, financial burdens, constant fatigue, social isolation (Stevens, 1990, 1994), and continual adherence to the child's care regime (Wegener & Aday, 1989; Youngblut, Brennan, & Swegard, 1994). Obtaining, keeping, and maximizing respite care continues to be a major challenge for many North American families of children with demanding home-care needs (Capen & Dedlow, 1998; Cernoch & Newhouse, 1997; Spalding et al., 2002).

Mothers as Caregivers

For most families in North America, it is the mother who assumes the primary child-care responsibilities at home (Bridges & Lynam, 1993; Eiser, 1993; Robinson, 1997). Mothers' personal sacrifices include giving up their careers and the attendant personal and financial losses. Some authors report that caring for children with special needs at home is worrisome and a constant struggle for mothers (Miles, Holditch-Davis, Burchinal, & Nelson, 1999; Monsen, 1999), requiring heightened vigilance (O'Brien, 2001). Furthermore, living with uncertainty (Cohen, 1995; O'Brien; Sparacino et al., 1997) contributes to mothers' stress and lack of flexibility in their lives. The stress of caregiving can strain a woman's personal resources and lead to mental and physical exhaustion.

Parental Stress and Coping in Children's Chronic Illnesses

Due to high stress levels, mothers of chronically ill children commonly suffer from chronic sorrow, depression, loneliness, and a lack of support

(Florian & Krulik, 1991; Gravelle, 1997; Miles et al., 1999; Monsen, 1999; Phillips, 1991) and often complain of feeling trapped (Brinchmann, 1999; Hendricks, De Moor, Oud, & Franken, 2000), chronic fatigue, guilt, anger, anxiety about the future (Gravelle; Murphy, 1991), social isolation (Brinchmann; Murphy; Stevens, 1990), and a lack of leisure time (Geary, 1990; Hayes & McElheran, 2002). The above studies, and an excellent review by Kirk (1998), reveal that the primary caregivers of chronically ill children experience significant physical, emotional, and social strain.

Knowledge about the child's condition and treatment and the skills to safely care for the child in a non-medical environment are essential means of parental coping (Gravelle, 1997; Hall, 1996; Sterling, Jones, Johnson, & Bowen, 1996). Heinzer (1998) found that parents directed their energies towards the special needs of the child rather than their own health and that of other members of their family. In the chronic-illness literature, social support is identified as one of the key resources for increasing individual family members' ability to cope (Dunst, Trivette, & Deal, 1988; Ray & Ritchie, 1993; Sterling et al.). Primary caregivers have identified the support of spouses, members of the immediate family, and friends as more valuable than that of health-care professionals (Florian & Krulik, 1991; Geary, 1990; Stevens, 1990).

Professional support is, however, critically important for families who have children with complex home-care needs. Mothers report that even when several family members have been trained to care for the child, it is difficult to provide care at home without some form of outside assistance (Dunst et al., 1988; Hayes & McElheran, 2002; Kirk, 2001; Ray & Ritchie, 1993). Parents in Olsen and Maslin-Prothero's (2001) study valued nursing respite support because it allowed them time to catch up on their sleep, recover emotional strength, and attend to their own personal hygiene. While the mothers in these studies did believe that respite was important, the majority felt it was inadequate. Despite receiving respite services, mothers still experienced significant levels of stress from caregiving.

Nursing Respite for Technology-Dependent Children

Children with medically complex conditions require specialized care and, when the caregivers need a break, respite care by a registered nurse (Aday & Wegener, 1988; Sherman, 1995; Stevens, 1990, 1994). Respite caregivers must be able to assess and respond to the changing needs of medically fragile children and be competent in the use of such technologies as tracheostomies, respirators, and suction equipment.

Parents find it difficult to deal with home-care nursing (Diehl et al., 1991; Murphy, 1991). They complain about poorly trained nurses and poor care, staffing inconsistencies (Hayes & McElheran, 2002; Murphy, 1991), and insufficient numbers of nursing respite hours (Gravelle, 1997; Petr, Murdock, & Chapin, 1995; Sherman, 1995; Stevens, 1990). All the parents in Sherman's study reported that nursing respite decreased mothers' somatic complaints (anxiety and depression). Parental caregivers experience less stress if they receive respite services. However, many mothers report that while nursing respite has many benefits, it can be a mixed blessing (Hayes & McElheran; Olsen & Maslin-Prothero, 2001; Ray & Ritchie, 1993).

Our practice experience and literature review identified a significant gap in knowledge on the effectiveness of current nursing respite programs in meeting the needs of families, particularly the needs of mothers of technology-dependent children. Program evaluation research is essential if policy-makers and service providers are to be informed about how best to meet the needs of this population (Tan, Hayes, & Hollander, 2000). Clearly, policy does not target families with high service needs in ways that adequately support them in caring for children with complex health conditions. While the shift to community-based health-care delivery may be saving governments and funding agencies a significant amount of money, it appears to be at significant cost to the well-being of primary caregivers and families. This study was a first step in exploring parental coping, particularly mothers' experiences with nursing respite services in the home setting.

Sensitizing Concepts

This component of the study was based upon two sensitizing concepts: stress and coping. These sensitizing concepts provided global boundaries for the exploration of the phenomenon of interest — mothers' responses to an in-home nursing respite program. Psychological stress was defined as "a particular relationship between the person and the environment that is appraised by the individual as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p. 19). Coping was defined as "constantly changing cognitive and behavioural efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, p. 19).

Method

The original study was a single-sample, descriptive evaluation carried out at three points: before starting the Nursing Respite Program (NRP), and 6 and 12 months after starting the NRP. The study included both quantitative and qualitative components. The quantitative analysis examined outcome measures relating to an number of variables: overall annual costs of the child's care, nature of nursing care, changes in the child's activities of daily living, and changes in caregiving demands for parents. The qualitative component was intended to draw a picture of parents' perceptions of how respite services affected their lives. This paper reports on the qualitative component for a subset of 10 mothers who were caring for technology-dependent children at home. A secondary constant comparison analysis was used to examine the transcribed interviews of the 10 mothers in discussing their experiences with an in-home nursing respite program (Hinds & Vogel, 1997; Strauss & Corbin, 1998; Thorne, 1994).

Sampling

The sample for the main project included all families (sequentially) newly admitted to the British Columbia NRP over a period of 15 months commencing in April 1994. A total of 27 families took part. There were incomplete data sets for nine of the 27 families (two families withdrew, four children died during the research, and three families were discharged from the program). The selection criteria were that all family members consent to participate and be able to speak and read English well enough to speak with a researcher and complete the pen-and-paper instruments (used for the quantitative evaluation), and that the child not be palliative. The criteria for inclusion in the current subset were that families participate in all three data collections and that the parents and observations speak to the issues of respite and parental stress and coping.

True theoretical sampling, as is customary in grounded theory, was not employed due to the inflexibility of the quantitative data collected. Nonetheless, parents and families were all excellent informants for the phenomenon of interest. The report presented here is based on a subset of the qualitative data, which was examined for theory related to the process of mothers' adapting to respite — from their own perspectives. The sample will be described below.

Data Collection

Ethical clearance was obtained from the University of British Columbia human ethics review committee. Data were collected using unstructured interviews (conversations) and participant observation. Typically, a home visit began with a general observation about the family situation, the complexity of care, and the progress of (or desire for) nursing respite services. The unstructured format encouraged participants to share their thoughts on home caregiving and respite. Family conversations were audiotaped and transcribed verbatim along with the researchers' dictated, detailed field notes.

Analysis

Transcripts, field notes, and coding memos were read to get a general sense of the themes in the data. Careful attention was paid to Strauss and Corbin's (1998) recommended analytical steps, a constant comparative method of collecting and analyzing data. Open coding began simultaneously with the reading of the first transcription and naturally progressed through the other analytic phases of axial and selective coding. As the analysis progressed, questions were asked of the data — for example: Why do some mothers seem to be content with the number of nursing respite hours they have qualified for, while others feel the need to advocate for their children and their situation? In the process of axial coding, relevant concepts emerged that were later condensed into categories and their properties and dimensions. Finally, the relationships between the relevant categories were determined, and the constant comparative method of data collection and analysis continued until there was saturation of all the relevant categories. During selective coding, a core variable was conceptualized that encompassed everything in the mothers' stories about the role of nursing respite in decreasing their stress and increasing their ability to cope: *learning to manage the system*.

Description of Sample

In all 10 families selected for this analysis, the mother was the primary caregiver. Seven of the mothers were married to the child's father. One had never been married to the child's father. Another had become separated from her husband since the birth of the child. One couple was an Associate Family who had been caring for the child for 8 years. (This British Columbia program remunerated families for caring for children in their homes, similar to foster families, with the biological parents remaining involved in the child's life.)

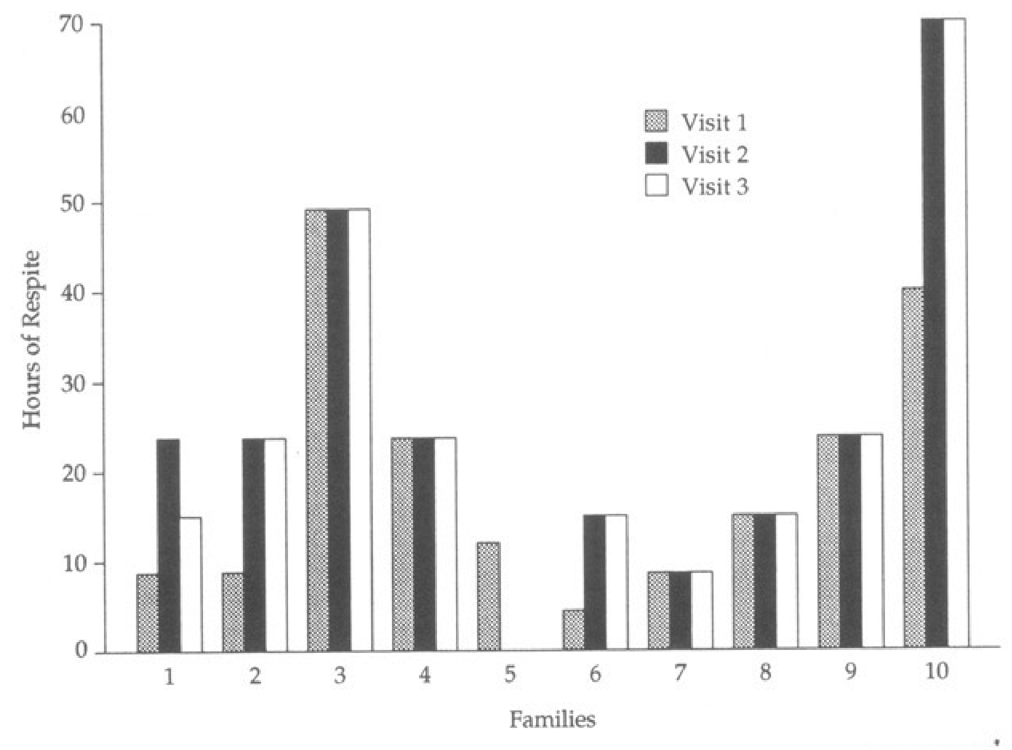
At the time of enrolment in the respite program, the technology-dependent children, consisting of five boys and five girls, ranged in age from 5 months to 16 years; there were seven infants (< 1 year of age), two toddlers, and one adolescent (see Table 1). The children's diagnoses varied considerably. They included: bronchopulmonary dysplasia, seizures, short gut syndrome, Nager syndrome, chronic renal failure, and tracheal malasia. The primary reasons why the children qualified for nursing respite were tracheostomy ($n = 2$), gastrostomy tube feedings ($n = 7$), home oxygen ($n = 6$), jejunostomy tube feedings ($n = 1$), and TPN ($n = 2$). Eight of the children were dependent on more than one of these life-saving measures.

Amount of respite. There was a wide range in the number of nursing respite hours the families were receiving at the time of the study (see Figure 1). The number of hours the family had been allocated at the time of the initial interview ranged from 4 to 70. In all but one instance the hours allocated per week were not flexible, meaning that unused hours from one week could not be saved for later. In the one family that had been assigned "flex" hours, the caregiver could accumulate unused time in order to have a larger block of continuous nursing respite hours.

Table 1 *Description of the Children*

Age	Diagnosis	Nursing Care
5 months	Bronchopulmonary dysplasia	O_2, C-pap respirator
5 months	Short gut syndrome	TPN, ostomy
8 months	Seizures	O_2, suction
8 months	Bronchopulmonary dysplasia	Tracheostomy care, G-tube
9 months	Short gut syndrome	TPN, G-tube
10 months	Bronchopulmonary dysplasia	O_2 therapy
10 months	Nager syndrome	Tracheostomy care, G-tube
21 months	Tracheal malasia	O_2, J-tube
2 years	Cerebral palsy, seizures	O_2 therapy
16 years	Chronic renal failure	Gastrostomy

Figure 1 *Allocated Hours of Respite*



Findings

The mothers in this grounded theory analysis told similar stories of *learning to manage the system* in order to maximize the benefits of nursing respite, specifically to decrease their own stress and increase their ability to cope. The core concept is seen to have four phases: *taking in, losing control, taking charge,* and *managing effectively within the constraints of inflexible rules.* In describing how they learned to manage the system, the mothers simultaneously illustrated a process of changing relationships with the health-care professionals in control of their child's care. These four phases have been named *blindly trusting, becoming enlightened, seeking effective collegial relationships,* and *establishing working relationships* (see Table 2).

The focus of this article is limited to a description of one of the findings: *learning to manage the system.*

The process of *learning to manage the system* started immediately when it became apparent to the mother that her child's condition was serious and needed tertiary-level medical intervention in order to sustain life. While the child was in hospital, the mother learned a great deal about her child's illness and care, how to deal with setbacks and

Table 2 *Learning to Manage the System*

Taking in	**Losing control**	**Taking charge**	**Managing effectively within the constraints of inflexible rules**
Learning the skills required for care Inflexible respite assessment criteria Assessment criteria do not tell the true picture	Transition from hospital to home Role of uncertainty System or program uncertainty Professional uncertainty Illness uncertainty Living with daily uncertainty	Learning the rules of the program Taking it one day at a time Taking control Keeping a positive outlook Just getting on with it Seeking social support	Mothers' recommendations for improving the program
Blindly trusting	**Becoming enlightened**	**Seeking effective collegial relationships**	**Establishing working relationships**

disappointments in her child's illness trajectory, and how to live with uncertainty. The period prior to the initiation of respite has been conceptualized as the *taking in* phase.

Taking In

During the *taking in* phase of *learning to manage the system,* the mothers spent a great deal of time and energy gathering information in order to assume the responsibilities of caregiving. The mothers' experiences with hospitalization were generally positive, and their stories reflect a trusting relationship with the health professionals involved in their child's care. Their stories revealed three variables that significantly affected their ability to *take in* information: *learning the skills required for care, inflexible respite assessment criteria,* and *assessment criteria do not tell the true picture.* These mothers felt that the NRP rules were too rigid, had the wrong focus, and did not consider families' "true situations." One mother described her feelings with the assessment phase as follows:

> *A nurse should go into the home for a week and assess the child and the whole thing, and get to see what the parent looks like every day, the main caregiver…because when you just come in for a 45-minute visit, or an hour and a half, you may see nothing. When they first came he slept through the whole visit so they thought he was okay; meanwhile they really didn't realize how bad it was.*

This mother's son had a severe seizure disorder, regularly experiencing eight seizures in a 24-hour period. She described her son's seizures as life-threatening because he would stop breathing and turn blue.

Prior to their initial contact with NRP personnel, the mothers carried their trust of the system over from their acute-care experiences and assumed that the child's transition from hospital to home would progress smoothly. They assumed that the NRP consultants would ensure that they received sufficient nursing respite to allow them to carry on a fairly normal life when their child was discharged home — meaning having time to do their chores both inside and outside the home and time for themselves (e.g., to exercise, read, visit their own physician).

As the time grew closer for nursing respite to begin, the mothers became disillusioned with the program. Most believed it would not live up to their expectations. Families whose respite commenced at or close to the time of discharge experienced less disenchantment with professionals than those who were left totally responsible for their child's care at home for some time. Simultaneously, this first phase of mothers' evolving relationships with the system's health-care personnel has been conceptualized as *blindly trusting*.

Blindly Trusting

Nine of the 10 mothers had developed good therapeutic relationships with the doctors and nurses during their child's initial hospitalization. They had learned to trust and depend on the professionals who cared for their critically ill child. Mothers believed that their future relationships with community-based providers would be the same. As it became clear that NRP and other community supports would be insufficient, their trust waned. The mothers assessed the adequacy of the number of respite hours on the basis of whether they were able to get enough sleep. Those who were able to get enough sleep generally viewed the program and their number of respite hours much more positively. One mother expressed her feelings in this way:

> *If you can get sleep all night, then you can handle the day. But it's when…you only get 2 hours of sleep in between each time…when you're up that much at night you can't function as well.*

When rest was inadequate and respite support seen as too little, the mothers felt their situations were not understood and their trust in community-based service providers was undermined. The next phase of *learning to manage the system* we have called *losing control*. The mothers experienced loss of control when care demands were excessive and they felt they were not coping.

Losing Control

The majority of mothers, at some point during the initial months of caring for their child, experienced a sense of *losing control*. They described this feeling as living with disorganization and various degrees of uncertainty. Their lives were unpredictable. They were unable to plan ahead or gain a sense of control over their child's and their own daily routines. One mother was extremely frustrated by the setbacks in her daughter's condition that delayed her projected initial discharge from hospital by 8 months. This rocky transition from hospital to home had a significant impact on her ability to cope:

> *They were going to send her home in May…. Then they discovered that her breathing wasn't very good…it set her back…and then…her feeding as well. They [the physicians] kind of jumped the gun, I think…. They were preparing us for discharge and they hadn't sorted her feeding out…*

> *That was May...end of May...and it's been, like, June, July, August, September — thinking she's coming home and then one thing after another. So it's frustrating.*

At the time of this conversation (before respite began), the mother was predicting that her daughter would be discharged about a month later. At the time of the next interview (6 months later), her daughter had been home for only 3 weeks. Even after an 8-month delay in her daughter's homecoming, the necessary supplies were not available right away: "She came home on Saturday and we never got our supplies until that Wednesday." This was the beginning of this mother's lack of trust in the system.

Living with uncertainty also significantly contributed to these mothers experiencing a loss of control. The mothers' accounts reveal four types of uncertainty: *program uncertainty, professional uncertainty, illness uncertainty,* and *daily uncertainty.* One mother expressed her feelings about *illness uncertainty* in this way:

> *In the back of your mind, over time he gets sick: "Is he going to make it through this?" And if you fretted about it all the time you'd drive yourself crazy. And the reality is, he may not make it through it, and that doesn't mean we love him any less — but it's painful, painful.*

Living with *daily uncertainty* markedly affected the physical and emotional well-being of these primary caregivers. For example, one mother described the toll that uncertainty took on her emotional health:

> *The time isn't there [to take care of anyone or anything else]... You're too tired...your brain is just in a frazzle and your nerves are jumping...you get to the point where you start snapping at one another and it's not because you want to...it's just like — boom, you explode — and then 5 minutes...you're sitting there and you're feeling sorry because you knew that it never should have happened. So then you apologize... I've broken down so many times from it, you know, from being tired.*

This young mother was expressing a lack of control over her emotions and her actions caused by exhaustion. The above quotation illustrates how *losing control* has interfered with her ability to cope effectively. During the *losing control* phase of *learning to manage the system* the mothers were also entering the second phase of their relationship with health-care professionals, named *becoming enlightened.*

Becoming Enlightened

Becoming enlightened meant that these mothers were coming to the realization that the NRP health-care personnel were not able to truly understand or empathize with their care responsibilities. Many mothers had expected to receive nursing respite services on demand and to have more choice in how and when they used their respite hours. The mothers did not remain in this second phase for long, because feelings of *losing control* were uncomfortable. As these mothers fought to gain a sense of control, they were naturally progressing to the next phase of *learning to manage the system,* named *taking charge.*

Taking Charge

In order to gain some control over their situations, the mothers used a number of coping strategies. *Taking charge* enabled them to focus on the positive aspects of their lives. Some examples of strategies they used are: (a) learning the rules of the program, (b) taking it one day at a time, (c) taking control, (d) keeping a positive outlook, (e) just getting on with it, and (f) seeking social support. Taking it one day at a time was a theme running throughout many of the mothers' stories. This is how one mother described the strategy:

> *No one knows what it's like until they experience it themselves, and everybody has a different way of dealing with things. The only thing is...you have to take it one day at a time and not get frustrated, because sometimes it's very frustrating, and you find yourself feeling very emotional about things, and you've just got to deal with it.*

Taking control for certain mothers meant fighting health-care personnel for what they believed they needed in order to cope. Three mothers had to fight "the system" to qualify for any respite hours, and another two mothers fought to receive more hours. The mothers found these battles exhausting and stressful:

> *A nerve-racking experience...I'm just so tired of the system and so tired of dealing with people and just always seeming to hit a brick wall constantly and just getting the run around, and we're just sick of it.*

Thus, during this phase, the mothers were beginning to take charge of the problems they were having with the NRP professionals and were entering the parallel relationship phase we have called *seeking effective collegial relationships.*

Seeking Effective Collegial Relationships

Despite the difficulties they were facing with various aspects of the NRP and the consultants who were its primary gatekeepers, the mothers started to accept the fact that they needed the support of these professionals in order to continue receiving NRP benefits. They began to compromise their expectations in order to receive maximum benefit from the nurses and the program. One mother who was initially denied services — and at the time of the third interview still felt she needed more respite hours — found positive things to comment on:

> *It's a really good program due to the fact it does help parents.... I really like the way they try to match the nurses to the medical needs of the child.... I'm sure lucky to have it, because if I didn't I don't know what I would do.*

The means that mothers used to cope in this phase were: *keeping a positive outlook, just getting on with it*, and *seeking social support*. When mothers were able to take control of their lives and were satisfied that their children were well taken care of by the nurses, they were progressing into the fourth and final phase of *learning to manage the system.* We have called this final stage *managing effectively within the constraints of inflexible rules.*

Managing Effectively Within the Constraints of Inflexible Rules

Managing effectively meant that mothers were able to exert maximum control over their lives. They were comfortable in their situations because they were able to predict certain outcomes in their own life and that of their child. This control was achieved mainly by using the coping strategies described in the *taking charge* phase of *learning to manage the system*. For example, mothers who focused on the positive were able to mobilize more strategies for dealing with their situations. One mother who adopted this attitude began to organize other forms of child care when she knew that respite services were going to be cut. Unlike many of the mothers in our study, she felt comfortable having family members care for her daughter. In the weeks prior to respite services being cut, this young, single, working mother trained her sister and her daughter's maternal grandmother to take over child-care responsibilities.

Establishing Working Relationships

Establishing working relationships meant that mothers were able to reconstruct a relationship of trust with health-care professionals. This trust was based on their ability to accept the limitations as well as the strengths of the professional. All 10 mothers spoke of the many positive aspects of the NRP and described having established trusting therapeutic relationships with the consultants and the nurses providing care. At this time, as at any other time in the transition to establishing (good/functional) relationships with community-based health-care professionals, the relationship could regress. We noted that the "roller-coaster ride" was influenced by threats to the stability of mothers' lives, such as frequent turnovers in nurses, cuts in the number of respite hours, or deterioration in their child's condition.

Discussion

The findings from this research show that mothers receiving a nursing respite program progress through a four-stage process of *learning to manage the system*. This is not an easy road. The participants indicated that they faced an uncertain future with their children and the process of building a relationship with health-care providers required more work and energy than they could sometimes give, as they struggled to care for their child within the demands of family and community life.

Among those who care for the chronically ill at home, living with uncertainty is now a familiar concept (Cohen, 1995; Stewart & Mishel, 2000). In their recent synthesis of the pertinent literature, Stewart and Mishel articulate the antecedents of parental uncertainty, all of which the mothers in our study described as challenges and adaptations in their care of their child: those that arise from individuals (that is, their children or themselves), those that are due to their child's condition and its changes, and those that arise from the environment, such as members of their support circle or specific health-care professionals. It is these antecedents and their consequences that constantly challenged the mothers in our study to journey (unevenly) forward in *learning to manage the system*, working all the while to "just manage," or "just get on with it," or simply just keep their heads at water level.

Learning to negotiate for all the resources they need and negotiating or "fencing" with the gatekeepers and service providers constitute additional strain for mothers (Thorne & Robinson, 1989; Wuest, 2000; Wuest & Stern, 1990) and require significant energy and time in already over-full, stressful lives. Consistent with the findings of Thorne and Robinson, the mothers in our study were guarded about their re-establishment of trust once they had mastered *learning to manage the system;* "walking carefully" was just one more challenge in the care of their child — a constant theme.

Lazarus and Folkman (1984) discuss professional assistance as a material resource for individuals in stressful situations. However, what has not been discussed in coping theory is the fact that material resources can in themselves be a source of stress. The mothers in our study used a process of *learning to manage the system* to manage a material resource, a nursing respite service. While this service did in fact enable mothers to care for their technology-dependent child at home, it also proved to be an additional source of stress. For example, mothers reported higher stress levels when there was a lag between time of discharge and time of initiation of respite services. These mothers demonstrated the same exceptional abilities, resourcefulness, and resiliency in coping with the rigidity of the NRP. Consistent with the findings of Lazarus and Folkman, the mothers in this study used both emotion-focused and problem-focused coping strategies to deal with their stressors.

The findings from this study illuminate significant gaps between the hospital and community arenas of nursing practice (Kaufman & Hardy-Ribakow, 1987; Perrin & Ireys, 1984; Spalding et al., 2002). In this study, mothers often criticized "the system" for its lack of organization and coordination in care delivery during the period when their child with special needs was ready for transfer from hospital to home. Like Olsen and Maslin-Prothero (2001), we found that the immediate discharge-planning phase and transition to home requires sensitive, coordinated support and good communication. This first separation from the security of the hospital environment and the expertise and support of acute-care professionals is a particularly vulnerable time, one in which nursing expertise could be better used to assist parents, partly as a basis for future home-care and health-care relationships (Thorne & Robinson, 1989).

Further advancing our knowledge about how government and policy-makers can meet the needs of this unique population of caregivers, our findings suggest that primary caregivers of technology-dependent children at home should be in communication with government and policy-makers. Only caregivers who have actually experienced day-to-day life first-hand can understand and speak about what services are needed. This does not mean that nurses do not play a role in advocating for these families. Nurse practitioners possess the knowledge and skills to ensure that adequate assessments are conducted of the child's technological needs and the family's strengths and ways of coping.

In our study, as in others (Murphy, 1991; Olsen & Maslin-Prothero, 2001; Sherman, 1995; Stevens, 1990, 1994), mothers were found to experience less stress with the day-to-day demands of caring as the result of receiving home-based nursing respite services. Similar to those in other studies, our participants valued nursing respite support because it allowed them to catch up on their sleep, recover emotional strength, run to the bank, or simply have a bath (Olsen & Maslin-Prothero). While the mothers agreed that respite is an important form of support, the majority felt it was inadequate (Gravelle, 1997; Spalding et al., 2002). Respite services enhance mothers' sense of control over their situation; nurses are in a critical position, as front-line care providers and consultants, to promote this sense of control. All health-care providers and government personnel must work with parents to develop more efficient and creative respite-care options, as part of an integrated system of care specifically aimed at individual children and their families (Spalding et al.).

As economic pressures result in cutbacks, it is important that nurses not only provide the best possible care for children and families in their homes, but also advocate for mothers and their children, individually and at the policy level (McKeever, 1996; Tan et al., 2000).

Implications for Nursing Research

As the current shift towards home care continues, it is likely that the complexity of the issues facing parents caring for the technology-dependent population of children will also increase. The implication of this trend is that more research is needed into the nature of caregiving for technology-dependent children. What kinds of services do families require to ensure that the needs of caregivers and children are being met? What resources do mothers perceive as most likely to ensure their physical and emotional well-being? What types of assistance do mothers perceive as most likely to allow them to cope during the initial transition from hospital to home? Intervention studies are sorely needed. Further research should include a larger sample with broader socio-economic and educational representation.

This theory needs further density, refinement, testing, and validation. This study lends eloquent support to the idea that nursing respite care is crucial to mothers' coping with almost intolerable situations. More research is needed to determine the characteristics these programs need in order to help families achieve optimal functioning. In short, more evaluation and policy research is essential to keep respite-care options for families, who extend the formal health-care system and save it money, on the policy-making and government agenda.

These mothers' accounts provide a graphic, detailed, and rich picture of the demands of caring for medically complex children at home and the impact of in-home nursing respite services. The findings highlight the assertion that "support of all families must be paramount, and private and public resources must be redirected to allow families the choice and control over their own lives" (Cernoch & Newhouse, 1997, p. 409).

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Comments or queries concerning this article should be directed to Beverley J. Valkenier, T201-2211 Wesbrook Mall, Vancouver, British Columbia V6T 2B5 Canada. Telephone: 604-822-7639. Fax: 604-822-7466. E-mail: bevv@nursing.ubc.ca

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Designer's Corner

The Missing Link

Kathleen Dracup

Nursing is unique among the health-care professions in its view of the patient as a biopsychosocial being. Other health-care disciplines bring a perspective that focuses on one aspect of this triad. For example, medicine as a discipline is based on a biological model of man, psychology is based on theories of cognition and emotion, and medical sociology focuses on the social roles and relationships created by disease and illness. Nursing theoretical models blend a variety of perspectives to reflect the biological, psychological, and social dimensions of the individual. One of nurses' unique contributions to the care of patients and families is the ability to blend these multiple perspectives, both in clinical care and in research.

In clinical care, this blending of different dimensions is seen every day. For example, nurses caring for critically ill patients carefully titrate vasoactive medications delivered intravenously to minimize systemic vascular resistance and maximize cardiovascular function, while they simultaneously titrate the information and social support they give to patients and families to minimize anxiety and maximize problem-focused coping skills. Cardiac function increases while anxiety decreases. Both are critical to a patient's survival.

In research, nurse investigators focus on the links among the biological manifestation of disease, the psychological response, and the social effects of an illness. Paging through any one of the discipline's research journals, one can see convincing evidence of the multiple perspectives used by nurses. For example, a nurse scientist studying asthma might focus on a combination of environmental hazards, physical characteristics, and emotional states as precursors to worsening asthma. Focusing on psychological or physical precursors alone would

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Kathleen Dracup, RN, FNP, DNSc, is Dean and Professor, School of Nursing, University of California, San Francisco, USA.

not provide insight into the complex interaction that occurs with airway inflammation and worsening asthma (Janson, 2000).

The study of the link between emotional and physical responses to illness is critical to the development of nursing science. Biophysiological and psychosocial variables coexist and interact. They are precursors to disease and they characterize the human response to disease. The study of these interactions and linkages is greatly enhanced by the use of biological markers.

Biomarkers

Biological markers are measurable properties that can be used to evaluate biological processes, pathological processes, and patient response to interventions. Several decades ago, nurse researchers used blood pressure, heart rate, and urinary or salivary cortisol to evaluate the stress response. More recently, biological markers and the term *biomarkers* have become equated with cellular and molecular markers. Today, a nurse researcher studying the effect of a nursing intervention on the stress response might use salivary secretory immunoglobulin A (sIgA), which is an important biological marker for the effects of stress on immune function.

The availability of biomarkers such as nitrous oxide, cytokines, and cardiac-specific biochemical markers (e.g., troponins I and T) has changed the way we think about disease and has caused major paradigm shifts in diagnosis and treatment. These markers provide critical measures that must be reflected in emerging nursing science. An important illustration is provided in the care and study of patients with heart failure.

B-Type Natriuretic Peptide: The New "White Count" for Heart Failure

Although heart failure is characterized by complicated cardiorenal, hemodynamic, and neurohormonal alterations, nurses caring for heart failure patients and nurse researchers evaluating interventions in this clinical population have been hampered by the lack of a reliable and valid marker of heart failure severity. The measure of the effectiveness of nursing interventions has often relied on the crude outcomes of rehospitalization rates or the subjective measure of symptom severity. Now there is a simple blood test that is relatively inexpensive and correlates with left ventricular pressure, amount of dyspnea, and the state of neurohormonal modulation in heart failure patients (De Lemos et al., 2001). B-type natriuretic peptide (BNP) is synthesized in the cardiac ventricles and is proving to be a sensitive and specific indicator of ventricular disorders. The release of BNP into the bloodstream is directly proportional to ventricular volume expansion and pressure overload, and may obviate the need for invasive and expensive hemodynamic monitoring (Maisel, 2000). Researchers studying nursing interventions designed to improve functional status and quality of life in patients with heart failure now have a powerful tool to assess the effect of such interventions on disease severity. Future studies of heart failure would be incomplete without such a measure.

Summary

The uniqueness of nursing research is derived from the philosophical view of the individual as a biopsychosocial being. Nurse scientists are prepared to illuminate the linkages among the biophysiological, psychological, and social domains, and this study is much enhanced by the increasing availability of valid and reliable biomarkers. Researchers need to develop expertise in the use of biomarkers and secure appropriate funding for their use. Missing links may be missing no longer.

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Author's Note

Comments or inquiries about this article should be directed to Kathleen Dracup, RN, FNP, DNSc, School of Nursing, University of California, 2 Koret Avenue, Room N319, San Francisco, California 94143-0604 USA. Telephone: 415-476-1805. E-mail: Kathy.Dracup@nursing.ucsf.edu

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Happenings

Nurses and the Canadian Institutes of Health Research

Denise Alcock

When the Canadian Institutes of Health Research was initiated in June 2000, nurse researchers wanted and expected greater access to research funding than had been awarded through the Medical Research Council but were not convinced that increased funding for health research in Canada would translate into greater access to funding to support nursing research.

The CIHR is now in its second year. Within the first year of its existence, a Governing Council, 13 Institutes, and 13 Institute Advisory Boards were established. Governing Council members, Scientific Directors, and members of Institute Advisory Boards are chosen not on the basis of their specific disciplines but rather on the basis of their expertise and their track record. Therefore, nurses should be proud that at least 17 registered nurses contribute to the decisional and advisory infrastructure of the CIHR. Nurses also serve as CIHR university delegates and on peer-review committees. It is important that nurses maintain a high profile on the CIHR. Nominations for participation on review committees are invited through the research vice-president (or equivalent) of educational or health-research institutions, or through the CIHR university delegate.

Opportunities for research funding and personnel support are greater now than at any time in our history. Innovative initiatives such as CAHRs (Community Alliances in Health Research), IHRTs (Interdisciplinary Health Research Teams), CADRE (Capacity for Applied and Developmental Research and Evaluation in Health Services and Nursing Research), CHSRF/CIHR Chair awards in health

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Denise Alcock, RN, PhD, is a member of the CIHR Governing Council, Executive Committee, and Nominating Committee, and is Chair of the Institutes Advisory Boards Renewal and Review Process.

services and nursing, NETs (New Emerging Teams), and the University Development Fund have all provided nurses with career advancement opportunities in research. Taking all funding sources into consideration, including fellowships, doctoral awards, partnership grants, and strategic funding opportunities, 245 nurses are currently being funded.

Pathways to success include applying for funding within a strategic funding area, being a co-investigator on a multidisciplinary research team whose membership crosses more than one of the CIHR pillars of research, and finding funding partners. Nurse researchers can inform themselves about individual Institute thematic initiatives as well as cross-Institute initiatives by monitoring the Web site for the CIHR and for each Institute. The Institutes are resources for nurses. The challenge for some health professionals is to answer the discipline-specific research questions within interdisciplinary research designs. With Institute cross-cutting research initiatives such as rural and remote health, global health research, and reducing health disparities by promoting the health of vulnerable populations, the fit for nursing research within each initiative is not difficult to discern. Strategic initiatives are prioritized by considering the following criteria: advances science, improves health, encourages innovation, builds research capacity, promotes an integrated approach (pillar and discipline crossing and community engaging), has the potential to improve the effectiveness of health services and products, is ethical and excellent.

By far the greatest share of CIHR funding is dedicated to the open competition for grants and awards. As of February 28, 2002, the CIHR was supporting 6,672 grants and awards, not including the Chairs or NCEs. This is the competition that nurses tell me is most challenging. In the March 2001 operating grants competition, the success rate of nurses was 11.11% and the overall success rate was 32.45%. In the September 2001 competition, the success rate of nurses was 23.33% and the overall success rate was 30.63%. We are moving in the right direction. Critical to success is, as always, the rigour of the proposal. This does not mean that the methodology must be quantitative. It does mean that the proposal must score at or above the cut-off for the particular competition. My nurse colleagues who serve on peer-review committees assure me that proposals are reviewed equitably by the multidisciplinary peer-review committees. Through the office of the CIHR Vice-President, Research, arrangements can be made to provide grantsmanship workshops. The CIHR recognizes the need to capacity-build researchers and research programs. Ask for help. One nurse peer reviewer has noted that researchers with institutions that provide scientific review in-house prior to grant submission enjoy higher success rates in competitions.

If nurses see themselves in pillar 3 or 4 and note that only 26 candidates in these pillars were awarded doctoral research awards in the last competition, they can be assured that the cut-off for the awards for all pillars was 4.07. The success rate in 2001 was 31% of the 83 applications for pillars 3 and 4 and 28% of the applications for pillars 1 and 2, which resulted in 110 awards from 395 applications. We must advance more applications. It should be noted that only one currently funded CIHR Canada Research Chair is awarded to a nurse.

The CIHR emphasis on knowledge translation, which is also reflected in strategic initiatives, supports mechanisms that increase the uptake of research to influence practice, programs, and policy. Nurses should be particularly attuned to the importance of knowledge translation, and they have the potential to make major contributions to practice, programs, and policy through their research.

Many opportunities and new initiatives appear regularly. Keep informed by monitoring the CIHR Web site, by maintaining contact with your institution's link with CIHR, and by attending the workshops offered in your region by CIHR staff or members of specific Institutes. Institutions also have a responsibility to capacity-build their researchers by offering pre-submission scientific review of grant proposals and grantsmanship workshops. Ask for advice from CIHR staff. Build strong multidisciplinary and intradisciplinary research teams — membership can be national and international. Learn all you can about the various Institutes. Do you have a natural affinity for one Institute, or are you more interested in cross-cutting initiatives? Consider a national nursing research forum that is dedicated to identifying and developing capacity-building strategies for the advancement of nursing research within the context of today's funding opportunities. Make application through the NET initiative or the new investigator awards or other capacity-building initiatives. Put forward your concerns and help translate them into a strategic initiative; nurses did a great deal, for example, to advance the rural and remote health initiative.

The CIHR is preparing for its own evaluation and accountability reporting. It has been incredible to witness the energy and the enthusiasm for positioning Canada as a research leader that will ensure healthier populations. All of us who take an active role in the CIHR see a major movement forward in health research in Canada. What do you see? Please let us know.

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Gerontological Content in Canadian Baccalaureate Nursing Programs: Cause for Concern?

Jennifer L. Baumbusch and Mary-Anne Andrusyszyn

Au cours des prochaines décennies, le nombre de personnes âgées au Canada devrait augmenter de manière spectaculaire. Cette transformation entraînera des répercussions sur les besoins en matière de professionnels de la santé spécialistes de la personne âgée, en particulier en ce qui concerne les infirmières. Le projet de notre étude visait à analyser le contenu axé sur la gérontologie dans les programmes de baccalauréat en sciences infirmières au Canada. On s'est servi du *Survey of Gerontological Curricula in Canadian Baccalaureate Nursing Programs* [Enquête sur les programmes d'études en gérontologie au sein des programmes canadiens de baccalauréat en sciences infirmières] de Earthy pour recueillir des données sur un échantillon de commodité constitué à partir des écoles et des facultés de sciences infirmières au Canada offrant le programme de baccalauréat. On a analysé ces données en utilisant des statistiques descriptives et de fréquence. L'étude révèle que la majorité des programmes intègrent la gérontologie, mais que seulement 8 % des heures en clinique portent sur les soins aux personnes âgées et 5 % des étudiantes choisissent la gériatrie comme dernier stage clinique avant d'obtenir leur diplôme. Les résultats suggèrent qu'il faudra développer des compétences au sein du corps professoral, miser sur l'interdisciplinarité en matière d'éducation en gérontologie au sein des sciences de la santé et se pencher sur le problème de l'âgisme au sein de la profession infirmière.

Over the next several decades the number of older Canadians will rise dramatically. This shift will have implications for the demand for health-care professionals, particularly nurses, educated to work with an aging population. The purpose of this study was to assess the status of gerontological content in Canadian undergraduate nursing curricula. Earthy's *Survey of Gerontological Curricula in Canadian Baccalaureate Nursing Programs* was used to collect data from a convenience sample of Canadian nursing schools and faculties with baccalaureate programs. Data were analyzed using descriptive and frequency statistics. Gerontological content was found to be integrated into the majority of programs, but only 8% of clinical hours had a focus on the nursing care of older adults and only 5.5% of students chose geriatrics for their final clinical practica prior to graduation. Implications include the need to develop faculty expertise, the potential for interdisciplinary gerontology education in the health sciences, and the need to address ageism in the nursing profession.

Jennifer L. Baumbusch, RN, MScN, DipGero, is Interim Director of Care, Kiwanis Care Centre, New Westminster, British Columbia, Canada. Mary-Anne Andrusyszyn, RN, MScN, EdD, is Associate Professor, School of Nursing, University of Western Ontario, London, Ontario, Canada.

In the face of an aging population, it is almost certain that in the future every nurse will spend some portion of her or his career working with older adults, yet the inclusion of gerontological content in undergraduate nursing programs remains limited. Canada's population, similar to that of other Western countries, is getting older. In the year 2000, 3.8 million Canadians (12.5% of the population) were over the age of 65 (Statistics Canada, 2001). Over the next several decades, there will be a dramatic rise in the proportion of older adults. With the increasing number of aging "baby boomers" in the forthcoming decade, it has been projected that by the year 2011 five million Canadians will be over the age of 65 and that by 2031 the number will rise to 8.9 million — more than one fifth (22%) of the population (Moore & Rosenberg, 1997). A significant portion of this older group will be frail elders (85 years or older), who often have the heaviest care needs (Gioiella, 1993). It is expected that between 2020 and 2030 health-care professionals will come to spend 75% of their time with older adults (Aiken, 1997). As the general population ages, furthermore, so do nurses. The majority of registered nurses (RNs) in Canada are in their mid- to late 40s (Canadian Nurses Association, 2001a). Moreover, there are fewer new graduates to replace these soon-to-be-retiring nurses (Sibbald, 1998). Together, these factors — an aging population and a decreased supply of nurses — create a need to adequately prepare graduating nurses to work in the complex specialty of gerontological nursing.

One of the greatest challenges facing nurse educators, then, is to critically examine current programs for their appropriateness in preparing graduating nurses to meet the health-care needs of an aging population. The purpose of this study was to examine the inclusion of gerontology in Canadian baccalaureate nursing programs. The study was guided by three research questions: *How much gerontological content is currently included in Canadian baccalaureate nursing programs? What gerontological topics are currently being taught? How is gerontological content currently being taught?*

Literature Review

While nurse educators have been aware of the aging population trend for some time, the movement towards increased gerontological content in baccalaureate nursing programs has been slow. An initial survey of gerontological content in Canadian programs was completed in 1978. Although all of the programs reported some gerontology, the quality and quantity of the content varied (Hirst, King, & Church, 1996).

In the early 1990s, Earthy (1991, 1993) surveyed generic baccalaureate nursing programs in Canada. Approximately half of the schools had integrated gerontological content in their programs. Seven of the 22 schools sampled offered elective gerontology courses, while only two schools had required courses in gerontological nursing. Less than 10% of students' clinical hours were spent in a gerontological setting, as opposed to the more traditional settings of obstetrics, pediatrics, medicine, and surgery. For final clinical practica, only 2.5% of students chose a gerontological nursing experience. Faculty expertise in this area was also lacking: only 5% of the 550 faculty members teaching in these programs had gerontological preparation at the master's or doctoral level.

In a more recent review of American undergraduate nursing programs, Rosenfeld, Bottrell, Fulmer, and Mezey (1999) found some progress in the inclusion of gerontological content. Over half (63%) of the schools reported an integrated approach to gerontology. Most of the remaining schools offered separate, required courses. However, in the programs that took an integrated approach, the actual amount of course time devoted to gerontology was less than 25%. Reviews of other health-care disciplines, including medicine (Dalziel & Man-Son-Hing, 1994), occupational therapy (Aiken, 1997; Klein, 2001), and social work (Barusch, Greene, & Connelly, 1990), indicated similar amounts of gerontological content.

Other researchers have studied the effectiveness of various delivery formats on students' attitudes towards caring for older adults. Strumpf, Wollman, and Mezey (1993) describe an enriched gerontological nursing program for undergraduates. In this program, students received in-class instruction from faculty with gerontological expertise, coupled with clinical experience with older adults in acute-care and chronic-care settings.

The impact of an aging population on the health-care system will become an increasingly significant factor in curriculum development in baccalaureate nursing education. To meet the health-care needs of the population in the early decades of the 21st century, graduating nurses will require core content in gerontological nursing to effectively engage in clinical practice. In this study, we examined the current status of gerontological nursing education in Canadian baccalaureate nursing programs.

Methods

This was a descriptive study. All Canadian faculties and schools of nursing offering baccalaureate programs were invited to participate. Initially, a letter of introduction and a questionnaire were mailed to the dean or undergraduate director of each program, along with a preaddressed, stamped envelope. The letter requested that a person familiar with the content of the baccalaureate program complete the survey. Three weeks after the initial mail-out, a second mailing was sent to non-respondents. Data were collected between October 1999 and March 2000. Ethical approval for the study was obtained from the University of Western Ontario's review board.

Instrumentation

We used the *Survey of Gerontological Curricula in Canadian Baccalaureate Nursing Programs Questionnaire* (Earthy, 1991), which collects data on school and faculty characteristics, curriculum, amount and placement of content, patient issues and care techniques, and clinical experiences. Earthy established content validity by reviewing 19 previous questionnaires and consulting gerontological nursing experts. As well, the questionnaire was pilot tested by three faculty members in local nursing programs. For the current study, minor modifications were made to the instrument with the permission of the author, which involved updating some terminology to better reflect the current language used in health care.

Sample Characteristics

Twenty-one schools returned a completed questionnaire, for a response rate of 55%. Three (14%) of the 21 schools offered only direct-entry BScN programs, six (29%) offered only RN-BScN programs, and 12 (57%) had combined direct-entry and RN-BScN programs. Over half (52%) of the schools offered master's programs and about one fifth (19%) offered doctoral programs. Three (14%) of the schools reported having certificate programs in gerontological nursing. The number of students in the programs varied (see Table 1).

Table 1 *Size of Programs*

No. of Years	No. of Students (Average)	No. of Students (Range)
1	108	35–265
2	86	8–240
3	89	9–500
4	78	4–500

Findings

Responses to the questionnaire provided information on the topics, mode of delivery, and quantity of gerontological content in Canadian baccalaureate nursing programs. The data included information on clinical content and time spent in gerontological settings. As well, information was gathered on faculty preparation in gerontological nursing.

Faculty

A total of 594 faculty members taught in the 21 programs that participated in the study. Of these, 29% had doctoral degrees, 54% had master's degrees, and 18% had baccalaureate degrees. Of these faculty members, only 5.7% had some educational background in gerontology, comparable to the 5% in Earthy's (1991) study, and 3% had adjunct or joint appointments in clinical gerontological settings. One third of the programs had faculty members who were conducting research related to older adults.

Content

Content areas of focus included: theoretical foundations of gerontological nursing, sociopolitical contextual issues, physiology, pharmacology, special-care considerations, assessment skills, and leadership. Of the 49 items listed under content, those reported by respondents ranged from 18 to 49, with a mean of 44. The range demonstrates the inconsistency of content among the programs. Items most often reported as "not offered" were: the history of gerontological nursing, gerontology as an interdisciplinary field, political issues, ethnic issues, and principles of rehabilitation and activation. Items not included on the survey but reported as present in a few programs were: elder care, care of the informal caregiver, personhood, and spiritual care.

Mode of Delivery

Over half of the programs (52.4%) had separate, required courses in gerontological nursing. The programs that did not have a required course tended to have electives. Additionally, the majority of programs had some degree of integrated gerontological content. Data on the mode of delivery (i.e., didactic or clinical) for patient issues and care techniques were gathered. The majority of these items — which focused on mobility, skin breakdown, continence, polypharmacy, alterations in sleep, pain management, and "the three Ds" — depression, dementia, and delirium — tended to be part of required course content and were delivered in didactic and clinical formats. Items that were primarily offered in didactic format only included sleep deficits with aging, socialization therapies, and substance and financial abuse. Substance abuse was the sole item that was offered only in elective courses in some programs.

Clinical Experiences

Clinical hours in "traditional" specialties taught in undergraduate programs followed an expected pattern. Medical/surgical accounted for the largest number of hours (417, or 40%). Although students might have primarily older clients in this portion of their clinical, without the theoretical focus of geriatrics in the classroom they may not develop skills specific to the assessment, planning, intervention, and evaluation of nursing care for older adults. Community experience accounted for the second-largest number of clinical hours (285, or 28%), followed by Maternal/Child (124, or 12%), Mental Health (119, or 12%), and Gerontology (86, or 8%).

In addition to clinical specialty areas, we collected data on time spent in clinical settings where students would come in contact with older clients. Acute Care Hospital accounted for the greatest number of hours (455, or 67%), followed by Chronic/Long-term Care Unit (105, or 16%), Rehabilitation Hospital (48, or 7%), Senior Centre or Club (26, or 4%), Seniors Day Care Unit (17, or 3%), Wellness Clinic (12, or 2%), and Private Residence of an Older Person (12, or 2%). Notably, the greatest number of clinical hours were devoted to settings with acutely and chronically ill older adults, rather than in health-promotion settings with healthy older adults.

For their final, consolidating clinical experience, only 5.5% of students chose a geriatric focus. In response to the question about students' choices for these final practica, some faculty members offered the following unsolicited comments: "Since most acute-care med-surg units have an overwhelming geriatric population and *bed-blockers*, the majority will care for the elderly"; "Older adults are in most hospital settings." These comments illustrate the misconception that caring for older clients is equivalent to having a learning experience as a gerontological nurse.

Limitations of the Study

This study had several limitations. Some respondents commented that the survey was confusing or that the questions were difficult to respond to accurately when the school had combined programs for direct-entry and RN-BSN students. As well, the survey was lengthy, taking approximately 1 hour to complete. Many respondents remarked on this fact, a notable one in an era when faculty resources are stretched. Finally, the voluntary nature of a survey makes it difficult to ascertain the generalizability of the information that is gathered.

Discussion and Implications

The findings of this study on the inclusion of gerontological content in Canadian baccalaureate nursing programs demonstrate that there remains much potential for development. Caring for older adults will become a major focus of nursing as the population ages. In the past, though, gerontological nursing has been stigmatized by perceptions that it requires less expertise and knowledge than other clinical specialties (Eliopoulos, 1982). A current indication of nurses' commitment to this specialty area is the number who pursue certification in gerontological nursing through the Canadian Nurses Association. Of the 8,820 nurses who were certified in 2000, 6% were in gerontological nursing, compared to 22% in perioperative nursing, which accounted for the highest percentage. Other areas of acute care, including critical care, emergency, nephrology, neuroscience, and oncology, accounted for a further 43% of certifications (Canadian Nurses Association, 2001b). With the historical attitudes towards gerontological nursing, it is not surprising that such a large proportion of nurses identify more with these clinical areas even though the majority of their clients are probably older adults. As the population ages, though, there will be a growing demand for gerontological expertise in all settings and the passion for this specialty will have to be ignited during a nurse's education.

The relatively small percentage of faculty who are academically prepared to teach and conduct research in gerontology is a challenge to making this specialty area a significant part of the classroom and clinical experience. The results of other, similar, studies also highlight the small resource pool of gerontological specialists among faculty members (Olson, 1994; Verderber & Kick, 1990). Historically, those faculty members interested in gerontology were self-taught or had entered nursing education through another clinical specialty (Holtzen, Knickerbocker, Pascucci, & Tomajan, 1993). In addition, surveys have indicated that the proportion of doctoral students pursuing academic careers in the specialty remains small (Mezey, Fulmer, & Fairchild, 2000). This raises concerns over the ability of current and future programs to develop and deliver curricula that adequately prepare students to work with older adults, regardless of a student's chosen specialty.

We must examine how best to maximize the academic knowledge and time of these experts. Traditional modes of distance education are rapidly expanding to virtual classrooms, where, through the Internet and videoconferencing, a large number of students can be taught by a core group of faculty members with gerontological expertise. The lack of well-developed gerontological content in other health sciences presents opportunities for faculties and schools to pool resources and offer interdisciplinary courses. If students have the benefit of clinical experience with experts in the field, they will be better able to extend their theoretical learning into real-life care of older clients.

Developing separate, specialized courses versus integrating gerontological content into existing programs remains an area of debate for educators. Although there is some question as to the amount of integrated content that students actually learn as distinct "gerontological nursing," there are also practical challenges to devoting entire portions of programs to one specialty. With growing diversity in populations, and with technological advances putting greater demands on nurses' time and energy, there is a significant amount of new content vying for inclusion in baccalaureate programs (Baumbusch & Goldenberg, 2000). Even when gerontological content does exist, the question is raised: What is essential? The range of topics included in the programs surveyed for this study demonstrates the inconsistency of information being offered to students. Previous suggestions regarding core content have included a wide range of areas: theories of aging, changes in normal aging, common problems of aging, the advocacy role of gerontological nurses, evidence-based care for older adults, differences in care of adults and older adults, and sociopolitical contextual factors that impact on the delivery of care to older adults (Baumbusch & Goldenberg; Gioiella, 1993; King, 1995). There is the further issue of integrating this content into programs, with an emphasis on the latter portions, in order to stress the complex nature of nursing care for older adults. Developing this type of comprehensive, practice-based content requires the involvement of clinical experts. As this study found that only 3% of faculty members have adjunct or joint appointments with clinical gerontological settings, there is a need to strengthen the connections between academia and clinical practice in order to create and deliver relevant content to students.

The debate between separate and integrated content continues to rage. In general, however, programs that place greater emphasis on aging issues — regardless of the nature of the program — have been shown to increase students' positive attitudes towards older adults (Mosher-Ashley & Ball, 1999). There are many opportunities for faculty to make the nursing of older adults interesting and stimulating, thereby encouraging students to pursue careers in this area upon graduation. With one third of faculty conducting research in the area of older adults, students could be introduced to a wide variety of older clients and health situations by participating in research programs while at the same time experiencing the connection between research and practice. These types of learning opportunities would enable students to experience first-hand the interface between the aging population and health-care policy and service delivery. Not only would they gain practical experience with older adults, through exposure to some of the broader issues of health care, but they might choose the burgeoning field of gerontology as their career path. Now and in the future, students need to have wide exposure to older adults in various stages of health and in non-traditional settings in order to truly experience the fulfilment that can come from working with this population. Programs that offer these types of opportunities will remain relevant and thrive as the health-care system shifts to meet the needs of an aging population.

Conclusion

The purpose of this study was to examine how much nursing students are learning about the care of older adults in Canadian baccalaureate nursing programs. Although there has been some progress since Earthy's (1991, 1993) study, there remain vast opportunities to enhance the nursing care of older adults through nursing education. Meeting this challenge requires a shift in attitudes towards gerontological nursing. "Care of older adults should be conceptualized more as an expansive synthesizing clinical experience than as a traditional specialty because the behaviour of elderly individuals is shaped by more factors than similar experiences in younger adults" (McBride, 2000, p. 23). If the current slow trend of integrating gerontological content into baccalaureate nursing programs continues, there is a risk that there will be an insufficient number of nurses prepared in the expansive specialty of gerontology to care for the diverse population of older adults in the coming decades.

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Comments or queries about this article should be directed to Jennifer Baumbusch, 4679 Pender Street, Burnaby, British Columbia V5C 2N2 Canada. Telephone: 604-298-1446.

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Double Agency in Clinical Research

Marie Edwards and Karen Chalmers

L'intérêt actuel pour la pratique infirmière fondée sur les résultats cliniques et scientifiques force parfois les infirmières à assumer simultanément deux fonctions auprès des mêmes personnes, c'est-à-dire les rôles de chercheuse et de prestataire de soins. Puisque la relation entre infirmière et patient repose sur la confiance, ce double rôle peut être une source de problèmes à la fois réels et apparents. Le présent article aborde les questions découlant de cette situation dans la recherche avec des êtres humains, particulièrement en ce qui a trait au recrutement et au consentement éclairé, à la cueillette des renseignements et au désistement des patients. Il propose en outre des stratégies visant à prévenir et à contenir les problèmes liés au double rôle, en s'inspirant des lignes de conduite établies dans les codes de déontologie et dans l'*Énoncé de politique des trois conseils : éthique de la recherche avec des êtres humains.*

The current focus on evidence-based practice in nursing may result in nurses playing 2 roles concurrently — that is, acting as researcher and caregiver at the same time and with the same people. Given the fiduciary nature of the patient-caregiver relationship, this double agency can give rise to problems, both real and perceived. In this paper, the issues associated with assuming dual roles in research with humans will be examined, particularly in relation to recruitment and informed consent, data collection, and participant withdrawal from a study. In addition, strategies to prevent or minimize problems related to double agency are identified, with attention to the guidance provided by professional codes of ethics and the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.*

Nursing's mandate for evidence-based practice is challenging the profession to systematically evaluate clinical practices. Much of this focus is on direct nursing interventions, often with ill, institutionalized patients. At the same time, more nurses are receiving master's level education and are encouraged by their employing agencies and professional organizations to mount or participate in research on nursing outcomes. Given nurses' clinical role, issues of double agency can arise. Double agency refers to fulfilling two roles concurrently — for example, acting as researcher and caregiver at the same time and with the same

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Marie Edwards, RN, MN, is a PhD student, University of Toronto, Ontario, Canada, and Lecturer, Faculty of Nursing, Helen Glass Centre for Nursing, University of Manitoba, Winnipeg, Canada. Karen Chalmers, RN, BScN, MSc(A), PhD, is Associate Professor, Faculty of Nursing, University of Manitoba.

people (Levine, 1992). While assuming dual roles can result in benefits for both the study participants and science, it can also cause problems, both real and perceived, with significant consequences. If nursing is to achieve its research mandate, greater awareness of double agency is paramount. The purpose of this paper is to examine issues related to double agency in research with humans and to make recommendations for preventing or minimizing problems with dual roles.

The Caregiver-Patient Relationship

To understand the problems associated with double agency, it is necessary to first understand the nature of the relationship between patients and their caregivers. The patient-clinician relationship is a fiduciary one. It is defined by Lemmens and Singer (1998) as a relationship "between unequals in which the more powerful party…is entrusted to protect the best interest or well-being of the less powerful party" (p. 961). There are two key aspects to this relationship: (1) it is based on a power differential, with the patient, who not uncommonly is ill and in need of assistance, occupying the more vulnerable position; and (2) it is founded on trust.

Out of any fiduciary relationship arise obligations, particularly on the part of the more powerful party, to show "undivided loyalty and commitment, unqualified by any element of clandestine self-interest or any competing loyalty" (Irvine, 1995, p. 216). It is not that clinicians ought never to have other interests, but, as expressed by Bloche (1999), "the more powerful the message of fidelity conveyed within a clinical relationship, the more compelling a social purpose should be to justify departure from the ethic of undivided loyalty" (p. 273). One need only read the Canadian Nurses Association ([CNA], 1997) *Code of Ethics for Registered Nurses* to see that nurses' primary loyalty is to the people under their care and their primary interest is the well-being of these people. This interest is rooted in the ethical principles of beneficence, involving the promotion of the welfare of others, and non-maleficence, involving the prevention of harm (Yeo & Molke, 1996).

Researchers, too, are concerned for the well-being of those individuals who participate in their studies. But researchers are likely to have additional interests: the discovery of knowledge; the application of that knowledge in the care of future patients; the maintenance of good relationships with funding bodies, including private sources like industry; and self-interests, including career advancement (Cattorini & Mordacci, 1993; Pellegrino, 1992). If the researcher is at the same time a caregiver, these other interests have the potential to influence, or at least to be perceived as influencing, the caregiver's professional judgement regarding the primary interest of patient well-being. This places the caregiver in a situation of a real or perceived conflict of interest (Lemmens & Singer, 1998).

Problems Associated With Double Agency

Three areas of a research study may be particularly problematic for the person who acts simultaneously as caregiver and researcher with a group of patients: (1) the recruitment and informed consent process, (2) the data-collection process, and (3) participant withdrawal from the study. In these three areas the primary interest of patient well-being may be negatively influenced by the interests of science. The goal of the recruitment phase is the enrolment of an adequate — usually predetermined — number of informed participants. Since adherence to study time lines is important, recruitment must proceed in a timely manner. This can lead to problems when the researcher is also a caregiver. For example, in order to ensure an adequate sample size, a researcher may exert pressure, subtle or otherwise, on his or her own patients to consent to participate. Given the power of the researcher/caregiver and the vulnerability of the patient, some patients may be reluctant to decline for fear of jeopardizing the patient-caregiver relationship and, by extension, their future care (Levine, 1992; Moreno, Caplan, Root Wolpe, & the members of the Project on Informed Consent, Human Research Ethics Group, 1998; Orb, Eisenhauer, & Wynaden, 2001; Pellegrino, 1992). It is also possible that the researcher/caregiver in such a situation will take advantage of the "therapeutic misconception," described by Miller, Rosenstein, and DeRenzo (1998) as "the tendency of patient volunteers to believe that the research procedures that they undergo were designed for their benefit" (p. 1450). The members of the United States Project on Informed Consent, Human Research Ethics Group, have suggested that the language used on consent forms may actually encourage "an illusion of therapeutic benefit, whether intentionally or not" (Moreno et al., p. 1954).

A second potential problem area for the researcher/caregiver is the data-collection process. Various authors have found that ethical and role conflict can occur when nurses engage in research that involves direct interaction with respondents, such as interviews or field research (Archbold, 1986; Lipson, 1984, 1991; Lowes, 1996; May, 1979, 1991; Namei, O'Brien King, Byrne, & Profitt, 1993; Orb et al., 2001). For example, in the course of a research interview a patient-participant may seek information or advice regarding personal health status or care from the nurse collecting the data. If the data collector is not in a direct clinical relationship with the participant, this is not a double-agency issue as defined here, but it can result in the nurse experiencing role conflict. It is also possible that a situation will arise during data collection wherein intervention and referral are necessary for the well-being of the participant. Orb et al. provide the example of a researcher interviewing victims of violence and triggering painful memories in the participants, resulting in participant distress. In this situation, the researcher must decide whether "to continue with the interview and gain more insight about the topic under study or to stop the interview and give advice or refer the participant to an appropriate treatment or counselling service" (p. 94). If the interviewer is both the participant's caregiver, with all the duties this entails, and the researcher, the primary interest of patient well-being might be unduly influenced (or might be perceived to be unduly influenced) by secondary interests associated with the need for complete data.

Problems can also develop around the withdrawal of participants from a study. Faced with competing interests, a researcher/caregiver may struggle with his or her obligation to ensure that participants receive the best care possible and come to the least harm possible, and as a result may delay withdrawing a participant when evidence of harm emerges. Such a situation can prove particularly complicated if the study is double-blind (Pellegrino, 1992). When is it appropriate to break the code to minimize harm? Compounding this problem is the fact that the participant, who ought to have the right to withdraw from the study at any time, may not feel free to withdraw without prejudice (Levine, 1992).

Perhaps the most worrisome consequence of real or perceived conflict of interest with double agency is the erosion of participants' trust in their caregivers (Lemmens & Singer, 1998). This can occur if participants believe their best interests are no longer the priority or if they question the motives of the researchers. Given that trust is the foundation of both the patient-caregiver relationship and the researcher-participant relationship, this is a serious concern. It is essential that the research community protect public trust. If that trust is eroded, it is quite possible that people will no longer participate in research and that the public will no longer support funding of research projects (Hanna, 2000). The advice Paul Ramsey offered researchers three decades ago still holds true today: "Act always so as not to abuse trust; act always so as to exhibit faithfulness to deserve and inspire trust" (Ramsey, 1970, p. 8).

Existing Guidance

When considering acting as caregiver and researcher with the same group of people, the researcher should seek guidance from the chair of the research ethics board or from some other knowledgeable person. Such feedback may assist the researcher in thinking through the ethical issues and structuring the research proposal. The CNA (1994) document *Ethical Guidelines for Nurses in Research Involving Human Participants* contains minimal discussion of the double-agency problem. Investigators are informed that the best interests of the participants ought to be their prime concern and are encouraged to disclose any areas of potential conflict of interest to a research ethics board. In the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Medical Research Council of Canada [MRC], Natural Sciences and Engineering Research Council of Canada [NSERC], & Social Sciences and Humanities Research Council of Canada [SSHRC], 1998), researchers are reminded of the ethical duties that govern potential or actual conflicts of interest for the clinician who also assumes the role of researcher (Section 2, Article 2.4). In order to preserve the trust relationship, researchers who do assume a dual role are advised to disclose this fact to study participants and to separate their role as researcher from their role as therapist, caregiver, teacher, advisor, or consultant throughout the entire research project, particularly during the process of recruitment and when securing informed consent. Conflict of interest matters are further elaborated on in Section 4 of the Tri-Council document. While these guidelines provide some direction to researchers and research ethics boards, the investigator is given no specific guidance in planning the proposal or dealing with the review process.

Recommendations

Strategies to prevent or minimize problems related to double agency will now be identified. Some of the recommendations that follow are made from a fairly strong position of consensus in the research ethics literature and research community. Others are raised more tentatively and will require ongoing discussion and debate as policies in research ethics evolve. The recommendations are directed to the key stakeholders in the research process: research ethics boards, researchers and their collaborators, research project employees, research administration offices, the patient ombudsman, funders, and educational institutions.

Research Ethics Boards

Research ethics boards (REBs) have a critical role to play in uncovering and preventing double-agency problems and in educating the research community regarding this issue. This role cannot be fully realized, however, without a well-informed and knowledgeable review panel. This might appear self-evident, but REBs may have insufficient budgetary and other resources to provide a full orientation to members on this as well as numerous other ethical issues. Most members may be selected for their specialized knowledge in substantive research areas, with few having had formal training in ethics. During busy meetings in which numerous protocols must be reviewed, there is little time for in-service education and self-study on ethical issues. Inadequate preparation for the role can result in a lack of recognition of double-agency problems or conflict among the membership concerning their gravity. We recommend initial and ongoing education of REB members.

Research ethics boards also have a responsibility to their research community, such as by educating researcher-practitioners in double-agency concerns. It is not clear how this issue is best addressed (e.g., workshops, one-on-one consultation with the REB chair, the provision of literature with REB forms), but there is no doubt that resource implications must be considered.

Considerable attention must be paid to the REB process to ensure that potential and actual conflicts are made transparent and resolved. The question arises: Does the REB have the policies and procedures to address and resolve conflict of interest issues? The usual process when such concerns arise in an REB is the "to-ing and fro-ing" of applications between the researcher and the committee. Concerns are raised by the REB and some changes may be made by the researcher, but the central issues are not addressed. Some of these difficulties are exacerbated by vague or imprecise REB review forms. The written forms should be structured to elicit the needed information, with the inclusion of specific questions regarding power relationships (e.g., whether or not the researcher is in a position of power in relation to potential participants), practitioner and researcher roles, and project funding sources.

It is important that REB members see evidence that the researcher has sensitively considered power and trust issues when developing the proposal. If this information is not transparent or is incomplete, the committee may not have confidence in the researcher's ability to fully understand double-agency issues. An additional potential area of conflict is the source of research funding (Parascandola, 2001). Both the Canadian Medical Association (1996) and the Canadian Nurses Association (1994), as well as the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (MRC, NSERC, & SSHRC, 1998), recommend that the source of funding for research be disclosed to the REB.

Finally, REBs require considerable resources to do their job effectively. These include release time for members from their other duties (especially the chair of the committee), adequate secretarial support, and budgets sufficient to host educational sessions.

Researchers and Their Collaborators

Researchers themselves are the most critical component of the double-agency debate. The importance of the trust relationship between the caregiver and the patient is central to the avoidance of any actual or perceived conflict of interest. It would appear self-evident that prevention of conflict is the most obvious course of action. The researcher should ask two central questions: Are there other places where I could recruit participants, besides from among the patients, students, and employees associated with my work? If there are other accessible sites, is there any rationale for not using them? These are different questions from: Will it be more inconvenient for me to recruit elsewhere?

If there are no other accessible sites, the researcher should carefully think through the power and trust issues as the proposal is being developed. The REB chair may be an important consultative source during this process. If the researcher concludes that he or she must function as a dual agent, he or she should provide the REB with evidence that there has been careful thought and attention to the concerns of double agency and evidence as to how potential or real conflicts will be managed throughout the research. Central to this discussion is consideration of the question: How do I create a climate, throughout the research process, in which the needs of patients (or others) are paramount?

This ought to entail recruitment through a third party (i.e., research coordinator, research nurse). Merely hiring a staff member to recruit and to secure consent is insufficient to ensure the prevention of harm. The researcher must develop policies and practices that will enable the research staff to function as neutral agents. Staff members are never fully in a position of neutrality when they are directly supervised by the researcher. Power differences must be recognized and handled sensitively, so that pressure to meet recruitment targets does not interfere with the process of free and fully informed consent. If it is not possible to recruit participants from another patient pool, the data should be collected by a third party (i.e., a person other than the clinician who is in a direct relationship with the patients). To minimize role conflict, clear boundaries should be established around the research interview. If questions regarding a participant's care or health status arise during the interview, the participant should be informed that the researcher will return to this subject after the interview. At the completion of the interview, the data collector ought to respond to the participant's questions in a general rather than specific way and refer the participant to the appropriate health-care provider.

A growing concern is the issue of clinicians and others who are involved in research outside of universities and institutions and not linked to an institution's REB review process. This is an issue in pharmaceutical trials and other industry research. We recommend that practitioners, at the very least, ask for a copy of the industry REB's approval and consult with the research office of the employing institution.

When the practitioner and researcher roles are not fully separate, we endorse Shimm and Spece's (1991) recommendation that potential subjects be informed of the funding source, amount, and mechanism (i.e., block or capitation funding, directly to the researcher or through the research office of the institution). This should apply even in the case of third-party recruitment and data collection.

Central to all of the above recommendations is the integrity of the researcher. It will never be possible for REBs, research administration offices, or other bodies to fully regulate the research process. In the end, each researcher must be aware of and sensitive to the issues when acting in a dual role.

Research Project Employees

Nurses are frequently hired by researchers to recruit participants, gather data, and manage research projects. It is important that research employees be educated in the various components of their role. This entails an understanding of their professional responsibilities and knowledge of the codes of ethics that guide their practice. For example, nurses in Canada should be familiar with the CNA (1994) document *Ethical Guidelines for Nurses in Research Involving Human Participants.* They should also understand the guiding principles of recruitment and informed consent and be alert to their questionable neutrality in relation to recruitment and retention of subjects.

Research employees will need advisement on dealing with participants who seek specific advice on their personal care or health status or who require some form of intervention or referral. We suggest that they also be given access to administrative support and REB support as needed if they identify ethical concerns that, from their perspective, are not successfully resolved by the research team.

Research Administration Offices

Research administration offices have an important role to fulfil in the prevention, early detection, and monitoring of problems of double agency. The research office of a university or other institution is responsible for establishing and/or approving policies for REBs. In order for the REBs to function effectively, they must have sufficient resources for reviews, education of researchers, and other supports. We see a major function of the research administration office as advocating for adequate supports from the senior administrative structure. Research administration also has a key role to play in the monitoring of research proposals, particularly in the case of studies involving double agency.

Another area of responsibility for the research office is managing or overseeing funds related to recruitment expenses. We do not support "finder fees" (direct payment to clinicians who enrol their patients). However, there are legitimate costs involved in enrolling patients in studies. The budget for such expenses should be transparent and subject to review.

Institutions also need to recognize the complexity of linkages with the private sector and assist in developing and communicating policies and procedures that ensure the appropriate handling of double-agency issues.

Patient Ombudsman

A patient ombudsman or some other designate should be available for all patients/participants in studies. Research participants need access to the name and telephone number of a neutral person or body to vet any questions, concerns, or complaints concerning subtle pressures to enrol in or remain in a study, particularly when the participant's caregiver is the researcher. This information should be communicated in the materials given to the participant at the time of recruitment.

Institutional Sponsors

The reductions in public-sector funding for research during the past decade have caused university and institutional researchers to seek funds elsewhere. Indeed many institutions, especially universities, are encouraging these linkages. We must all become sensitive to the seductive power that research funding holds for researcher-practitioners and institutions alike. The threat of "institutional hubris" (Pellegrino, 1992, p. 364) is a powerful force in encouraging researchers to strive for prestigious grants. With such systemic pressure, researchers may lose sight of potential harms.

Educational Institutions

The major focus in research training is theoretical and methodological. We recommend that adequate attention be given to the ethical components of research, particularly issues related to conflict of interest, power and coercion, and trust. The focus of ethics education in undergraduate programs is, appropriately, the client. It is important, however, that students be exposed to ethical issues in research at the undergraduate level. This knowledge base can then be expanded in graduate education as research training increases.

Summary

In order to ensure the protection of research participants, all parties involved in the research process need to understand the potential conflicts surrounding double agency. With greater clarity of the issues, researchers, REBs, and administrators will be more sensitive to the problems associated with dual roles in research and better able to identify strategies to prevent such problems from arising. Central to the above discussion and recommendations is the basic integrity of the researcher. It will never be possible for REBs, offices of research administration, or other bodies to fully regulate the research process. In the end, each researcher must be aware of and sensitive to the issues when acting in a dual role.

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Culture & Gender

March 2003 (vol. 34, no. 4)

Culture and gender have been identified as important determinants of health. For this issue, we invite papers that examine the interaction of culture and gender with other health determinants, and the influence of culture and gender on the outcomes of nursing interventions. Manuscripts that describe research studies, present a systematic review, or provide a theoretical analysis will be considered. We are particularly interested in papers that focus on innovative interventions designed to mediate the influence of culture or gender on collective health action, individual behaviour change, social environments, health-service utilization, or health status. We welcome papers describing studies undertaken either in Canada or internationally.

Guest Co-editors: Dr. Nancy Edwards and Dr. Judy Mill
Submission Deadline: July 15, 2002

Nursing Care Effectiveness

June 2003 (vol. 35, no. 1)

In the context of the changes that are currently taking place in health-care systems, it is imperative that the effectiveness of nursing care be systemically studied and highlighted in research reports. Additionally, it is critical that the policy implications of such research be specifically addressed. For this issue of the Journal, we invite papers that examine nursing-care effectiveness in terms of health outcomes for individuals, families, groups, communities, or populations and from the perspective of cost to clients and to health-care systems. We will consider manuscripts that describe research studies, present a systematic review, discuss the implications of nursing-care effectiveness research on policy, present methodological issues, or provide analysis of theoretical and/or ethical issues.

Guest Editor: Sandra M. LeFort, PhD, RN
Submission Deadline: October 15, 2002

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L'École des sciences infirmières de l'université McGill est à la recherche de professeurs à plein temps au rang de professeur adjoint qui peuvent contribuer à l'élaboration de programmes de recherche en sciences infirmières. Les programmes reposent sur les recherches et l'expertise clinique qui existent déjà à l'École et dans les établissements de santé qui lui sont rattachés. Les candidats doivent avoir un intérêt dans l'un des domaines de recherche suivants : oncologie, santé cardiovasculaire, santé des femmes et des enfants, santé mentale, vieillissement, familles et administration des soins infirmiers. Les candidats retenus enseigneront aux trois cycles et établiront un programme de recherche de pointe, en plus d'encadrer des étudiants de 2^{e} et 3^{e} cycles. Ils consacreront au moins 50 % de leur temps à la recherche et à d'autres activités académiques.

Les candidats doivent être titulaires d'une maîtrise en sciences infirmières, d'un doctorat en sciences infirmières (ou en voie d'obtention) ou dans une discipline connexe et posséder un dossier en recherche et en publications. Il est souhaitable que les candidats aient une expérience en enseignement et une connaissance pratique des deux langues officielles (français et anglais).

L'École dispense deux programmes de 1er cycle (BScN et BN), une porte d'accès unique aux programmes de 2^{e} cycle en sciences infirmières (M.Sc [appliquées] pour les non-infirmières, programme de maîtrise pour les infirmières et programme de doctorat en sciences infirmières). L'École entretient des rapports de travail étroits avec l'Université de Montréal et fait partie d'un centre de formation régional chargé de constituer un effectif de chercheurs dans le domaine de l'administration des soins infirmiers. Le modèle de soins infirmiers de McGill axé sur la famille et la collaboration constitue une base philosophique solide pour ses programmes d'enseignement, de recherche et de formation clinique. L'École fait partie intégrante solide d'un réseau de centres interdépendants d'excellence en sciences infirmières où la pratique, l'enseignement et les recherches en sciences infirmières sont parfaitement intégrés.

L'Université McGill est située au coeur de Montréal, ville dynamique, et centre culturel du Québec. Les professeurs et étudiants jouissent de la diversité d'une ville multiculturelle dont le charme et l'atmosphère chaleureuse lui confèrent un caractère unique en Amérique du Nord. L'Université McGill comprend un ensemble intéressant de gens et de cultures qui contribuent à un milieu des plus stimulant et productif. L'excellence de sa réputation dans le domaine de l'enseignement, de la recherche et de l'érudition attire étudiants et professeurs du monde entier.

Les candidats que ces postes intéressent sont priés de faire parvenir leur curriculum vitae et le nom de trois répondants. Le processus de sélection se poursuivra jusqu'à ce que les postes soient comblés. Pour toute question relative à ces postes, veuillez communiquer avec: Susan. E. French, PhD; vice-doyenne et directrice, École des sciences infirmières, bureau 201, pavillon Wilson, Université McGill, 3506, rue University, Montréal (Québec) Canada H3A 2A7. Courriel : susan.french@mcgill.ca. Tél.: 514-398-4154; télec.: 514-398-8455.

Tous les candidats possédant les qualifications requises sont invités à postuler pour ces postes; cependant, nous tenons à signaler que les citoyens canadiens et les résidents permanents du Canada se verront accorder la priorité. L'Université McGill souscrit à l'équité en matière d'emploi.

Western

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The Faculty of Health Sciences, School of Nursing, at The University of Western Ontario invites applications for 2 full-time faculty positions effective January 1, 2003:

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The School of Nursing is one of 5 schools (Communication Sciences and Disorders, Kinesiology, Occupational Therapy and Physical Therapy) and an interdisciplinary program – Bachelor of Health Sciences in the Faculty of Health Sciences. Start-up research funds and the support of the Nursing Research Unit are available. University-wide programs to enhance teaching are offered regularly. The School is proud of the outstanding success of its BScN and MScN graduates, and will start a PhD program in September 2002. Educational and research programs are supported by excellent relationships with hospitals and community agencies.

Interested applicants should send a curriculum vitae, documents supporting qualifications, and the names, addresses, and contact numbers of three referees to:

Dr. Angelo Belcastro, Dean
Faculty of Health Sciences, Room H125, Health Sciences Addition
The University of Western Ontario, London, Ontario N6A 5C1
http://www.uwo.ca/fhs/

The deadline for receipt of applications is July 10, 2002.

Positions are subject to budget approval. The University of Western Ontario is committed to employment equity and welcomes applications from all qualified women and men, including visible minorities, aboriginal people and persons with disabilities. All qualified candidates are encouraged to apply; however, Canadian citizens and permanent residents will be given priority.

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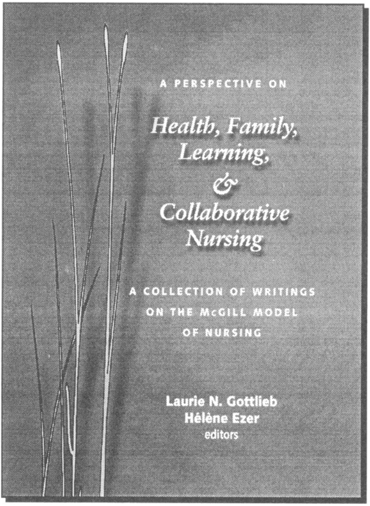

A PERSPECTIVE ON

Health, Family, Learning, & Collaborative Nursing

A COLLECTION OF WRITINGS ON THE McGILL MODEL OF NURSING

Laurie N. Gottlieb
Hélène Ezer
editors

Information for Authors

The *Canadian Journal of Nursing Research* is a quarterly journal. Its primary mandate is to publish nursing research that develops basic knowledge for the discipline and examines the application of the knowledge in practice. It also accepts research related to education and history and welcomes methodological, theory, and review papers that advance nursing science. Letters or commentaries about published articles are encouraged.

Procedure: 1. Articles must be written in English. 2. Authors are requested *not* to put their name in the body of the text, which will be submitted for blind review. 3. Only unpublished manuscripts are accepted. 4. All research studies must have received IRB approval. 5. A written statement assigning copyright of the manuscript to the *Canadian Journal of Nursing Research* must accompany all submissions to the Journal. 6. Manuscripts should be submitted by e-mail to the Editor, c/o joanna.toti@mcgill.ca

Manuscripts

Manuscripts must be prepared in accordance with the Fifth Edition of the *Publication Manual of the American Psychological Association*. Research articles must follow APA style for presentation of the literature review, research questions and hypotheses, method, and discussion. All articles must adhere to APA guidelines for references, tables, and figures. Footnotes are to be avoided.

Title page: This should include author(s) name, degrees, position, information on financial assistance, acknowledgements, address, and present affiliation. This page should also include keywords as well as a suggested running head for the article.

Abstract: Research articles must include a summary of 100–150 words describing the purpose, design, sample, findings, and implications. Theory and review papers must include a statement of the principal issue(s), the framework for analysis, and summary of the argument.

Text: The text should not exceed 20 double-spaced typed pages, including references, tables, and figures.

References: The references are listed in alphabetical order, double-spaced, and placed immediately following the text. All author names must be included for each reference. Journal names must be spelled out in full.

Tables and figures: Tables and figures should appear only when absolutely necessary, up to a maximum of four. They must be self-explanatory and summarize relevant information without duplicating the content of the text. Each table must include a short title, omit abbreviations, and be typed on a separate page. Figures must be in camera-ready form. Tables and figures should be placed at the end of the paper, after the references.

Review process and publication information: *The Canadian Journal of Nursing Research* is a peer-reviewed journal. Manuscripts are submitted to two reviewers for blind review. The first author will be notified following the review process, which takes approximately 12 weeks to complete.

Electronic copy: Authors must provide satisfactory electronic files of the accepted final version of the manuscript.

Renseignements à l'intention des auteurs

La *Revue canadienne de recherche en sciences infirmières* est publiée quatre fois par année. Son mandat premier est de diffuser les travaux de recherche axés sur le développement des connaissances et leur mise en pratique au sein de la discipline des sciences infirmières. La revue accepte également les articles de recherche traitant d'éducation et d'histoire, ainsi que les articles sur la méthodologie, la théorie et l'analyse critique qui contribuent à l'avancement des sciences infirmières. Les lecteurs et lectrices sont invités à faire parvenir leurs commentaires sur les articles publiés dans la revue.

Modalités : 1. Les articles doivent être rédigés en anglais. 2. Pour garantir l'anonymat des auteurs pendant l'examen des articles, on demande à ceux-ci d'éviter d'indiquer leurs noms dans le corps du texte. 3. Seuls les manuscrits inédits seront acceptés. 4. Tous les projets de recherche doivent avoir reçu l'approbation d'un comité d'éthique. 5. Une déclaration de cession du droit d'auteur à la *Revue canadienne de recherche en sciences infirmières* doit accompagner toutes les propositions d'article. 6. Les manuscrits doivent être soumis par courriel à la rédactrice en chef a/s: joanna.toti@mcgill.ca.

Manuscrits

Le manuscrit doit respecter les normes précisées dans la cinquième édition du *Publication Manual of the American Psychological Association*. Tous les articles de recherche doivent répondre aux critères de l'APA relativement à l'état de la question, aux questions et aux hypothèses de recherche, à la méthode suivie et à la discussion des résultats. Les figures, tableaux, illustrations et références doivent aussi obéir aux normes prescrites. Prière d'éviter les notes de bas de page.

Page titre : La page titre du manuscrit doit donner le nom, l'adresse et l'affiliation des auteurs ou auteures, ainsi que leurs diplômes, l'aide financière reçue et les remerciements. Elle doit également indiquer les mots-clés pertinents et offrir une suggestion de titre pour l'article.

Résumé : Les articles de recherche doivent comprendre un résumé de 100 à 150 mots qui expose l'objectif, la méthode, l'échantillon, les résultats et les conclusions de l'étude. Les articles théoriques et les analyses critiques doivent présenter les principaux objectifs recherchés, le cadre d'analyse et un résumé de la discussion.

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Tableaux et figures : On ne doit avoir recours aux tableaux et aux figures que dans les cas où cela est absolument nécessaire, jusqu'à un maximum de quatre. Ceux-ci doivent être suffisamment explicites et résumer les données pertinentes en évitant les redites. Chaque tableau doit porter un titre, être exempt de toute abréviation et dactylographié sur une page séparée. Les figures doivent être prêtes à photographier. Les tableaux et les figures doivent être placés à la fin de l'article, à la suite des références.

Examen des manuscrits et renseignements relatifs à la publication : La *Revue canadienne de recherche en sciences infirmières* est une revue fondée sur l'évaluation par les pairs. Deux réviseurs examineront le manuscrit à partir d'une copie anonyme. On avisera le premier auteur de leur décision au terme du processus, lequel nécessite douze semaines environ.

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Canadian Journal of Nursing Research
Revue canadienne de recherche en sciences infirmières

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Le Point : Le soutien et l'adaptation